Continuity of Care

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

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Contents

Executive Summary

Context and aims ................................................................. 5
Method ............................................................................ 5
Main findings .................................................................. 6
    Part A  Mapping the evidence .............................................. 6
            Definitions ................................................................ 6
            Review of priority areas .............................................. 6
    Part B  Conceptual analysis: what are the issues and their
            implications? Focus on methodological challenges
            and innovatory approaches ........................................ 6
            Limitations of this scoping exercise ............................ 7
    Part C  Recommendations ................................................ 7
            Definition: the elements of continuity .......................... 7
            Research priorities ................................................... 8

Report

Introduction ........................................................................ 10
    Background ...................................................................... 10
    Multidisciplinary working .............................................. 10
Part A  Mapping the evidence: literature overview and
        evidence from organisations and individuals 12
    1 Search strategy .......................................................... 12
    2 Criteria for considering studies in the review .............. 13
    3 Results .......................................................................... 13
            Review of the literature ............................................. 13
            Definitions and conceptual boundaries ...................... 14
    4 The subject areas ......................................................... 15
            4.1A Cardiovascular disease ........................................ 15
            4.1B Diabetes ............................................................. 16
            4.2 Cancer .................................................................... 16
            4.3 Care of older people .............................................. 18
Continuity of Care

4.4 Mental health .................................................................20
4.5 Primary care .................................................................25
4.6 Maternity care ...............................................................29

Part B Conceptual analysis .................................31

5 The challenge of understanding patients’ trajectories through care ........................................31

6 Continuity of care is a relational idea, not a constant entity .........................................................31

7 Thinking laterally .........................................................32

8 Some key organisational/structural/professional/relational issues highlighted in existing research ..........................................................33

8.1 Unintended consequences, informal solutions ..........33

8.2 Attributes and processes – balancing conflicting elements of continuity ..................................................34

8.3 Transfers and discharges: interfaces between different parts of the health care system and their impact on continuity of care ..........................................................36

9 What are the possible gaps in the research? ..........38

9.1 .. Explaining the meaning of ‘continuity’ and going beyond ‘failures of communication’ .................................38

9.2 The importance of the specificity of context and the patient’s perspective ..........................................................38

9.3 Understanding when discontinuity as well as continuity may be valued ..........................................................39

9.4 The problems as well as the possibilities of improving communication between professionals and patients in relation to continuity of care ..........................................................39

9.5 Neglected settings on research in continuity of care ..........................................................40

9.6 Continuity of care and quality of care ..........................................................41

9.7 New technologies and continuity of care ..........................................................41

9.8 The importance of researching the process of continuity ..........................................................42

10 What are the methodological challenges highlighted in existing research? ..........................................................42

10.1 Studying conflicting priorities ..........................................................43

10.2 The need for a longer-term perspective ..........................................................43

10.3 Clear definitions and hypotheses ..........................................................43

11 What methodological approaches and innovations are likely to be fruitful? ..........................................................43

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Continuity of Care

11.1 Gaps already bridged ................................................................. 43
11.2 Action research ........................................................................ 44
11.3 Longitudinal studies ................................................................. 45
11.4 Follow-up studies ...................................................................... 45

Part C Discussion and recommendations ...................... 46
The concept of continuity of care: implications for reviewing current knowledge ............................................ 46
Definition of elements of continuity of care ................. 46
Recommendations for research priorities ..................... 47
R1: Studies of experienced continuity – to include process-based and longitudinal studies ......................................... 47
R2: The effect of elements of continuity of care on outcomes other than satisfaction .................................................. 48
R3: Innovative and multidisciplinary approaches ............. 48
R4: Systematic reviews ................................................................. 49

Part D List of appendices ................................................. 50
Appendix 1 Summary tables of studies referred to in Part A. 51
Appendix 2 Ratings definitions and data extraction sheet for Continuity of Care Scoping Exercise ...................... 121
Appendix 3 Other evidence from organisations and individuals ...................................................................................... 125
Appendix 4 Contact with other health care researchers (I) . 128
Appendix 5 Contact with other health care researchers (II) 134
Appendix 6 References .................................................................. 140
Executive Summary

Context and aims

The SDO conducted a listening exercise in 1999 to identify priority areas for research. Continuity of care emerged as one of nine identifiable themes. A scoping exercise was called to identify the likely directions for research and specified four aims, or issues:

Issue 1 Definitions and conceptual boundaries of continuity of care in the literature
Issue 2 Proposed working definition for the SDO research programme
Issue 3 Any existing evidence of impact of continuity of care on the process, outcomes and costs of care
Issue 4 Evidence on how to achieve continuity of care and barriers to this.

The scoping contract was awarded to a multidisciplinary team from three universities with expertise in epidemiology, health services research, sociology, anthropology, social work, general practice and mental health.

Method

There were two main thrusts to the work:

1. a rapid but systematic overview of the literature to outline what is already known and to identify gaps in existing research, together with a survey of voluntary organisations and communication with known active research workers

2. a conceptual analysis to describe and interpret the issues and suggest new lines of study.

In addition, closer attention was paid to the following NHS priority areas:

- cancer care
- cardiovascular disease
- diabetes
- mental health

and also to care of older people with particular reference to the interface with social care.
Main findings

**Part A Mapping the evidence**

**Definitions**

The term ‘continuity of care’ is frequently used but much less often defined (Issue 1). More than ten distinct definitions were found. Of the definitions that were made, the three most common were:

- *longitudinal or provider continuity* – seeing the same professional
- *continuity across the secondary/primary care interface* – concerning discharge from specialist to generalist care
- *continuity of information* through records – either written or electronic.

Note that mental health researchers have focused on the definition of continuity and, in particular, they add the dimension of flexibility, where care provision adjusts to the evolving needs of the patient.

**Review of priority areas**

Because of the lack of specificity, few studies have been able to assess the impact of continuity of care (Issue 3) in any conclusive manner. Many gaps in care provision are indicated but their rationale is seldom addressed or criticised. A number of cross-sectional surveys describe a positive association between patient satisfaction and provider continuity. There are few experimental studies where a specific approach to enhancing continuity and assessing the outcome has been subject to rigorous trial in order to make a reasonable deduction of causality. General practice sees continuity of care as a core value and so has generated a considerable literature.

Similarly, investigation of barriers to continuity (Issue 4) has not generally been preceded by enough qualitative and pilot work to clarify research questions and test methods. Most studies testing methods of enhancing continuity were in the fields of mental health, primary care and maternity care.

**Part B Conceptual analysis: what are the issues and their implications? Focus on methodological challenges and innovatory approaches**

Critical analysis suggests that continuity of care is seldom an isolated or one-dimensional virtue which can be enhanced without some corresponding and even conflicting effect. Examples include quick access versus seeing the same professional, or better access to specialists conflicting with uprooting from home support. Schemes to enhance
Continuity of care may be unacceptably costly to deliver in day-to-day service, and may not deliver what patients experience as continuity.

While many surveys have sought the views of patients, these have almost exclusively taken a professional perspective of care. Little is known about patients’ priorities for continuity of care, and the dynamics of health trajectories in context which give rise to changing needs, or how to take account of these in making care more relevant and accessible.

Continuity of care will usually be a ‘complex intervention’ and hard to study in isolation. There is therefore a need for longitudinal process-orientated studies that apply critical analysis to the contextuality and contingency of continuity of care. Gaps in care can be seen as inevitable and natural and ways in which professionals overcome these can be highlighted for wider application. The possibility of positive effects of discontinuity is also recognised.

Another case for a longitudinal approach is to follow patients’ care pathways over time in order to highlight the interaction between the priorities of patients and professionals and how these are negotiated. At the organisational and structural levels, unintended side effects in relation to continuity of care may occur between managerial policy and day-to-day practice, for example the implementation of ‘the nursing process’.

Limitations of this scoping exercise

The timescale, combined with the very wide field of enquiry, has meant that we have not been able to map the literature thoroughly enough to be sure of being either inclusive or exclusive (Part A). Restricting the literature to the main databases implies the risk of bias towards publications demonstrating an advantage for continuity of care.

This has been balanced by the critical and questioning analysis in Part B.

Part C Recommendations

This scoping exercise proposes a multi-aspect definition of continuity with six elements (Issue 2). Most studies will only address one or two of these, but careful definition is a precondition for useful research in this field.

Definition: the elements of continuity

1 The experience of a co-ordinated and smooth progression of care from the patients’ point of view (experienced continuity).

To achieve this central element the service needs:

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

3 effective communication between professionals and services and with patients (cross-boundary and team continuity)
Continuity of Care

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).

Research priorities

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

R1: Studies of experienced continuity – to include process-based and longitudinal studies

- Studies from the patient’s perspective which 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 the ways in which 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, e.g. 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.

R2: 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
Continuity of Care

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 patients’ experiences of high-quality processes of care in different settings may themselves constitute important outcomes of health care.

**R3: Innovative and multidisciplinary approaches**

The following more general suggestions are made 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 mixed qualitative and quantitative approaches to this question.

- Studies that 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 that 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.

**R4: Systematic reviews**

- A systematic review of patients’ experiences of continuity of care. Such a review would go beyond what could be achieved in this rapid mapping exercise. It would take time and so should run in 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 into intermediate or residential care settings
  - those with mental health problems.

These areas in particular were identified as needing wider searching criteria. The last three were also identified as priority areas by voluntary organisations.
Continuity of Care

The Report

Introduction

Background

In today’s National Health Service rapid technological and service developments are taking place in a fast-evolving social context. There is refreshing and overdue emphasis on orientation of care systems towards the concerns and preferences of the users. As service developments tend to run ahead of the ability of many users and professionals to comprehend or evaluate them, there are calls for better ‘continuity of care’ as a way of making sense of change. Continuity of care is often lauded but seldom defined. While there is much rhetoric, evidence remains elusive.

Concepts such as the patient’s ‘journey’ or ‘trajectory’ (Frankenberg, 1987) through health care are helpful in examining continuity from the patient’s perspective and emphasise the need for process-based research. Continuity of care is a broad but fluid concept and more specific definitions are therefore sought for pragmatic as well as rhetorical reasons (Starfield, 1980). However, in this scoping exercise we have taken the approach that continuity of care may also be a proxy for a variety of values, beliefs and assumptions held by numerous stakeholders in health care, including patients, and that these values may sometimes be in conflict with each other. Continuity of care may be one expression of such values but in other combinations they may manifest themselves for example as coherence, choice or convenience.

The existing medical literature perhaps inevitably tends to be limited to professional perspectives on care provision. Proper consideration of patients’ views must involve a wider review and may challenge the assumptions underlying both present and proposed care patterns. Relatively little is known of patients’ own values, particularly how they prioritise them (Ratcliffe and Buxton, 1999) in relation to continuity of care. It has therefore been difficult to treat continuity of care as separate from the other themes identified in the SDO’s listening exercise. The briefing paper rightly highlighted co-ordination/integration across organisations as including many overlapping issues but we think many of the other themes should also be regarded as cross-cutting.

Multidisciplinary working

The research team brought a wide palette of skills and experience, both academic and professional. This spread of expertise led us to adopt two complementary but contrasting approaches to the exercise. Expertise in
epidemiology and systematic reviews enabled us to lead the more formal mapping of the existing literature and the survey of voluntary organisations from Imperial College. At Brunel University we employed sociological, anthropological and qualitative research skills for a more ‘by hand’ literature search, thinking laterally about continuity of care from a range of perspectives, critically analysing a variety of conceptual and research approaches and conducting an e-mail consultation of medical sociologists. In addition, Sally Richards at the University of Southampton contributed particularly to the interface with social care, focusing on the needs of the elderly. In Patty Pitman we were fortunate to recruit a research assistant who was also an experienced mental health worker in order to widen our understanding of the needs of those with serious mental illness.
Part A Mapping the evidence: literature overview and evidence from organisations and individuals

1 Search strategy

1.1 Medline full text search of years 1966 to 2000 using the following key words, combined with patient or user or client or consumer and evaluation studies or qualitative studies or ethnography or randomised controlled trial or clinical trial.

<table>
<thead>
<tr>
<th>Continuity of patient care</th>
<th>Case management</th>
<th>Care planning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Team care</td>
<td>Seamless care</td>
<td>Multi professional working</td>
</tr>
<tr>
<td>Multi agency working</td>
<td>Inter agency working</td>
<td>Inter professional working</td>
</tr>
<tr>
<td>Interpersonal continuity</td>
<td>Key workers</td>
<td>Care experience</td>
</tr>
<tr>
<td>Care process</td>
<td>Expectations</td>
<td>Check ups</td>
</tr>
<tr>
<td>Periodic health checks</td>
<td>Discontinuity</td>
<td>Information</td>
</tr>
<tr>
<td>Gaps</td>
<td>Transitions</td>
<td>Longitudinal</td>
</tr>
<tr>
<td>Interfaces</td>
<td>Satisfaction</td>
<td>Advocacy</td>
</tr>
</tbody>
</table>

1.2 Cochrane Library (Cochrane Controlled Trials Register, Database of Abstracts of Reviews of Effectiveness, the Cochrane Database of Systematic Reviews) using the term continuity. Issue 3, 2000.

1.3 The King’s Fund Database (HMIC) 1989 to 1999 using key terms: continuity of patient care, case management, user involvement, care planning and patient centred care.

1.4 Psychlit 1974 to 2000 using continuity of care and key workers combined with evaluation studies.

1.5 SIGLE 1980 to 2000 using continuity of care.

1.6 AMED (Allied and alternative medicine) 1985 to 2000 using the term continuity of care.


2 Criteria for considering studies in the review

We restricted the search to articles in the English language. The abstracts of articles were read and the full articles were included in the scoping exercise if they met our inclusion criteria that continuity of care was either part of an intervention being evaluated, or was a measure of outcome or process and the study mentioned the patients’ perspective and described an evaluation and/or results of research. This meant we included results from studies that were more descriptive without evaluation. The aim of this was to exclude opinion pieces, descriptions of services or essays without reference to any research. (Some of these are mentioned in Part B.) We judged an article to report the patient’s perspective if the results included patient outcomes or views, rather than those of staff providing the service. This judgement had to be made on the abstract only, because of resource limits.

Full articles were read and summarised using a data extraction sheet, if we were able to retrieve copies within the time available. When it was not possible to obtain the full article we relied on the abstract. Reference lists of all included articles were scanned for further relevant articles. Each paper was rated on three five-point scales:

- **relevance** (to policy or research – the aims of this scoping exercise, including relevance to the patient’s perspective)
- **evidence** (methodological quality – was it a good study, even if of limited relevance?)
- **concept** (clarity of continuity definition, often lacking, in spite of relevance and or/quality).

We agreed a simple rating scheme at a full team meeting after some experience of reviewing papers. The full scheme is attached, with the data extraction sheet, in Appendix 2. Criteria were agreed to cover both quantitative and qualitative studies.

3 Results

**Review of the literature**

Electronic searching yielded a total of 2301 citations from Medline, Cochrane Library, King’s Fund, PsychLit and AMED. Of these, 95 met our inclusion criteria and were read; they are summarised in Appendix 1.

Articles were categorised into broad subject areas to reflect the national policy initiatives:

1A Cardiovascular disease
1B Diabetes
2 Cancer
3 Care of older people
4 Mental health.
Articles in other areas were classified according to subject area:

5 Primary care
6 Maternity.

Miscellaneous areas where few articles were identified are not described in the text of this report; some details of these are tabulated in Appendix 1.

The results of the literature search are presented according to the issues identified by the SDO programme. Within each subject area we present our findings on:

- the evidence of the impact of continuity of care (or lack of it) on the process and outcomes of care, and costs and disbenefits
- the evidence on how continuity of care can be effectively achieved, and the barriers to achieving this.

In addition, we have identified gaps in research.

We begin with a discussion of our findings related to the definitions and conceptual boundaries of continuity of care used in the literature.

**Definitions and conceptual boundaries**

The need for clarity of definition of continuity of care has long been acknowledged (Starfield, 1980). However, suggestions for rationalisation and careful definition have not so far been widely adopted. The following ten definitions have been used.

1. **Longitudinal.** How much or for how long the patient has seen the same provider. No assessment of relationship or of quality of interaction.
2. **Relationship/Personal.** The relationship with the provider is assessed in some way.
3. **Team.** As Longitudinal, but with a group or team of care providers either in primary or secondary care.
4. **Geographic.** Care is given/received in person on one site.
5. **Cross-boundary.** Typically hospital/specialist outreach to primary care. Only one instance so far of tertiary to secondary outreach from ICU! (Russell, 1999)
6. **Regimen/Comprehensive.** Reference to a common and usually ‘comprehensive’ treatment programme indicating a multi-skilled team or teams (Bachrach, 1981).
7. **Flexible.** Care adjusts seamlessly and interactively as the individual patient’s needs evolve over time.
8. **Information/Records.** Includes computer links and shared records and where outreach is not interactive.
9. **Interactive remote** care including consultation by telephone, real-time computer, email.
10. **Experienced** continuity from the patient’s viewpoint.

Definition of continuity of care and its conceptual boundaries has received particular attention in the areas of mental health (Bachrach,
Continuity of Care

1981), primary care (Starfield, 1980; Freeman and Hjortdahl, 1997) and maternity services. This is in contrast to the other areas covered in this scoping exercise.

4 The subject areas

4.1A Cardiovascular disease

We reviewed eight articles covering a broad range of interventions and including patients with a variety of cardiovascular conditions (Close and Proctor, 1999; Ekman et al., 1998; Jolly et al., 1998; Kaplan, Greenfield and Ware, 1989; Preston, 1997; Rawl et al., 1998; Thomson, Ersser and Webster, 1995; Widén Holmqvist et al., 1998). Continuity of care was peripheral to all of the studies.

4.1A.1 The evidence of the impact of continuity of care (or lack of it) on the process and outcomes of care, and costs and disbenefits

None of the studies directly measured continuity of care (Close and Proctor, 1999; Ekman et al., 1998; Jolly et al., 1998; Kaplan, Greenfield and Ware, 1989; Preston, 1997; Rawl et al., 1998; Thomson, Ersser and Webster, 1995; Widén Holmqvist et al., 1998), although some of the interventions evaluated services that had been organised with the aim of improving it. Studies evaluating specific interventions examined the effects in a change to service delivery, for example structured nurse follow-up (Ekman et al., 1998; Jolly et al., 1998; Rawl et al., 1998), or home rehabilitation (Widén Holmqvist et al., 1998). One intervention study evaluated the impact of coaching patients to participate in care during an office visit (Kaplan, Greenfield and Ware, 1989). Qualitative studies (Close and Proctor, 1999; Preston, 1997; Thomson, Ersser and Webster, 1995) examined patients’ reactions to and experiences of illness; the theme continuity of care did not feature in the interview schedules and therefore was not consistently addressed. However, patients expressed concerns related to continuity of care that included receiving inadequate information (Close and Proctor, 1999; Thomson, Ersser and Webster, 1995). Although some patients experienced reduced level of anxiety, the results from studies evaluating some form of structured nurse follow-up failed to detect whether this type of care impacts on the process of care, or if it substitutes for doctor-led care for patients with cardiovascular disease (Ekman et al., 1998; Jolly et al., 1998; Rawl et al., 1998).

4.1A.2 The evidence on how continuity of care can be effectively achieved, and the barriers to achieving this

Targeting patients directly, by providing them with individualised information on their care and coaching on how to participate in care during a consultation, does appear to improve outcomes for patients with hypertension or diabetes (Kaplan, Greenfield and Ware, 1989). Blood pressure control was improved for patients with hypertension, and
Continuity of Care

glucose control for those with diabetes (Kaplan, Greenfield and Ware, 1989).

4.1A.3 What are the possible gaps in the research?

We did not identify any studies that directly addressed the impact of continuity of care on process and outcomes of care, nor on costs, for patients with cardiovascular disease.

4.1B Diabetes

4.1B.1 The evidence of the impact of continuity of care (or lack of it) on the process and outcomes of care, and costs and disbenefits

One study (Piette, Weinberger and McPhee, 2000) recruited patients with type 2 diabetes with the aim of assessing the effect of automated disease management calls with nurse follow up to provide continuity of care. Patients recruited to this trial were from a multilingual population with inadequate health insurance. Patients who were English speaking reported greater satisfaction with continuity of care.

4.1B.2 The evidence on how continuity of care can be effectively achieved, and the barriers to achieving this

The study by Piette et al. was one of the few to address the views of patients from ethnic minority groups. Although those patients with diabetes who were English speakers reported greater satisfaction with continuity of care, the study failed to detect improved rates of satisfaction for continuity of care for those who did not speak English.

4.1B.3 What are the possible gaps in the research?

Studies of adequate size to examine the issues facing patients from ethnic minority groups regarding continuity of care and how interventions can be designed to overcome these gaps.

4.2 Cancer

We found eight eligible studies (Johansson et al., 1999; O’Malley et al., 1997; Boman et al., 1999; Smith et al., 1999; Jarrett, Payne and Wiles, 1999; Addington-Hall et al., 1992; Smeenk et al., 1998; van Harteveld, Mistiaen and Dukkers van Emden, 1997).

4.2.1 The evidence of the impact of continuity of care (or lack of it) on the process and outcomes of care, and costs and disbenefits

Four studies examined the care of patients discharged from hospital: three trials and one survey of patients offered outreach care. By far the most comprehensive was a Swedish integrated care randomised trial which fielded a dedicated team to give quick home-care nurse referral, shared records, good GP links and a dedicated hospital-based co-
ordinating project group (Johansson et al., 1999). This generated large increases in both contacts and patient satisfaction but costs were not detailed.

An American primary care-based study examined uptake of cancer screening (breast and cervix) in a multi-ethnic group of women (O’Malley et al., 1997). This telephone survey showed that higher uptake was associated with receiving primary care from just one site. Levels were further enhanced when regular care was from one physician at this site. The cross-sectional method did not allow any assumption of causality but the authors did not examine alternative explanations of their findings.

4.2.2 The evidence on how continuity of care can be effectively achieved, and the barriers to achieving this

Three studies were concerned to document and perhaps ultimately reduce the number of professionals that a patient might encounter. One successful Swedish controlled trial was mainly designed with this in mind (Boman et al., 1999). A Scottish study (Smith et al., 1999) found that a typical cancer patient encountered at least 28 different doctors in the first year after diagnosis. In Southampton a nurse-led survey documented the considerable number (up to 20) of part-time shift-working community and specialist nurses encountered by dying patients receiving palliative care at home over periods of only a few weeks (Jarrett, Payne and Wiles, 1999).

All the studies reported some benefit from continuity of care as variously defined. The benefits in the trial by Addington-Hall et al. (1992) were very small. The open trial conducted by Boman et al. was unusual in reporting a successful intervention to improve continuity associated with a significant improvement in the study patients’ ‘sense of coherence’ scale, which represents the individual’s way of looking at life in general (Boman et al., 1999).

4.2.3 What are the possible gaps in the research?

Our search found relatively few papers in this area. Cancer has such a major impact on patients’ lives that it would seem to offer the potential for important quality gains if their experience of care from diagnosis onwards can be improved. Understandably, most studies have originated from specialist centres wishing to improve and extend their care. Hence there has been an emphasis on provision of outreach initiatives.

- Tracking patients’ experience of NHS cancer care to develop suitable trial questions

In the British NHS context of an effective primary care system combined with increasingly specialised cancer care concentrated on major tertiary centres, there is a clear need to track patients’ experience from suspicion through diagnosis to ongoing treatment and care. There are promising developments in informational continuity using IT to evaluate. Less often prioritised are questions on how the care process affects patients’ ability to cope with and
Continuity of Care

indeed recover from cancer. Underlying the study by Smith et al. (1999) is the assumption that too many specialists may lead to disorganised and truly discontinuous care. Better understanding of the intersectoral interfaces is needed to set up an appropriate trial, for example to assess the costs and benefits of involving fewer professionals or of co-ordinating their working more effectively.

- Clinical responsibility in complex care programmes

One challenge with all complex care systems is that of clinical responsibility. Who is in charge, and where does the buck stop for difficult decisions that patients may face, particularly if they suffer from a serious health problem such as cancer? Understanding such questions suggests the need for a qualitative thread running alongside any formal trial.

4.3 Care of older people

We reviewed 15 articles examining continuity of care for older people (von-Sternberg et al., 1997; Parkes and Shepperd, 2000; Anttila et al., 2000; Lough, 1996; McWilliam and Sangster, 1994; Simpson, Scothern and Vincent, 1995; Epstein et al., 1990; Wasson et al., 1996; van Achterberg et al., 1996); Jackson, 1994; Payne et al., 2000; Klop, van Wijmen and Philipsen, 1991; Naylor, Bowles and Brooten, 2000; McWilliam, 1992; Naylor et al., 1999).

4.3.1 The evidence of the impact of continuity of care (or lack of it) on the process and outcomes of care, and costs and disbenefits

There is little evidence of research focusing specifically on continuity of care in health services for older people. However, the vast and diverse literature on the organisation and processes of care for elderly people in health care settings is often centrally concerned with continuity-related issues. Much of this research is located in the interface between secondary and primary care and particular attention has been paid, in the UK and elsewhere, to the process of discharge planning for vulnerable groups of older people and to the organisation of post-discharge care.

One of the most important aspects of the health–social care interface for older people is discharge planning. Jackson's 1994 review of the literature from a gerontological nursing perspective found a lack of rigorous research in this area (Jackson, 1994). The studies were mostly descriptive and the few experimental studies had limited follow-up and a mixture of positive and negative results. Jackson points out that it is difficult to prove that discharge planning, which is assumed to promote continuity of care between hospital and community, has a direct impact on health status as it is only one of many factors impacting on patient outcomes. She also found mixed evidence on the impact of discharge planning on costs and, crucially, a lack of evidence that discharge planning programmes included consultation with patients and families about their concerns surrounding the discharge or about their own perceptions of need (see also Section 8.3). The problem of interpreting
Continuity of Care

contrasting findings in very different experimental studies continues with more recent research (von Sternberg et al., 1997; Parkes and Shepperd, 2000; Anttila et al., 2000).

We only found one study in this area (care of older people) with the explicit aim of improving and testing continuity. Wasson et al. (1996) looked at provider continuity in outpatient care. The study group who saw the same outpatient physician more of the time were more satisfied, with fewer and shorter hospital admissions. Another study, of care co-ordinators for older people living in communities in the Netherlands, is also unusual in its effort to operationalise and improve different elements of continuity – interdisciplinary, interpersonal and informational (van Achterberg et al., 1996).

4.3.2 The evidence on how continuity of care can be effectively achieved, and the barriers to achieving this

Qualitative studies investigating the experiences of older patients discharged from hospital point consistently to a need for more effective co-ordination and communication and planning of care. For example, Lough (1996) interviewed patients with congestive heart failure after their discharge from hospital, and found a need for an ongoing care plan which would enable patients and informal and professional care-givers to manage a changing and uncertain illness trajectory (see also McWilliam and Sangster (1994) and Simpson, Scothern and Vincent (1995)). Qualitative studies investigating the implementation of discharge processes also reveal the many challenges involved in improving co-ordination and communication in complex environments where role confusion and conflicting organisational goals are common (McWilliam and Sangster, 1994).

The effectiveness of the transfer of patient information between hospital and community settings has been investigated in a systematic review of research in the field of discharge planning (Payne et al., 2000). Evidence was sought for answers to key questions, for example: what are the formal and informal strategies for the transfer of information? is IT used? and why does communication breakdown? The researchers found only limited evidence directly related to their concerns and a lack of empirical research in this area. The database produced from this study will soon be available for further research. Jackson (1994) found mixed evidence on the impact of discharge planning on costs, assessed mainly through lengths of stay and readmission rates. Crucially, a Cochrane systematic review of discharge planning (Parkes and Shepperd, 2000) reports that although discharge planning may lead to a reduction in length of stay, and in some cases may reduce readmission to hospital, it is important to take into account the context in which policies such as discharge planning are being implemented. A further problem identified by this review is the selection of measures of outcome. None of the studies included in the systematic review addressed a key aim of discharge planning: the effectiveness of communication between different providers.
Continuity of Care

Continuity of care, as a concept, is seldom explicit in this literature. Where it is mentioned, its meaning is usually implicit and seems to refer to continuity of provider and/or geographic continuity. Alternatively, continuity may appear as an ‘X factor’ which is invoked to explain unexpected or unwelcome findings, as in a study of geriatric assessment (Epstein et al., 1990) which suggested that one of the reasons for little benefit being detected was the lack of continuity post-assessment.

4.3.3 What are the possible gaps in the research?

There is a growing literature on older people’s experiences of health care which points to serious shortcomings in the organisation of care and in care processes from the user perspective. However, currently it is difficult to disentangle continuity issues from other aspects of the care process that impact on service users, such as resource constraints, eligibility criteria, and the sensitivity and interpersonal skills of professionals in their dealings with patients. Further research is urgently needed to illuminate the meaning of continuity of care from the user perspective and to determine how and in what ways continuity is significant for service users.

In the UK context much of the research on care processes for older people, particularly at the health/social care interface, has quickly become outdated in the light of continuing changes in the organisation of care. Indeed, the situation has evolved further since this scoping exercise was commissioned. The effect of the latest changes, announced in the recent NHS Plan, which will bring health and social services into partnership in care trusts, will need to be carefully assessed. Their impact on continuity of care will need to be an explicit element in the research agenda.

4.4 Mental health

We reviewed 31 studies concerned with mental health or substance abuse (Johnson et al., 1997; Bachrach, 1981; Tessler, 1987; Ware et al., 1999; Houl et al., 1983; Bindman et al., 1997; Brekke et al., 1999; Hall, et al., 1994; Paykel et al., 1982; Bindman et al., 2000; Brindis, Pfeffer and Wolfe, 1995; Godley et al., 1994; Malla et al., 1998; Marshall, Lockwood and Guth, 1995; Muijan et al., 1992; Tyrer et al., 1995; Tyrer et al., 1998; Herman et al., 2000; Kopelowicz, Wallace and Zarate, 1998; Olfson et al., 1998; Morgan, 1989; Tessler and Hayes-Mason, 1979; Marshall et al., 2000; Holloway et al., 1995; Bjoerkman et al., 1995; Ramana et al., 1999; Repper, Ford and Cooke, 1994; Tansella et al., 1995; Teague, Drake and Ackerson, 1995; Tyrer et al., 2000; Tyrer and Remington, 1979).

Definitions and conceptual boundaries

Mental health context

Continuity of care has been regarded as an important issue in the development of mental health services. With the shift from long-stay hospitalisation (where longitudinal and geographical continuity are intrinsic) to community-based care, concern became focused on
Continuity of Care

how aftercare services should be organised to meet the needs of patients who have long-term, often lifelong, difficulties. Severe and enduring mental health problems, by their nature, present special challenges to continuity. Earlier definitions and classifications were sensitively analysed and brought together by Johnson et al. (1997). They identified the following dimensions as relevant to severe mental illness (our comments appear in italics):

1. continuity of service provision (the patient remaining in touch with the services – *longitudinal*)
2. extent of breaks in service delivery (*gaps* – often the converse of 1)
3. continuity of contact with particular professionals (*longitudinal, perhaps with personal/ relational*)
4. implementation of plans for services (*arguably not a specific aspect of continuity as such*)
5. co-ordination with primary care services (*cross-boundary*)
6. co-ordination with informal carers and with formal carers outside the specialist mental health services (*again, cross-boundary*).

- **Broad definitions**

Three studies (Bachrach, 1981; Tessler, 1987; Ware et al., 1999) offered broad definitions of continuity of care including multiple dimensions or elements. In an early overview of continuity of care and mental health services, Bachrach (1981) defined continuity as ‘a process involving the orderly, uninterrupted movement of patients among the diverse elements of the service delivery system’.

The most common elements of continuity highlighted in the studies we included in the review were regimen/comprehensive (Hoult et al., 1983; Malla et al., 1998; Marshall, Lockwood and Gath, 1995; Muijan et al., 1992; Tyrer et al., 1998; Kopelowicz, Wallace and Zarate, 1998) and cross-boundary (Tessler, 1987; Bindman et al., 1997; Bindman et al., 2000; Brindis, Pfeffer and Wolfe, 1995; Herman et al., 2000; Kopelowicz, Wallace and Zarate, 1998; Olfson et al., 1998; Morgan, 1989). Three studies focused on relationship (Hall, et al., 1994; Paykel et al., 1982; Repper, Ford and Cooke, 1994), two were team (Brekke et al., 1999; Teague, Drake and Ackerson, 1995), two longitudinal (Godley et al., 1994; Tyrer and Remington, 1979) and one geographic (Tansella et al., 1995). One study focused on the patient perspective (Bjoerkman et al., 1995) and one concerned the element described by Bachrach (1981) as responsibility. This highlighted the need, in severe mental illness for a ‘continuity agent’ who may deliver direct care but whose primary role is to co-ordinate services and ensure implementation of plans (Muijan et al., 1992). This also applies in other groups with complex needs such as children with cardiovascular disease (Sullivan, 1995) (see Section 8.3.3), older people (4.3) and people with a terminal illness (4.2).
Continuity of Care

- More specific definitions

Five of the 31 studies offered clear definitions of continuity elements (Ware et al., 1999; Brekke et al., 1999; Hall et al., 1994; Paykel et al., 1982; Bindman et al., 2000).

One study examined whether the implementation of the Care Programme Approach (CPA) improved continuity and whether patient outcomes improved as a result. It identified and defined three continuity elements: the perceived accessibility of services and knowledge about them (experienced continuity), the number of key workers in a defined period of time (longitudinal), and the proportion of time out of contact with services (gaps – see above) (Bindman et al., 2000).

In a US ethnographic study of the meaning of continuity of care in mental health services (Ware et al., 1999), six mechanisms of continuity were identified with the aim of producing a standardised measure of continuity of care. These included ‘pinch-hitting’ (workers being prepared to carry out tasks usually outside their remit), troubleshooting (anticipating potential problems), smoothing transitions, creating flexibility, speeding the system up, and contextualising (positive reframing of dysfunctional behaviour). We see these elements as aspects of team continuity but they were not looked at in relation to outcomes.

A ‘2x2’ experimental study by Hall (1994) compared the effects of desipramine and ‘counsellor continuity across inpatient and outpatient treatment’ (compared with a placebo and standard care) in the treatment of cocaine abusers. Personal (relational) continuity was found to enhance abstinence and treatment attendance. Paykel et al. (1982), in a randomised controlled trial, compared supportive home visiting by community psychiatric nurses (CPNs) to routine outpatient care for patients with neurotic diagnoses. ‘Longer consistent care from one person was associated with higher patient satisfaction and earlier discharge from care’, although there was no effect on symptoms, social adjustment or burden on families.

4.4.1 The evidence of the impact of continuity of care (or lack of it) on the process and outcomes of care, and costs and disbenefits

We identified 12 studies which described or evaluated comprehensive treatment programmes, where the intervention involved a strong continuity element (Hoult et al., 1983; Brekke et al., 1999; Paykel et al., 1982; Brindis, Pfeffer and Wolfe, 1995; Godley et al., 1994; Malla et al., 1998; Marshall, Lockwood and Gath, 1995; Muijan et al., 1992; Tyrer et al., 1995; Tyrer et al., 1998; Herman et al., 2000; Kopelowicz, Wallace and Zarate, 1998). Eight of these were well-conducted randomised controlled trials (Hoult et al., 1983; Paykel et al., 1982; Marshall, Lockwood and Gath, 1995; Muijan et al., 1992; Tyrer et al., 1995; Tyrer et al., 1998; Herman et al., 2000; Kopelowicz, Wallace and Zarate, 1998). Several studies showed clear benefits. In a randomised trial comparing supportive home visiting by CPNs with routine outpatient
Continuity of Care

Care, personal continuity was associated with higher patient satisfaction and earlier discharge from care (Paykel et al., 1982). A randomised controlled trial comparing intensive support at home to standard hospital care showed clear benefits from home treatment. These included an 80% reduction in hospital stay, slight improvement in psychopathology and functioning, and increased patient and staff satisfaction (Muijan et al., 1992). It was made clear that standard care involved outpatient appointments only. In a small prospective study examining the effectiveness of a psychosocial rehabilitation clubhouse, Brekke et al. (1999) found that service continuity had more influence on symptoms than intensity of contact, whereas intensity had more influence on hospitalisation and psychosocial functioning.

4.4.2 The evidence on how continuity of care can be effectively achieved, and the barriers to achieving this

Six of the studies identified a discrete activity aimed at increasing continuity (Tessler, 1987; Hall et al., 1994; Brindis, Pfeffer and Wolfe, 1995; Herman et al., 2000; Kopelowicz, Wallace and Zarate, 1998; Olfson et al., 1998). An intervention involving an intake clinician following 112 psychiatric patients through hospital admission and co-ordinating discharge plans was found, over time, to increase patient acceptance, improve linkage to recommended services, improve community adjustment, and reduce family and public complaints (Tessler, 1987). Kopelowicz, Wallace and Zarate (1998) demonstrated that early outpatient attendance could be improved by 48%, for a small group of patients with psychotic disorders. This was achieved through providing sixteen 45-minute structured training sessions to prepare them for community adjustment. Another continuity tool, ‘Critical Time Intervention’, an enhanced level of care straddling the transition from a New York homeless shelter to community housing, was found to reduce negative symptoms of schizophrenia in homeless men (Herman et al., 2000).

Service barriers to continuity

There was some evidence of discontinuity at the primary/secondary interface with poor communication between GPs and psychiatric teams being identified as a continuity failure (Bindman et al., 1997). In another study where ethnography was used to look at the process of 106 referrals to psychiatric outpatients, a complex referral pattern emerged in which management difficulties were as influential in referral decisions as severity of illness. Referrals took between three months and one year, doctor/patient relationships deteriorating if the referral process lengthened, only 19% of referral letters stated an explicit reason and, despite evident social problems, no patient was referred to social services (Tessler and Hayes-Mason, 1979). Outcomes can be related to factors other than the care process. When integrated care by a multidisciplinary team was evaluated in a randomised controlled trial, a 14% reduction in bed use and associated costs was achieved on two sites, but at a third, costs doubled. This was found to be a result of inadequate bed provision, necessitating extra contractual purchasing, an
Continuity of Care

outcome that was unrelated to the direct care being offered (Tyrer et al., 1998).

- **Continuity and ‘control’ of patients**

  In the field of mental health, patient barriers to continuity may actually be more disruptive than organisational obstacles. Psychiatric care can be experienced as unacceptably oppressive by service users, and psychotic patients frequently lack awareness of their illness, particularly during acute exacerbations. Delusional and paranoid symptoms increase the likelihood of poor engagement with services and, as this can be associated with increased risk, service developments intended to overcome this barrier such as assertive outreach, supervised discharge and proposed changes to the Mental Health Act, are moving towards greater coercion and control.

  Some studies were found which focused directly on the problem of acceptance of service. A prospective survey of 146 psychiatric inpatients, which aimed to predict compliance with care on the basis of patient characteristics, found that patients who had schizophrenia, were married and felt more hopeless were more likely to comply with aftercare (Tessler and Hayes-Mason, 1979). Olfson et al. (1998) tested a simple measure, an outpatient clinician making face-to-face or telephone contact with schizophrenic patients prior to discharge from hospital, and found increased outpatient attendance and reduction in symptoms of hostility and suspicion.

- **Continuity of care and ethnic minorities**

  The over-representation of black and other ethnic minority patients in the psychiatric inpatient population highlights the importance of paying attention to the needs of these groups. In 15 of the studies no reference was made to ethnicity. In 11, the ethnic composition of the patient groups was stated but only one reported efforts to ensure that ethnicity of subjects was representative of the community (Muijan et al., 1992). Two studies looked at continuity issues in relation to black patients. In a prospective study evaluating the relationship between implementation of the CPA and continuity of care, Bindman et al. (2000) failed to detect a difference in continuity of care experience between patients of different ethnic groups. In a separate study by the same authors (Bindman et al., 1997) measuring communication and joint working between GPs and psychiatrists, although GPs perceived that their involvement with black patients was less than with white patients, this differed from the perceptions of black patients themselves. The suggestion that poor relationships with GPs contributed to black patients’ later poor engagement with psychiatric services was therefore not supported. An unanswered question is whether black patients have lower expectations of their GPs.

- **Disbenefits**

  One of the barriers to provision of care is the difficulty in locating service users and targeting those with the highest level of need. When procedures are put into place to improve tracking and levels
of contact and service delivery, use of resources can increase. This was found by Tyrer et al. (1995) in a randomised controlled trial which showed that keyworking under the CPA was effective in increasing client contact but this resulted in increased bed usage. A review of five randomised controlled trials of case management (Marshall et al., 2000) showed that although client contact increased under case management, bed usage doubled. However Holloway et al. (1995) identified seven studies reporting a significant decrease in admissions, while two reported an increase and six found no differences.

4.4.3 What are the possible gaps in the research?

There are difficulties in accessing the perceptions of some service users, whose views and beliefs may fluctuate and whose suspicion of the mental health system may extend to the research process. There are gaps in our understanding about how users experience mental health services, their views and values. Finally the trend towards greater coercion in mental health care may raise ethical issues and warrants efforts to find alternative solutions which may be more acceptable to service users.

4.5 Primary care

We found 17 studies (Becker, Drachman and Kirscht, 1974; Freeman and Richards, 1994; Hjortdahl and Borchgrevink, 1991; Freeman and Richards, 1990; Hjortdahl and Laerum, 1992; Flocke, 1997; Freeman and Richards, 1993; Freeman, 1989; Kibbe, Bentz and McLaughlin, 1993; Howie et al., 1999; Flocke, Stange and Zyzanski, 1997; Taira et al., 1997; Fleming and Andersen, 1986; Rubenstein et al., 1996; Hjortdahl, 1992; Del-Mar and Wright, 1995; Wasson et al., 1992).

4.5.1 The evidence of the impact of continuity of care (or lack of it) on the process and outcomes of care, and costs and disbenefits

Evidence from primary care complements that from other areas of medicine. Continuity of care is one of the core defining features of general practice all over the world, yet evidence for its importance and proper role as an agent of improved outcomes other than satisfaction is still scanty.

- **Longitudinal continuity**

  In one of the earliest trials (1974) Becker, Drachman and Kirscht set up two similar paediatric outpatient clinics in the USA, the only difference being that the study clinic offered continuity of provider (physician), that is *longitudinal continuity*. Mothers were interviewed nine months later. All staff were interviewed and clinic utilisation assessed. There were impressive satisfaction benefits in the continuity clinic for both staff and patients. The clinics ran more smoothly with shorter waiting times, longer consulting times and greater disclosure of personal problems to physicians. The authors described the whole process as ‘beneficial mutual reinforcement’.

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The only comparable trial, also in USA outpatient practice, was for long-term care of elderly men (Wasson et al., 1996) and is described in Section 4.3. Here again, longitudinal continuity was associated with better satisfaction and also reduced costs in the form of fewer and shorter admissions to hospital. However, a cross-sectional study of patients with epilepsy in England failed to find any significant association between longitudinal continuity (seeing the same doctor more) and aspects of epilepsy care (Freeman and Richards, 1994). In Norway, Hjortdahl and Borchgrevink (1991) found a mixed set of associations of GP-reported resource use with longitudinal continuity in their survey. More continuity was associated with fewer tests in shorter consultation times but with more prescribing, referrals and sickness certification. This area needs further study, preferably with at least medium-term follow-up. The wide range of longitudinal continuity with strong positive association with rising age was documented in a retrospective record survey in England in 1990 (Freeman and Richards, 1990). There was less marked association with reporting a major health problem and none at all with gender or with length of time registered in the practice. The most potent factor, however, was the use of a personal list GP registration system where patients were not normally allowed to consult with other GPs in the group.

• **Relational or personal continuity**

Enhanced patient satisfaction was also found by Hjortdahl and Laerum (1992) in Norway in their large post-consultation questionnaire survey. Here the quality of patient–GP relationship was assessed and correlated significantly with satisfaction (relational continuity), while the frequency and duration of contact was relatively much less important. Flocke (1997) confirmed this finding in the USA in testing her ‘Components of Primary Care’ index which includes questions on preference for a regular physician and on interpersonal communication. In an interview survey, Freeman and Richards (1993) were able to find how English patients in group practices were more critical of and discriminating about their doctors when they could choose any doctor rather than be confined to their registered GP in a personal list system. In another analysis of his data, Hjortdahl studied the doctors’ side of this relationship to look at how long and how intensively GPs had to have seen patients in order to feel responsible for them and then to know them well (Hjortdahl, 1992). Responsibility was significantly associated with knowing the patient for at least three months over at least two consultations, but knowledge demanded much more: five years, or at least six consultations in the past year.

The balance of evidence is that more provider continuity is associated with greater satisfaction and lower costs. **Relational continuity** is more relevant but much more difficult to measure and at least a moderate level of **longitudinal continuity** is necessary for patients to make therapeutic relationships with professionals (Freeman and Hjortdahl, 1997).
4.5.2 The evidence on how continuity of care can be effectively achieved, and the barriers to achieving this

Appointments with medical staff are normally mediated by practice receptionists, who are sometimes blamed for being a barrier between patient and doctor. An observational survey of receptionists at work in four large English group practices suggested that they do indeed have some potential for enabling patients to see their chosen doctor, but that this is limited by practice resources and policies, normally dictated by the doctors (Freeman, 1989). The only study to try a comprehensive set of policies to enhance longitudinal continuity is that of Kibbe, Bentz and McLaughlin (1993). Using a comprehensive policy of continuous quality improvement applied by all staff, Kibbe and colleagues were able to achieve a highly significant 64% rise in longitudinal continuity.

- Forced discontinuity?

A less attractive recent feature of US primary care is forced discontinuity, where patients have to enrol with a new doctor annually when their company's insurer swaps policies owing to price or other competition. Flocke, Stange and Zyzanski, (1997) were able to show disadvantages in care process; interpersonal communication, doctor’s knowledge of the patient and patient’s preference were coupled with a substantial reduction in longitudinal (usual provider) continuity.

4.5.3 What are the possible gaps in the research?

- Understanding barriers to better relational continuity

We still know very little about understanding barriers to greater personal continuity and then to improving it. Qualitative work is needed to unpick how both patients and professionals (including managers and receptionists) trade-off their priorities for continuity against pressures for rapid access and increased role specialisation. We need to find out how to be more flexible in helping patients to access a personal doctor or nurse when appropriate – this means understanding how patients’ concerns may vary, as does their expertise in finding their way through the health care system. Studies which track patients’ care trajectories are therefore needed. The concept of the ‘inverted U’ is helpful. Extremes of quick access to an impersonal professional and equally of being locked in to a single provider seem unacceptable, but the best balance will vary with the patient’s personal and medical context.

- Continuity and outcomes in an evolving primary health care service

Underlying these issues is a central question for primary care, particularly general practice, as it evolves. Primary care sets high value on treating the patient as a person rather than emphasising the disease process. Personal/relational continuity is closely linked to this aim. What is the added value of relational continuity? Can we assess this in terms of improved health outcomes and/or reduced costs over time so that we can prioritise care provision to best advantage? There is currently almost no such evidence in the
Continuity of Care

British context. Change is happening in any case with *continuity of team* and practice (with improved and computerised records and secondary care links) tending to replace continuity with individual professionals. The effects of such developments on patients and staff need to be evaluated. While better *continuity of information* may give promising service improvements (Del-Mar and Wright, 1995; Wasson *et al.*, 1992), there is little evidence so far to show whether this can compensate for any decline in longitudinal or relational continuity.

Clearly aspects of continuity of care are, or should be, relevant to patients’ interactions with non-medical members of primary and community health care teams. While there is much anecdotal evidence of their vital role in improving continuity for patients, no relevant studies were found in this area.

- **Implementing change**

Finally, we need to know how to implement change. Howie and colleagues (1999) have shown that patients feel better, as assessed by feeling more enabled, when they knows the doctor well and when consultations are of adequate length. But many GPs perceive that pressure of demand prevents them from providing a better service. Action research may provide a useful approach to finding the best approach to the challenge of offering good access for urgent but often short-lived problems, such as feverish children, and appropriate relational continuity for effective consultations for more chronic problems, such as depression or diabetes.
4.6 Maternity care

Continuity of care was variously described or implied. Definitions offered included:

- a stated commitment to a shared philosophy of care
- a strict adherence to a common protocol for care during pregnancy and/or childbirth
- a system whereby those who are discharged from hospital are routinely referred to community services, or the actual provision of care by the same caregiver or small group of caregivers throughout pregnancy, during labour and birth (Hodnett, 2000b).

4.6.1 The evidence of the impact of continuity of care (or lack of it) on the process and outcomes of care, and costs and disbenefits

Twelve studies were identified and included in this scoping exercise (Hodnett, 2000b; Binstock and Wolde-Tsadik, 1995; McCourt et al., 1998; Page et al., 1999; Brown and Lumley, 1998; Giles et al., 1992; Hundley et al., 1997; Rowley et al., 1995; Shah et al., 1993; Tucker et al., 1996; Waldstrom and Turnbull, 1998; Hodnett and Roberts, 2000). Eight of the studies compared midwifery care (either as one-to-one care or team care) with standard care (Hodnett, 2000b; McCourt et al., 1998; Page et al., 1999; Giles et al., 1992; Hundley et al., 1997); Rowley et al., 1995; Tucker et al., 1996; Waldenstrom and Turnbull, 1998). One of the studies (Tucker et al., 1996) included GP care as part of the team. All but one of the studies report increased levels of satisfaction for women receiving some form of team care provided predominantly by midwives. Team care in some cases appears to reduce the amount of intervention during labour and delivery (Rowley et al., 1995; Tucker et al., 1996), for example induction of labour.

4.6.2 The evidence on how continuity of care can be effectively achieved, and the barriers to achieving this

Compared with other areas, a sizeable body of research is emerging in the area of maternity services examining interventions that aim to improve continuity of care. The main focus of research is some form of midwifery care. Three systematic reviews have been conducted: two examined the effectiveness of continuity of care by midwives (Hodnett, 2000b; Waldstrom and Turnbull, 1998), and the other (Hodnett and Roberts, 2000) examined the effect of home visiting providing social support for socially disadvantaged women. It appears that team care, or other similar alterations to services that aim to reduce the number of people women see, result in improved satisfaction (however, see Section 8.1 below). An evaluation of the home-based maternity record across eight countries highlighted the need to choose an appropriate person to introduce change, and that a change in systems should be accompanied by training materials at the introductory stage. It is likely
Continuity of Care

that this applies to the introduction of other new ways of delivering services aimed at improving continuity of care.

4.6.3 What are the possible gaps in the research?

The research in this area focuses on evaluating adjustments to care delivery that aim at improving continuity of care. In a few cases continuity of care is measured, usually by proxies such as the number of staff women had to see, or familiarity with staff (Page et al., 1999. Further work is required to explore the relationship between continuity of care and measures of outcome such as induction of labour, episiotomy rates, and pain relief during labour. This would show how the outcomes relate to interventions specifically defined in terms of the types of continuity and care provider being studied.
Part B  Conceptual analysis

5  The challenge of understanding patients’ trajectories through care

6  Continuity of care is a relational idea, not a constant entity

7  Thinking laterally

8  Some key organisational/structural/professional/reational issues highlighted in existing research

9  What are the possible gaps in the research?

10 Methodological challenges highlighted in existing research

11 What methodological approaches/innovations are likely to be fruitful?

5  The challenge of understanding patients’ trajectories through care

As we have highlighted in earlier sections of this report, there are significant definitional problems associated with the term ‘continuity of care’, with consequent related research findings being almost inevitably diverse and often conflicting. Furthermore, much of the research in this general area has focused on very particular issues linked to certain known organisational ‘bottlenecks’, or on specific matters of major professional interest. Research on the ‘patient’s perspective’ has been relatively neglected in most of these studies, even though almost all of them profess to be ‘patient-centred’ or ‘patient-orientated’. While it is the case that from both an organisational and a professional point of view ‘continuity’ – whatever it is taken to mean – is considered an implicit virtue, there is very little research that gets to grips with continuity in terms of the potentially complex world of the patient’s personal health care trajectory. This is understandable. It is far easier to tackle specific and bounded professional or organisational concerns. Yet it is vital to research and explain how people (patients) move through the health care system, and what they expect of it, through all the stages of life, and in the context, among other factors, of their gender, ethnicity, and class and so on – let alone considering the specific forms of ill health that have brought them into contact with the system. Thus, understanding the process whereby patients’ health care trajectories link into the health care system is essential to successfully undertaking realistic and long-term organisational and professional planning in the area of continuity of care (Frankenberg, 1987).

6  Continuity of care is a relational idea, not a constant entity

Following these arguments, ‘continuity of care’ is most appropriately considered as a relational idea. The context is not only the individual
relationship between the doctor, nurse or other health care professional and the patient at a particular point in time, but also the relationship between the patient and their own life stage, their long-term as well as short-term goals, and the social context (familial, employment and so on) within which they live. Given this complex context, we should not expect to find a ‘one size fits all’ view of continuity of care. Thus on a priori grounds it should be anticipated, if we move to focusing genuinely on the ‘patient’s perspective’, that not only will different groups of patients have radically different views of what ‘continuity of care’ is, and its value, but that individual patients will hold very different views of what it may be, both over time as they go through different life stages, and even at the same time for different health care purposes. In other words, once we move beyond what has been the conventional view that ‘continuity of care’ should be considered as an issue located mainly or only in specific managerial or professional concerns, then our approach to researching and understanding the idea and its implications must draw on a wider range of perspectives and methods than have been hitherto employed. By drawing on such a wider range of perspectives and methods we argue that there is a far greater likelihood of ultimately producing a workable synthesis of research findings which can be implemented and will meet the expectations and aspirations of patients, managers and professional staff.

7 Thinking laterally

The literature on continuity of care has been important to review but despite the large numbers of papers apparently focused on this area, for the most part their authors have symbolically and ritually paid obeisance to the idea, but have signally failed to explicate or analyse it substantively. In this respect it may be helpful if we pursue our argument by thinking laterally, and raise some general issues and concerns arising both directly from existing studies on continuity of care, and from other broader studies that point in innovative directions (Allott and Robb, 1998).

We identified these by a hand search and analysis of abstracts from the Web of Science database. We selected papers using similar search terms to the strategy outlined in Section 1 of Part A; we retrieved and further critically analysed papers from this source. We also used individual journal collections known to us (e.g. in sociology and anthropology) and other resources such as REGARD, Sociological Abstracts, and the Joseph Rowntree Foundation Knowledgebase.
8 Some key organisational/structural/professional/relation issues highlighted in existing research

8.1 Unintended consequences, informal solutions

It often appears to be taken for granted at managerial level that, in principle, the health care system either is or could be organisationally easily capable of ensuring ‘continuity of care’. Where this does not occur, managerially it is likely to be seen as the result of professional or personal failings. However, what are considered to be inherent ‘system’ gaps in communication – losses of information or momentum – or in the delivery of care are often taken for granted in the everyday practice of professionals. Such gaps may arise from the unintended side effects of organisational and technical change, and even from the introduction of interventions specifically designed to improve ‘continuity of care’. Cook, Render and Woods (2000) reviewed a Veterans’ Affairs funded series of studies on the problematic effects for patients of health care transitions between sectors of US health care. The firm implication of their review is that, in effect, all health care systems – however carefully constructed – will endemically generate problems in relation to transitions and transfers of patients. They suggest that a more profitable focus is one that identifies and builds on the almost always innovative efforts of professional staff in practice, which allow the circumvention of inevitable defects in the formal design of health care systems. Examples included discharge planning documents, ‘report’ activities and even private notes kept in case official records are lost.

However, unintended and problematic effects of organisational change can also occur which expose different and competing elements of continuity. For example Farquhar, Camilleri-Ferrante and Todd (1996) found that introducing team midwifery to increase continuity of care at the point of delivery had the effect of reducing continuity of carer in antenatal and postnatal stages – which patients regretted. In this particular study small teams of two or three midwives managing all antenatal and postnatal care, and separate sets of midwives managing the intrapartum period, were all replaced by a larger team of seven midwives who managed the complete antenatal, postnatal and intrapartum period. This increased the team continuity and co-ordination of the health care framework, but decreased the personal and relational continuity from the patient’s point of view, as patients had contact with many more midwives. This work also highlights the problem with drawing too firm a conclusion from some of the existing research in which it is not clear whether the beneficial effects and satisfaction reported are due to greater continuity, or to midwifery care as distinct from care from other providers. Randomised controlled trials and other research focusing on outcomes (as described in Section 4.6.3) need to specify which part of the system is being identified as the intervention. These points were made at the Department of Health Colloquium on maternity care in 2000 (see Appendix 5).
Such research suggests that considerable caution needs to be exercised in implementing either major system changes, or tactical organisational changes designed to remedy specific aspects of continuity. Considerable attention must be paid to their unintended effects/defects, and to informal remedies which arise to try to remedy them.

8.2 Attributes and processes – balancing conflicting elements of continuity

8.2.1 Trade-offs

Recently the idea of ‘trade-offs’, commonly deployed in analyses in health economics, has been used to evaluate how patients balance continuity in health care against a range of other alternative attributes. Of particular interest is the extent to which patients value the process of health care, against its outcome. Ratcliffe and Buxton (1999), studying patients who have had a successful liver transplantation, use the technique of conjoint analysis to assess the relative importance of what are described as ‘process attributes’, including continuity of contact with the same medical staff, in relation to the outcome. In this study participants were able to make trade-offs between the ‘process attributes’, as well as between them and outcomes, with older people in particular valuing continuity highly.

8.2.2 Wider social context of trade-offs

However, studying ongoing processes, which is essentially what research on continuity must involve, does raise methodological issues about the use of terms like ‘process attributes’ – which apparently entrap a dynamic process within a static idea (an attribute). One study on trade-offs in relation to continuity which appears to acknowledge and manage many of these problems is that by Wilson et al. (1994) on native Canadians, examining the effects of relocation from native communities for dialysis treatment. The ‘trade-off’ here was between patients’ continuous contact with their own community (lack of which was causing serious social problems), and that of continuity with the senior professional caregivers at an urban hospital. These kinds of trade-offs, albeit in this case in a non-British setting, do indicate the importance of the social context of continuities in health care, which may challenge more narrowly and individually conceived trajectories in the physical management of a condition. This has clear relevance to the provision of appropriate care to frail older people in the UK.

8.2.3 Trade-offs should be studied in real time

The ways in which different priorities are balanced by patients, and indeed by health care professionals and managers, suggest that further research is needed into the trade-offs that each group may make in particular circumstances. However, it will be important to ensure that indeed these trade-offs are studied within the ‘real time’ processes to which they relate, rather than only in retrospect with the ex-post facto construction of such factors as ‘process attributes’.
8.2.4 Compromising continuity: the effects of competing organisational priorities

Continuity of care may often be threatened by conflicts at organisational and structural levels. Heslop, Elsom and Parker (2000) have highlighted the structural issues that lay behind the identification of the organisational need to improve continuity of care between emergency department, psychiatric outpatient, inpatient and community services for people seeking mental health care (see Section 4.4 above). These issues included most importantly the implicit impact of new policies (such as de-institutionalisation) which challenged existing informal and formal working practices, as well as increased demand resulting from demographic changes. Recognising the impact of such changes Heslop and colleagues show how emergency department nurses successfully negotiated further training opportunities and shifts in work allocation particularly through the development of a new triage tool. Previously the nurses had been overloaded with cases and smooth onward referral was problematic. Afterwards patients were more easily referred to others on the basis of agreed and established criteria.

8.2.5 Lack of input from patients

Similar issues have been raised by Hibberd (1998) in relation to policies to increase community services and reduce inpatient care. Hibberd argues that seamless care has been particularly impeded by the competitive philosophy of the internal market. The solution is the need to develop a new model of inter-sector teamwork if seamless care is considered a high priority. Such policies, and indeed Hibberd's intended solution, run a very substantial risk of having little or no input from the ultimate users of services, that is patients. This message comes out clearly in the analysis by Wyke et al. (1999). They address issues of continuity at an organisational and structural level, using five case studies to draw lessons for future NHS policy developments. This study was part of a national evaluation of total purchasing pilots (TPPs) and investigated the policy consensus on continuing and community care, and the historical context, structures and processes involving those setting up TPPs. They found a striking lack of user involvement in this process, and a common neglect of population-based health needs assessments.

8.2.6 Gaps between policies and local implementation

The problematic gap, in terms of continuity, between organisational factors and managerial policies and the everyday practice of health care, is noted by Porter and Ryan (1996). They used ‘critical realist’ ethnographic methods to investigate why awareness of policies does not always translate into practice. Although nurses in the study understood the importance of personal continuity in ‘the nursing process’, this perspective was in conflict with the imperatives of senior staff whose focus was on the insufficiency of economic and staff resources to provide the individualised care that the nurses felt was essential to their
view of the ‘nursing process’. Thus a task-oriented care management system, largely inimical to nursing continuity, remained in place.

8.2.7 Unforeseen consequences of change

The implications of this commentary are that managerial and organisational changes have a considerable impact on many issues of practice which are often not foreseen. Furthermore such changes are particularly likely to have an impact on continuity of care, as they frequently reconfigure boundaries between components of health care, producing new points of potential fracture. These changes then require informal mechanisms, constructed by individual staff or groups of staff or by patients and their families, to bridge gaps in care produced by these changes.

8.3 Transfers and discharges: interfaces between different parts of the health care system and their impact on continuity of care

There is no doubt that the majority of studies on ‘continuity of care’ have focused on issues of transfers and discharges between different parts of the health care system, and between the health care and formal and informal social care system. Organisationally and professionally, these points provide the most visible potential fractures in continuity of care. Many studies have noted difficulties at these points. The predominant concentration, perhaps understandably, has been on professional and organisational views, rather than on patient perspectives. Nonetheless a number of studies have begun to chart the patient’s situation and views (see Section 4.3.2). For example Clark and Dyer (1996) have highlighted the clash, and the gap, between hospital and community organisational imperatives. In their investigation of procedures for older people they note the difficulties between occupational therapy hospital discharge routines and the model of assessment prescribed by community care reforms. Their observation of older people and their carers revealed that the episodic nature of occupational therapy home visits, and their focus almost entirely on the point of discharge, mitigated against a continuing process of consultation and enhancement of independence. Such consultation was considered especially important as the needs of older people changed over time.

8.3.1 An example of the patient perspective

Another example of problems associated with discharge issues is given by Noyes (1999), who explored the views and experiences of young ‘ventilator-dependent’ people about their health and social care, education, and aspirations for the future. Noyes found they needed well co-ordinated services, yet these young people and their parents felt the disorganisation and inefficiency of the hospital system of discharge led them to much longer inpatient stays than necessary. They felt that little effort was put into possible transfers to an adult service environment and more transfers than they thought were necessary occurred between
Continuity of Care

NHS hospitals for treatment. Suggestions from the ventilator-dependent young people included the need for an inter-agency discharge policy and a key person to co-ordinate their care. This echoes the mental health co-ordinator of Hoult et al. (1983) (see Section 4.4).

8.3.2 Moving from integrated paediatric to fragmented adult care

A related study (Sawyer et al., 1998) which focused on transfer of young people with spina bifida from paediatric to adult health care found similar problems. The absence of co-ordinated multidisciplinary care in the adult health care system for this group is evident compared to their care in a paediatric setting. Transfers between services highlight many structural, financial and cultural differences between health care settings. Planning, implementation and evaluation of the transfer and the associated transition call for sophisticated and sensitive processes.

8.3.3 A secondary care solution – a continuity co-ordinator

One attempted solution to some of these problems is documented by Sullivan (1995) in describing the role of the patient care co-ordinator in the clinical setting of the Cardiovascular Program at Boston Children’s Hospital. This role combines utilisation review and management, discharge planning and liaison between parents, health care funders, community and hospital care providers, and the multidisciplinary hospital health care team. It includes an education/development component because of the complex implications of the disease treatment and the number of professionals and agencies involved in discharge/aftercare. The role is thus wholly geared towards achieving several simultaneous aspects of continuity – bridging gaps and resolving conflicts between numerous parties which might affect continuity – for example, between the hospital protocol for aftercare and the routines and resources of community services. Indeed, specific professional posts which are dedicated to such tasks have been considered to be a way of providing a formal, as opposed to an informal bridging mechanism, for managing in particular secondary–primary care transitions. Posts of this kind are common in services for older people (albeit more limited in scope than in the Boston Children’s Hospital example).

8.3.4 Ethical issues in secondary care discontinuity

However, other research has challenged the conventional central role of hospital-based care in relation to the issue of continuity. Pantilat, Alpers and Wachter (1999) discuss the ethical implications raised by the discontinuity of care imposed by the ‘hospitalist’ model of health care now being introduced in the USA. In this model a hospital-based secondary specialist assumes all responsibility for the patient’s treatment while in hospital, in contrast to the previous key role of the patient’s usual primary care physician. The situation is becoming more analogous to the British system of secondary care. In their research, Pantilat and colleagues use case studies to investigate problems arising in the hospital setting in relation to issues of confidentiality and trust concerning the patient’s HIV status. It appeared in their research that
Continuity of Care

major treatment decisions in a hospital setting may be problematically uninformed by existing comprehensive primary care knowledge. The importance of this study is that it demonstrates that discontinuity of care and knowledge is not just a technical issue, but may have profound ethical implications for patients.

8.3.5 Continuity poses difficult problems and may need much managerial will and persistence.

It is clear that most studies of the interface between different components of the health care system, and particularly secondary and primary care, demonstrate major problems in relation to experienced continuity – even with relatively little work having been undertaken directly on patients’ perspectives. Despite many similar analyses, and many attempts to find viable solutions, it is clear that the problems have often proved intractable – especially from the patient’s point of view. In part, this seems to be because of a failure to understand how patients’ perspectives might be incorporated more effectively in transfers and discharges, and also because of a lack of administrative and managerial knowledge of the practical lessons learnt in daily health care practice (or indeed the will to embrace these lessons).

9 What are the possible gaps in the research?

9.1 Explaining the meaning of ‘continuity’ and going beyond ‘failures of communication’

It will be clear from the above brief analysis that most of the work in the area of continuity of care seems to be practitioner-led or manager-led. Correspondingly where patients’ or users’ views are sought, definitions of continuity of care are often not conceptually sensitive to the ways in which such patients or users may understand the idea. In many respects the idea seems to be treated as professionally an almost self-evident issue, belying its ambiguous and multi-faceted nature. In this context something very general called ‘communication’ is often blamed for failure to ensure that continuity. In this context ‘communication’, presumably an aspect of team and cross-boundary continuity, often seems to be a similarly unexplained idea hiding many other more relevant and potent variables.

9.2 The importance of the specificity of context and the patient’s perspective

The major lesson from existing studies is that we must move beyond generalities about broad problems in ‘continuity of care’ and ‘failures of communication’ to examine very specific issues and contexts. We must examine the perspectives of all the parties involved and how indeed ‘continuity’ may still be established by a particular range of actions and practices, often of an informal kind. In this respect there is a huge gap in knowledge on how patients understand continuity and how they
Continuity of Care

themselves may bridge discontinuities in health care. Furthermore we
know little about the times, places and circumstances in which
continuity is more or less valuable, or indeed problematic to patients.
Similarly we also know little about how patients may trade-off the many
possible forms of continuity against each other, or relate the outcomes
of their health care to the processes through which that care is
undertaken. We also know little about the experience and views of
particular groups of patients, at particular life stages, within particular
family settings, with specific ethnicities, and – apart from pregnancy and
childbirth – of particular genders.

9.3 Understanding when discontinuity as well as
continuity may be valued

It is important to challenge and explore some basic assumptions which
seem implicitly to have guided much previous research. Most basic is
the assumption that ‘continuity’ in health care is an unmitigated and
inevitable good from a patient’s point of view. Given people’s complex
health care and life trajectories it seems highly probable that at times,
and perhaps at many times, continuity may be seen as a major problem
by patients. Patients may want only a ‘one-off’ transaction with a
virtually anonymous health care provider at key points in their life. At
other times they may wish to have greater continuity, either relational
or informational. They may wish to have continuity for some health care
conditions, or for certain issues, and not for others. In some cases
continuity of care based on congruence of knowledge between health
care provider and patient may be considered by patients to be a
problem – and in any case may not be possible.

9.4 The problems as well as the possibilities of
improving communication between professionals and
patients in relation to continuity of care

9.4.1 Improved communication could remove choice for
patients

As we have noted above, the need for ‘improved communication’ seems
to have become a routine phrase in considering remedies to problems in
continuity of care. At one level this seems indisputable – even a truism.
However we must be cautious and reflective in relation to this position.
Not only is the almost ubiquitous reference to communication frequently
ill defined, it is by no means as obvious as it appears that congruence in
communication between doctor (or other professional) and patient is a
universal panacea – or even that it can realistically be implemented. In
a recent article, Beagan (2000) charts some of the difficulties arising
from what she calls ‘the relentless socialisation’ in medical training
towards a common professional outlook, neutralising differences
between doctors, and by implication producing a neutral communicative
context in relation to patients.
Continuity of Care

9.4.2 Patients may value differences between doctors

Doctors, as Beagan points out, are as socially positioned as their patients, and a cloak of neutrality and uniformity belies underlying differences. There is evidence not only that these differences continue to operate, but that they may be highly valued, and moreover in some intriguing work such as that of Sachs (1989) that they may be therapeutically important and reinforce rather than subvert the doctor–patient relationship. In other words, it may be precisely the differences rather than the similarities between doctor and patient that allow an effective long-term as well as short-term relationship to occur (Frank, 2000). In more colloquial terms, in certain circumstances patients value strangers rather than friends as their health care advisors. This may be a particularly important issue in considering the range of ways in which patients evaluate ‘continuity of care’.

9.5 Neglected settings on research in continuity of care

9.5.1 Residential care and prisons

Some of the most interesting work on continuity of care is that which relates to settings other than the more conventional boundary between primary and secondary care. Some of this work relates to demographic groups that are relatively small but present especially problematic issues for policy and practice. For example, such a case is managing the health of children both during and following stays in foster or residential care. There are potential paradoxes here, for while in one sense residential care may appear to those outside to provide statutory and institutional continuity, there is considerable evidence that it provides neither that nor continuity in health care. A piece of work in which similar considerations are explored is Pettinari and Piper’s ESRC-funded work in 1999 and 2000 at King’s College on the continuity of health care in prisons: ‘Social organisation of prison health care in two institutional frameworks’, Department of General Practice and Primary Care, Guy’s, King’s and St Thomas’s School of Medicine.

9.5.2 Mental health care settings

In mental health care settings there is a particular need to examine the user perspective in the transitions, transfers and discharges that may frequently occur, and of course in terms of inpatient continuity of care. A user perspective would add substantially to the far more usual professional or organisational research in this area which tends to focus on pathological outcomes, and may well reveal additional important information in relation to some vexed questions of public policy, particularly the issue of control/supervision (see Section 4.4.2).
9.6 Continuity of care and quality of care

In evaluating the quality of care, which has become a major concern within health services research, our review has suggested, as we indicate in summary below, that we need to treat the process of care as just as important as the outcome of care. Evaluations of the quality of care, especially by patients, are likely to focus as much on the procedural aspects of their contact with the formal health care system as on categorical and retrospectively considered outcomes. By procedural aspects here we mean whether the sequence of events (the processes) in the patient’s trajectory of health care was undertaken in a proper, orderly, respectful and competent way such that, whether the formal outcome of a tranche of health care on other criteria was negative or positive, the process through which that outcome occurred was considered by patients as well as professional staff to be of high quality. There are very few studies that investigate this process, in which experienced continuity is a significant element.

9.7 New technologies and continuity of care

Much work is now being undertaken on various technical means of managing the electronic transfer of information on patients between health care professionals and organisations. It is important for patients’ perspectives to be sought on this issue. While such transfers may facilitate some professional and organisational goals in relation to continuity, it is not at all clear that in many settings, or for many groups of patients, such mechanisms would be welcome or viable. Of course, in addition to the potential role of transfers of traditional health care information between professionals (and perhaps increasingly to patients?), other major developments are occurring which raise a range of other issues about continuity. The increasing role of screening at various life stages, and particularly now genetic screening, raises a complex range of ethical as well as technical issues. There is a need managerially to try to ensure consistent professional access to this kind of information while at the same time maintaining a robust ethical position – for example in relation to clear rules of confidentiality on the one hand, and fully informed consent on the other. For many patients genetic knowledge in particular may be considered to be of an especially sensitive kind, in relation to which those issues of confidentiality (who has access to the information), and informed consent are a major concern. How do we balance (trade-off?) patients’ perspectives on these issues with professional concerns when they may be quite different? Although there is some work in relation to specific conditions such as HIV infection, the rapid spread of genetic testing in relation to an increasing range of conditions, and an increasing range of demographic groups, suggests that more research is urgently needed in this area.
Continuity of Care

9.8 The importance of researching the process of continuity

An overriding issue, which comes out of this review, is the importance of considering ‘continuity of care’ as a process. This means something which is set in a relational context (for example between doctor and patient, or between the patient and their family), in which perspectives may change either rapidly and/or radically over time. This may appear to be a self-evident point. However, at a time when the focus of most research in the NHS is on ‘outcomes’ it requires a reorientation to consider the ongoing aspects of continuity of care. Considering continuity of care from a patient’s perspective, as we have been asked to do, suggests a very different approach to conventional concerns with particular and usually time-limited transitions such as those from secondary to primary care in relation to individual medical conditions. It suggests that studies most of all have to be placed in the continuing context of patients’ lives. This means in particular their changing health care and life goals, their family and employment situations, and other salient social factors, as well as the setting of what has become a very dynamic and changing health care environment.

In these contexts it may be that patients will not necessarily want, or anticipate, one single and relatively unchanging kind of continuity of care, but will wish for more malleable structures and frameworks which fit with their own changing lives and aspirations. It may be helpful to add here that we should not confuse the trajectory of the disease (in relation to medical diagnosis and management) with the trajectory of a patient’s life. A long-term condition may imply particular kinds of continuities of care from a medical point of view. But social or other changes in a patient’s life, almost irrespective of the course of the disease, may give rise to quite different perspectives on the kinds of continuity or discontinuity of care that a patient may wish to have. We should also note that it is possible that discontinuity of care may become a highly valued commodity if a patient feels that their regular and routine (and continuous) health carer has failed to identify or deal with significant difficulties that they may have. In the case of multiple sclerosis it is a common complaint by patients that their regular doctors fail to fully investigate almost all symptoms which they report, and that the doctor ‘blames everything on the MS’. In such cases, discontinuity in the form of moving to another doctor or health care advisor may be welcomed, however hard in practice it may be for that to be achieved.

10 What are the methodological challenges highlighted in existing research?

It should now be clear from the earlier sections of this report that we consider that there are major methodological challenges arising from existing research. In part these challenges arise from the ways in which much research in the past has been built on the basis of very particular professional concerns, and in part because unspecified assumptions about continuity of care have often been embedded in that research.
10.1 Studying conflicting priorities

Continuity is a multidimensional concept, involving potential conflicts between, and different values given to different aspects of continuity between patient groups. Additional research needs therefore to be based on methodologies which enable the investigation of such conflicts and values, located as they are between and within particular groups and particular settings.

10.2 The need for a longer-term perspective

Studying continuity of care of course also implies a longitudinal perspective. Consequently good research in this field will require more time and labour than, for example, the frequently over-used cross-sectional, and largely retrospective questionnaire-based research. However, it would be possible to address potential cost-saving, as well as quality issues through such methods.

10.3 Clear definitions and hypotheses

As we have noted, one of the problems of much existing research is that it appears to be based on established (but often unclear) sets of assumptions about the key parameters of continuity of care. In many respects this has led to the deployment of sophisticated quantitative methodologies before initial exploratory and pilot work has been fully and effectively undertaken. As we indicated in the section above there is considerable and vital scope at an early stage for the generation of both well-grounded variables and sensible and clear hypotheses, which reflect the known difficulties in implementing effective change. It is no longer adequate to refer to ‘continuity of care’ without specifying the aspect or aspects being considered. We define a range of aspects in Part C.

11 What methodological approaches and innovations are likely to be fruitful?

11.1 Gaps already bridged

11.1.1 Formal and informal gap bridging

Of particular value will be research that considers situations where, formally or informally, gaps in continuity of care are being bridged. Many such ‘bridges’ are likely to be local, to have arisen out of hard-won practice, and may be relatively invisible to senior NHS managers. Nonetheless such research could provide valuable examples of how in practice issues of continuity of care have been managed by both patients and staff, which may be able to be encouraged in other settings. Such research is likely to involve a detailed ‘ethnographic’ kind of approach to ascertain exactly how problematic situations have been tackled.
Continuity of Care

11.1.2 A persistent gap revealed by repeated follow-up

Research by Sundby Olsen and Schei (1994) demonstrates some common difficulties that attend the effective management of discontinuities in health care. Their study documents the problems that resulted from infertility patients attending a Norwegian clinic being seen by a different doctor at each visit. These problems had been noted and directives issued to overcome them in 1974, but follow-up studies in 1983 and 1988 indicated no change in the situation. In such situations, which may be surprisingly common, a more appropriate research approach would focus on the identification of the processes, possible structural factors and/or conflicts which might explain why such a lack of continuity persists. In addition it would take account of the ways in which those involved have tried to bridge these gaps in continuity, or indeed may have other interests or objectives which take priority and thereby work against achieving the competing goal of continuity. This kind of research requires the involvement and confidence of people at all levels of an organisation, and therefore experienced, skilled and sensitive researchers.

11.1.3 Summary

The taken-for-granted, everyday nature of gaps in continuity needs to be studied as a naturally occurring phenomenon, so that the range of both formal and informal means of bridging them (which may already exist) can be discovered and drawn upon. However, because of their nature, gaps in continuity may not always be apparent, nor bridges over those gaps clear, especially to those most closely involved (Cook, Render and Woods, 2000). This means that often research needs to be highly innovative and investigative, with the identification of key variables as part of the research process, leading to the generation of hypotheses which can then be tested through more traditional formal techniques. The rationale for this type of research strategy may need to be pursued vigorously and rigorously, in the context of the value of emergent design approaches (Murphy et al., 1998).

11.2 Action research

Action research may be of particular value. Heslop, Elsom and Parker (2000) illustrate how structural and organisational factors which had an impact on continuity of care across emergency and psychiatric services for people seeking mental health care were addressed within a participatory action research framework. Meyer (2000) makes the case for action research drawing on her work on user and carer involvement in discharge processes, and practice across interprofessional boundaries and between different settings. This method may allow the more effective incorporation of patients’ perspectives, as well as those of staff and other stakeholders in identifying and implementing valued features associated with continuity of care.

Careful consideration needs to be given to the compatibility of action research with other methodologies. The strengths of this approach, such as its inclusion of lay participants and its focus on the gap between
research and practice, need to be appreciated. But we must recognise that it would not be appropriate to combine it, for example, with techniques which attempt to control knowledge among participants of the intended effects of change Fulop et al. (in press).

11.3 Longitudinal studies

Longitudinal, process-based studies following patients through pathways of care are essential. Such an approach, likely to be ethnographic in character, would be based on detailed and relatively continuous investigation of the trajectories of sets of patients at especially critical health care junctures. It would allow for the effective inclusion of patient (and carer) experiences and perspectives. It would highlight continuities and discontinuities, and reveal in much greater detail than hitherto the nature of possible conflicts between patient and professional priorities and imperatives. It would also reveal the range of informal ways of managing discontinuities in health care.

11.4 Follow-up studies

In the light of the large number of current and planned managerial and organisational changes in the NHS, it will be important to undertake follow-up studies to consider their unintended effects in relation to continuity of care.
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.

**Definition of elements of continuity of care**

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

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.

R1: 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.
**Continuity of Care**

**R2: 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.

**R3: 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.
R4: 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
  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 1  Summary tables of studies referred to in Part A

Cardiovascular and diabetes, Cancer, Care of older people, Mental health, Primary care, Maternity, and four papers in miscellaneous areas not otherwise included (Lee, Levine and Schultz, 1996; Kao et al., 1998; Wallace and Soloman, 1999; Parkerton, 2000).

Appendix 2  Ratings definitions and data extraction sheet for Continuity of Care Scoping Exercise

Appendix 3  Other evidence from organisations and individuals

Appendix 4  Contact with other health care researchers (I)
  • Canadian Health Service Research Foundation and others
  • Personal Care Group

Appendix 5  Contact with other health care researchers (II)
  • BSA Medical Sociology Register Survey

Appendix 6  References
## Summary table of studies

### Cardiovascular and Diabetes: Table 1

<table>
<thead>
<tr>
<th>Author</th>
<th>Study design</th>
<th>Intervention</th>
<th>Aim</th>
<th>Patient group</th>
<th>Setting</th>
<th>Outcomes – in relation to continuity of care</th>
<th>Length of follow-up</th>
<th>Rating:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Close, H. and Proctor, S.</td>
<td>Qualitative</td>
<td>n/a</td>
<td>To explore patients’ perceptions of their needs and interpretations of progress; and carers’ perceptions of their own needs and those of patients; and professionals’ definition of contribution to care</td>
<td>Patients recovering from a stroke</td>
<td>General hospital medical wards</td>
<td>Patients expressed uncertainty about prognosis, and professionals not passing on information; patients formed relationships with particular members of staff which may be compromised by staff changes, transfers to wards</td>
<td>n/a</td>
<td>• 2</td>
</tr>
<tr>
<td></td>
<td>Interviews with 9 patients and 8 carers</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• 2</td>
</tr>
<tr>
<td>Ekman, I. et al</td>
<td>RCT</td>
<td>Nurse-monitored outpatient shared care</td>
<td>To ease transition after hospitalisation</td>
<td>Elderly patients with moderate to severe heart</td>
<td>Sweden, Göteborg 1/2 interface</td>
<td>Failed to detect a difference in hospital admissions or days in hospital</td>
<td>6 months</td>
<td>• 2</td>
</tr>
<tr>
<td>Feasibility of a nurse-monitored, outpatient</td>
<td>158 patients randomised</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• 5</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• 2</td>
</tr>
</tbody>
</table>
**Continuity of Care**

<table>
<thead>
<tr>
<th>care programme for elderly patients with moderate to severe, chronic heart failure</th>
<th>into 2 groups (a) shared care (b) usual care</th>
<th>programme from an inpatient rehabilitation unit by enabling patients to recognise and monitor symptoms of deterioration</th>
<th>failure</th>
<th>Only a minority of patients were eligible (13–17%) No evidence of beneficial effects (although structured CoC may increase detection rate of problems and therefore increase hospitalisation)</th>
</tr>
</thead>
</table>

*Eur Heart J, 1998*
## Cardiovascular and Diabetes: Table 2

<table>
<thead>
<tr>
<th>Author</th>
<th>Study design</th>
<th>Intervention</th>
<th>Aim</th>
<th>Patient group</th>
<th>Setting</th>
<th>Outcomes – in relation to continuity of care</th>
<th>Length of follow-up</th>
<th>Rating:</th>
</tr>
</thead>
</table>
| Jolly, K. et al.  
Follow-up care in general practice of patients with myocardial infarction or angina pectoris; initial results of the SHIP trial  
*Family Practice*, 1998 | RCT – cluster randomisation | Nurse-led programme to ensure follow-up care is provided in general practice after hospital discharge of MI or angina pectoris | To assess effectiveness of nurse-led follow-up | Patients recovering from a myocardial infarction or with angina pectoris | General practice | The intervention group reported increased use of cardiac rehabilitation programme T 37% C 22% and number of sessions attended T 5/6 C 3/6. No change in hospital-led services, health lifestyle or prescription of preventive medications (e.g. statins) | 4 months | • 2  
• 2  
• 3 |
| Kaplan, S.H., Greenfield, S. and Ware, J.E.  
Assessing the effects of physician–patient interactions on the outcomes of chronic disease  
*Medical Care*, 1989 | 4 RCTs | Patients provided with individualised information about their medical care in the form of their medical records, an algorithm describing disease management, coaching to participate in care during office visit | Assess effect of an intervention designed to improve physician–patient communication on health status | Patients with ulcer disease, diabetes, hypertension, or breast cancer | Outpatient VA clinic, private practice, or clinic at a teaching hospital | Better blood pressure and blood glucose control in the intervention group | 4–18 months | • 2  
• 5  
• 3 |
### Continuity of Care

<table>
<thead>
<tr>
<th>Authors</th>
<th>Study Design</th>
<th>Study Description</th>
<th>Population</th>
<th>Setting</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Piette, J.D., Weinberger, M. and McPhee, S.</td>
<td>RCT</td>
<td>Automated disease management calls with nurse follow-up on diabetic patients</td>
<td>Patients with type 2 diabetes, a multilingual population of patients who are poor and with inadequate health insurance</td>
<td>General medicine clinics</td>
<td>Greater satisfaction with continuity of care (English speakers only)</td>
</tr>
</tbody>
</table>

*Medical Care, 2000*
## Cardiovascular and Diabetes: Table 3

<table>
<thead>
<tr>
<th>Author</th>
<th>Study design</th>
<th>Intervention</th>
<th>Aim</th>
<th>Patient group</th>
<th>Setting</th>
<th>Outcomes – in relation to continuity of care</th>
<th>Length of follow-up</th>
<th>Rating:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preston, R. M.</td>
<td>Qualitative Interviews with 12 adults</td>
<td>Health education material</td>
<td>To what extent health information advice given by community cardiac support nurses was translated into everyday domestic setting</td>
<td>‘Coronary family groups’</td>
<td>Home</td>
<td>Focus on lay beliefs of coronary heart disease and how information is used by the family</td>
<td>n/a</td>
<td></td>
</tr>
<tr>
<td>Rawl, S.M. et al.</td>
<td>RCT</td>
<td>Structured nurse contact before and after discharge (3 in-person contacts at 1–2 days before discharge, 30 days after discharge and at 4 months; and telephone contact 48 hours after discharge)</td>
<td>To ease transition after hospitalisation and improve health outcome</td>
<td>Age range 21 to 89 years Majority of patients were recovering from a CVA or orthopaedic condition</td>
<td>Hospital and community</td>
<td>Failed to detect a difference on hospitalisations, complications, outcomes of rehabilitation. Patients in the treatment group experienced significantly less anxiety at 4 months follow-up: T mean 29 (9.9), C 44.7 (15.3) p&lt;0.001</td>
<td>4 months</td>
<td>4, 5, 4</td>
</tr>
<tr>
<td>Thompson, D.R., Ersser, S.J. and</td>
<td>Qualitative Interviews</td>
<td>n/a</td>
<td>To explore any patterns</td>
<td>Patients recovering</td>
<td>Home</td>
<td>Most appropriate person to provide</td>
<td>n/a</td>
<td>1, 2</td>
</tr>
<tr>
<td>Webster, R.A.</td>
<td>The experiences of patients and partners 1 month after heart attack</td>
<td>J Adv Nursing, 1995</td>
<td>in the experiences of patients and their partners 1 month after first heart attack</td>
<td>from a heart attack, and their partners</td>
<td>advice and support is not clear, patients expressed a preference for family doctor; however, not always satisfied with information provided</td>
<td>• 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Widén Holmqvist, L. et al.</td>
<td>A randomised controlled trial of rehabilitation at home after stroke in southwest Stockholm</td>
<td>Stroke, 1998</td>
<td>RCT Home rehabilitation substituting for hospital-based rehabilitation</td>
<td>To evaluate rehabilitation at home after early supported discharge from hospital</td>
<td>Patients recovering from a stroke</td>
<td>Home or hospital, day care/outpatient care</td>
<td>Increase in active participation in the planning of rehabilitation programme for patients allocated to home rehabilitation</td>
<td>3 months</td>
</tr>
</tbody>
</table>
## Continuity of Care

### Cancer: Table 1

<table>
<thead>
<tr>
<th>Author</th>
<th>Study design</th>
<th>Intervention</th>
<th>Aim</th>
<th>Patient group</th>
<th>Setting</th>
<th>Length of follow-up</th>
<th>Outcomes – in relation to continuity of care</th>
<th>Conclusion</th>
<th>Rating:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Addington-Hall, H.J. et al.</td>
<td>RCT standard vs. co-ordinators</td>
<td>Two nurse co-ordinators</td>
<td>To measure the effects of co-ordinating NHS and voluntary services</td>
<td>554 cancer patients not expected to survive 1 year</td>
<td>Secondary care</td>
<td>1 year</td>
<td>Interviewed patients and carers at home Physical and psychological morbidity Satisfaction Carer problems</td>
<td>Few differences – slight advantages</td>
<td>• 5</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Sense of Coherence Scale (Antonovsky) (sig. +ve result) Study-specific scale • demographic • hospital stay • received body image • social support • perceived pain • psycho-social well-being</td>
<td>The care model with high personnel continuity had a significant positive effect on the patients’ emotional state, mental well-being and perception of postoperative pain evaluated 1 year after surgery</td>
<td>• 4</td>
</tr>
<tr>
<td>Boman, L. et al.</td>
<td>Non-RCT</td>
<td>Seeing the same staff + better structure + firm operation date + shorter hospital stay</td>
<td>Evaluate the models of breast cancer care</td>
<td>Patients undergoing surgery for breast cancer 29 established care 115 continuity care</td>
<td>2nd Care</td>
<td>1 year</td>
<td>Study-specific well-being</td>
<td>Few differences – slight advantages</td>
<td>• 5</td>
</tr>
</tbody>
</table>

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### Continuity of Care

#### Cancer: Table 2

<table>
<thead>
<tr>
<th>Author</th>
<th>Study design</th>
<th>Intervention</th>
<th>Aim</th>
<th>Patient group</th>
<th>Setting</th>
<th>Length of follow-up</th>
<th>Outcomes – in relation to continuity of care</th>
<th>Conclusion</th>
<th>Rating:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jarrett, N.J., Payne, S.A. and Wiles, R.A.</td>
<td>Qualitative interview</td>
<td>9 terminally ill patients and 12 lay-carers interviewed concerning 12 patients</td>
<td>Experience and perceptions of terminal care</td>
<td>9 terminally ill patients and 12 lay-carers</td>
<td>Urban, at home, intermediate; 1/2 CoC; Southampton UK</td>
<td>n/a</td>
<td>Three emerging themes were: role perceptions and domains of responsibility; economic and practical problems; CoC and communication</td>
<td>This paper emphasised the different kinds of nurses involved in domiciliary terminal care; Too many professionals especially nurses led to communication problems; many nurses part-time; this made it difficult to form therapeutic relationships</td>
<td>Recommend • info (e.g. booklet) describing roles of professionals • special attempt to improve provider continuity • fairer distribution of resources according to need</td>
</tr>
<tr>
<td>Johansson, B. et al.</td>
<td>RCT</td>
<td>Intensified Primary</td>
<td>Compare Intensified</td>
<td>391 newly diagnosed</td>
<td>2^0 + 1^0 care</td>
<td>6 months</td>
<td>Hospital Anxiety &amp; Depression Scale</td>
<td>Large increase in contacts and</td>
<td>4</td>
</tr>
</tbody>
</table>

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Appendix 1
# Continuity of Care

## Appendix 1

**cancer care: a randomized study of home care nurse contacts**

*J Adv Nursing, 1999*

<table>
<thead>
<tr>
<th>Primary Care</th>
<th>Care (IPC)</th>
<th>Primary Care vs. controls</th>
<th>cancer patients, Sweden</th>
<th>(HADS) 18-item Q. re contacts in primary care including patients’ views</th>
<th>significant satisfaction (Cost not stated)</th>
</tr>
</thead>
<tbody>
<tr>
<td>IPC (+rehab)</td>
<td>quick referral to home care nurse (HCN)</td>
<td></td>
<td></td>
<td>N contacts with home care nurse</td>
<td>• 3</td>
</tr>
<tr>
<td>1 rehab only</td>
<td>inform GP</td>
<td></td>
<td></td>
<td></td>
<td>• 2</td>
</tr>
<tr>
<td>1 standard care</td>
<td>hospital records copied to PCT</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>project group (oncology) supervision of HCNS</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Continuity of Care

### Cancer: Table 3

<table>
<thead>
<tr>
<th>Author</th>
<th>Study design</th>
<th>Intervention</th>
<th>Aim</th>
<th>Patient group</th>
<th>Setting</th>
<th>Length of follow-up</th>
<th>Outcomes – in relation to continuity of care</th>
<th>Conclusion</th>
<th>Rating:</th>
</tr>
</thead>
<tbody>
<tr>
<td>O’Malley, A. et al.</td>
<td>Telephone survey</td>
<td>Health care usage and social demography, health status, insurance, ‘acculturisation’</td>
<td>To examine how CoC affects its use of breast and cervical cancer screening in multiethnic patients</td>
<td>1420 multiethnic black/Hispanic (62% response) 7 groups, New York, USA</td>
<td>n/a</td>
<td></td>
<td>Utilisation rates of:clinical breast exam; mammography; Pap smears including: 1 ever screened 2 recently screened according to guidelines</td>
<td>More CoC, more uptakes of screening; Biggest effect was in women in the lowest uptakes</td>
<td>5 3 4</td>
</tr>
<tr>
<td>Smeenk, F.W.J.M. et al.</td>
<td>Quasi-experimental</td>
<td>Specialised support for 1 care team by nurse co-ordinator +</td>
<td>To test special home care programme in reducing readmission</td>
<td>Terminal cancer patients in Holland S79 +C37 =</td>
<td>2/1 interface supplementation</td>
<td>1 month Only 45 patients followed up with QOL</td>
<td>Benefit on all four measures; Authors argue that the continuity (i.e., communication)</td>
<td>4 4 4</td>
<td></td>
</tr>
</tbody>
</table>
## Continuity of Care

| effects on re-hospitalization and quality of life | place of residence (inside or outside Eindhoven) | 24-hour telephone • transmural home team • collaborative record • specific care protocols | 116 (but 54 dropped out, N=62) | 1 care scores (face-to-face questionnaires) \( p<0.01 \) 2.0  
- Death at home (instead of hospital) \( \uparrow \) (NS)  
- Survival time \( \uparrow \) (NS) | 1\(^{st}/2^{nd}\) was all important Very little extra service (8 requests only) |

*Patient Education & Counselling, 1998*
### Cancer: Table 4

<table>
<thead>
<tr>
<th>Author</th>
<th>Study design</th>
<th>Intervention</th>
<th>Aim</th>
<th>Patient group</th>
<th>Setting</th>
<th>Length of follow-up</th>
<th>Outcomes – in relation to continuity of care</th>
<th>Conclusion</th>
<th>Rating:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Smith, S.D. et al.</td>
<td>Qualitative survey</td>
<td>n/a</td>
<td>Examine patients’ recollections recording their encounters with doctors during cancer care. Examine the value of these encounters. Determine total no. of doctors encountered.</td>
<td>50 cancer patients, in Lothian, Scotland</td>
<td>Not stated</td>
<td>n/a</td>
<td>Mean no. of doctors seen Up to 1 year 28 (max. 31 in 6 months) Greater than 1 year 35 (max. 73 in 25 months) Emergent themes: 1. CoC – problem of having to restate story, and to break relationships or fail to make them. 2. Doctor’s manner. 3. Breaking bad news. 4. Inadequate information and explanation. 5. Honesty. 6. Good communication. 7. Prompt and</td>
<td>Recommend: • consultant-led service • better interprofessional communication • more critical evaluation of: – OP follow-up – patient-held records. This may increase patients’ confidence that care is secure and consistent even when they cannot see the same doctor at all times.</td>
<td>4</td>
</tr>
</tbody>
</table>

**Appendix 1**

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### Continuity of Care

<table>
<thead>
<tr>
<th>van Harteveld, J.T.M., Mistiaen, P.J.M.L. and Dukkers van Emden, D.M.</th>
<th>Survey of health care</th>
<th>3 outreach visits by community nurse</th>
<th>To evaluate post-discharge home visits</th>
<th>Cancer patients not indicated for community nurses of discharge</th>
<th>8 hospitals in Amsterdam $2^0 \rightarrow 1^0$</th>
<th>Number and type of patient</th>
<th>Most patients and staff liked it (NB: uncontrolled satisfaction study; it suggests inadequate discharge planning)</th>
<th>6/12 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home visits by community nurses for cancer patients after discharge from hospital: an evaluation study of the continuity visit</td>
<td>337 offered 168 accepted 112 received</td>
<td>Delayed referral</td>
<td>6/12 months</td>
<td>Patient evaluation questionnaires</td>
<td>Nurse evaluation questionnaires</td>
<td>Nurse focus groups</td>
<td>8 hospital(s) in Amsterdam $2^0 \rightarrow 1^0$</td>
<td>Number and type of patient</td>
</tr>
<tr>
<td><em>Cancer Nursing</em>, 1997</td>
<td>To evaluate post-discharge home visits</td>
<td>To evaluate post-discharge home visits</td>
<td>To evaluate post-discharge home visits</td>
<td>To evaluate post-discharge home visits</td>
<td>To evaluate post-discharge home visits</td>
<td>To evaluate post-discharge home visits</td>
<td>To evaluate post-discharge home visits</td>
<td>To evaluate post-discharge home visits</td>
</tr>
</tbody>
</table>

### Care of Older People: Table 1.1

<p>| Anttila, S.K. et al. | RCT | Encouragement to contact and visit out patient clinics. Support from home nurses. Information about medication. Mechanism to ensure flow of information between hospital and outpatient clinics | Assess cost effectiveness of post-discharge programme on urgent hospital care and to improve the continuance of the use of hospital care | 204 elderly patients aged 75+ | City, Finland | Mean follow-up 2 yrs |
| Epstein, A.M. et al. | RCT | Comp. geriatric assessment or 2nd opinion internist | To evaluate the effectiveness of comprehensive geriatric | 600 elderly (75+) patients in poor health | HMO; Rhode Island | 3–12 months |</p>
<table>
<thead>
<tr>
<th>Study Title</th>
<th>Design</th>
<th>Data Source</th>
<th>Data Collection</th>
<th>Data Interpretation</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jackson, M.F. Discharge planning: issues and challenges for gerontological nursing</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td>Critique of the literature on discharge planning for acutely ill hospitalised elderly patients which challenges big assumptions of discharge planning processes, including newly provided CoC which improves health status</td>
<td>n/a</td>
</tr>
<tr>
<td>Klop, R. van Wijmen, F.C.B. and Philipsen, H. Patients’ rights and the admission and discharge process</td>
<td>Qualitative interviews of patients and their professional carers</td>
<td>None – descriptive study</td>
<td>To find out the meaning of discharge (from hospital) for patients and for carers</td>
<td>Hospital discharge patients needing home care, 11 patients + GP+ comm. nurse + hospital nurse + specialist</td>
<td>20 – 10 months, Netherlands, 3 months</td>
</tr>
</tbody>
</table>
## Continuity of Care

### Care of Older People: Table 1.2

<table>
<thead>
<tr>
<th>Author</th>
<th>Title</th>
<th>Outcomes – in relation to continuity of care</th>
<th>Conclusion</th>
<th>Rating:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anttila , S.K. et al.</td>
<td>Cost-effectiveness of an innovative four-year post-discharge programme for elderly patients</td>
<td>Difference in the use of institutional care before and after the project&lt;br&gt;Measurement of costs</td>
<td>Continuity somewhat better maintained in the intervention group, but no indication of how continuity was conceptualised or measured (presumably longitudinal perhaps with informational)</td>
<td>3 2 2</td>
</tr>
<tr>
<td>Epstein, A.M. et al.</td>
<td>Consultative geriatric assessment for ambulatory patients. A randomized trial in a health maintenance organization.</td>
<td>Use of medical services and costs&lt;br&gt;Health status&lt;br&gt;Patient satisfaction</td>
<td>Showed little benefit in health status in intervention groups. Suggestion that lack of continuity post-assessment may explain disappointing outcome</td>
<td>3 4 2</td>
</tr>
<tr>
<td>Jackson, M.F.</td>
<td>Discharge planning: issues and challenges for gerontological nursing. A critique of the literature</td>
<td>n/a</td>
<td>1 Difficult to prove that new discharge planning affects health status by improving CoC&lt;br&gt;2 Mixed conclusions re impact of discharge planning in CoC&lt;br&gt;3 Lack of ?? new DP improves quality of life&lt;br&gt;Useful literature review on difficult aspects of discharge planning outcomes, but little specifically on CoC</td>
<td>3 3 2</td>
</tr>
<tr>
<td>Klop, R. van Wijmen, F.C.B. and Philipsen, H.</td>
<td>Patients’ rights and the admission and discharge process</td>
<td>• What patients were told (very little)&lt;br&gt;• Their tendency to ask questions</td>
<td>Patients more passive than expected&lt;br&gt;Very little information given</td>
<td>2 2 2</td>
</tr>
</tbody>
</table>

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## Care of Older People: Table 2.1

<table>
<thead>
<tr>
<th>Author</th>
<th>Title</th>
<th>Study design</th>
<th>Intervention</th>
<th>Aim</th>
<th>Patient group</th>
<th>Setting</th>
<th>Length of follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lough, M.A.</td>
<td>Ongoing work of older adults at home after hospitalization</td>
<td>Semi-structured interviews within 2 weeks of hospitalisation</td>
<td>None</td>
<td>To describe hospital to home transition process as experienced by elders with congestive heart failure (CHF)</td>
<td>Adults of 65+ after hospitalisation and discharge for CHF 25 patients (12 male; 13 female) Range 66–91 years. Mean age 71</td>
<td>Adults at home after discharge from a hospital in a large metropolitan community in the USA</td>
<td>Unclear – readmission rate checked at 3 months Some know to have died within a year</td>
</tr>
<tr>
<td>McWilliam, C.</td>
<td>From hospital to home: elderly patients’ discharge experiences</td>
<td>Qualitative semi-structured interviews and observation of discharge planning process</td>
<td>None</td>
<td>To describe experience of elderly patients</td>
<td>12 elderly patients (aged 65+) and their carers and professionals</td>
<td>Urban Ontario, Canada</td>
<td>10 days</td>
</tr>
<tr>
<td>McWilliam, C.L. and Sangster, J.F.</td>
<td>Managing patient discharge to home: the challenges of achieving quality of care</td>
<td>Qualitative study 1 observation of discharge process 2 review of patient records 3 in-depth and semi-</td>
<td>n/a</td>
<td>To explore and describe factors other than medical condition and treatment which shaped the quality of the discharge experience of older patients with continuing care needs from urban and rural settings</td>
<td>21 older people aged 65+. Also purposeful sample of informal and professional care givers</td>
<td>Primary/secondary interface, urban and rural London, Ontario</td>
<td>Up to 12 weeks</td>
</tr>
<tr>
<td>Authors</td>
<td>Title</td>
<td>Methodology</td>
<td>Outcome</td>
<td>Participants</td>
<td>Setting</td>
<td>Timepoints</td>
<td></td>
</tr>
<tr>
<td>-------------------------</td>
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<td></td>
</tr>
<tr>
<td>Naylor, M.D. et al.</td>
<td>Comprehensive discharge planning and home follow-up of hospitalised elders: a randomised clinical trial</td>
<td>Structured interviews of patients, carers and expert informants</td>
<td>To examine the effectiveness of advanced practice nurse-controlled discharge planning and some follow up intervention for elders at risk of hospital readmission</td>
<td>363 elderly men, aged 75</td>
<td>2 urban hospitalsPhiladelphia, USA</td>
<td>2, 6, 12, 24 weeks post-discharge</td>
<td></td>
</tr>
</tbody>
</table>
# Continuity of Care

## Care of Older People: Table 2.2

<table>
<thead>
<tr>
<th>Author</th>
<th>Title</th>
<th>Outcomes – in relation to continuity of care</th>
<th>Conclusion</th>
<th>Rating:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lough, M.A.</td>
<td>Ongoing work of older adults at home after hospitalization</td>
<td>Qualitative study which identified 3 key processes in transition from hospital to home, for people with chronic illness:</td>
<td>Key finding: patients needed a post-hospital plan which provided them with ongoing information, additional resources and supportive assistance</td>
<td>• 3</td>
</tr>
<tr>
<td></td>
<td>Ongoing work of older adults at home after hospitalization</td>
<td>• managing the illness</td>
<td></td>
<td>• 2</td>
</tr>
<tr>
<td></td>
<td>Ongoing work of older adults at home after hospitalization</td>
<td>• caregivers’ lives</td>
<td></td>
<td>• 2</td>
</tr>
<tr>
<td></td>
<td>Ongoing work of older adults at home after hospitalization</td>
<td>• quality of life challenges</td>
<td></td>
<td></td>
</tr>
<tr>
<td>McWilliam, C.</td>
<td>From hospital to home: elderly patients’ discharge experiences</td>
<td>n/a</td>
<td>Need better communication and co-ordination of discharge process (GP highlights problem of integrating family physician into discharge planning)</td>
<td>• 3</td>
</tr>
<tr>
<td></td>
<td>From hospital to home: elderly patients’ discharge experiences</td>
<td></td>
<td>Very interesting study of psychological factors involved in discharge process, but nothing new in terms of problems involved</td>
<td>• 4</td>
</tr>
<tr>
<td></td>
<td>From hospital to home: elderly patients’ discharge experiences</td>
<td></td>
<td></td>
<td>• 2</td>
</tr>
<tr>
<td>McWilliam, C.L. and Sangster, J.F.</td>
<td>Managing patient discharge to home: the challenges of achieving quality of care</td>
<td>The size, complexity, structure and nature of the health care system (including collusion of anonymity) create a work context which often undermines accessibility, co-ordination, continuity, comprehensiveness, patient-centredness and, ultimately, effective care. In particular the current focus on efficiency may undermine these goals</td>
<td>Interesting and useful study, illuminating many of the complexities of the discharge process from the patient and provider perspectives but no attempts to define/unpack what is meant by continuity</td>
<td>• 3</td>
</tr>
<tr>
<td></td>
<td>Managing patient discharge to home: the challenges of achieving quality of care</td>
<td></td>
<td></td>
<td>• 4</td>
</tr>
<tr>
<td></td>
<td>Managing patient discharge to home: the challenges of achieving quality of care</td>
<td></td>
<td></td>
<td>• 2</td>
</tr>
<tr>
<td>Naylor, M.D. et al.</td>
<td>Comprehensive discharge planning and home follow-up of hospitalised elders: a randomised clinical trial</td>
<td>Readmission, time to first readmission, acute care after discharge; costs, functional status, depression and patient satisfaction</td>
<td>Discharge planning and home care for at-risk elders; reduced readmission, increased time to readmission, and reduced costs</td>
<td>• 2</td>
</tr>
<tr>
<td></td>
<td>Comprehensive discharge planning and home follow-up of hospitalised elders: a randomised clinical trial</td>
<td></td>
<td>Comment: Demonstrates how individualised discharge</td>
<td>• 3</td>
</tr>
<tr>
<td></td>
<td>Comprehensive discharge planning and home follow-up of hospitalised elders: a randomised clinical trial</td>
<td></td>
<td></td>
<td>• 1</td>
</tr>
<tr>
<td>planning and follow-up has significant effect on readmission rates for at-risk elderly patients, and on health care costs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Care of Older People: Table 3.1

<table>
<thead>
<tr>
<th>Author</th>
<th>Study design</th>
<th>Intervention</th>
<th>Aim</th>
<th>Patient group</th>
<th>Setting</th>
<th>Length of follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Naylor, M.D. <em>et al.</em> Patient problems and advanced practice nurse interventions during transitional care <em>Public Health Nursing</em>, 2000</td>
<td>Secondary analysis of care logs written by Advanced Practice Nurses (APNs), Coded using Omaha system</td>
<td>n/a</td>
<td>To examine  - the problems experienced by elders who were hospitalised and discharged to home  - the interventions used by APNs  - the linkages between patient problems and APN interventions</td>
<td>124 elderly (65+) 37% African-American</td>
<td>1&lt;sup&gt;st&lt;/sup&gt;/2&lt;sup&gt;nd&lt;/sup&gt; interface Philadelphia, USA</td>
<td>n/a</td>
</tr>
<tr>
<td>Simpson, R.G., Scothern, G. and Vincent, M. Survey of carer satisfaction with the quality of care delivered to in-patients suffering from dementia <em>J Adv Nurs</em>, 1995</td>
<td>Single interview including structured questions yielding qualitative data and open questions analysed with grounded theory approach</td>
<td>n/a</td>
<td>Are patients/carers satisfied with the caring of dementia as is currently developed? Are patients/carers perceptions of high quality care the same as service providers? Methodological testing</td>
<td>Cases of patients with dementia (41), discharged from hospital after assessment/emergency admission/respite care</td>
<td>2&lt;sup&gt;nd&lt;/sup&gt; care and 1&lt;sup&gt;st&lt;/sup&gt;/2&lt;sup&gt;nd&lt;/sup&gt; interface Urban Leicester, UK</td>
<td>n/a</td>
</tr>
</tbody>
</table>
### Continuity of Care

<table>
<thead>
<tr>
<th>van Achterberg, T. et al.</th>
<th>Coordination of care: effects on the continuity and quality of care</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><em>Int J Nurs Stud, 1996</em></td>
</tr>
</tbody>
</table>

**Methods:**
- 2 matched groups
  - 1st (N=65) allocated a care co-ordinator
  - 2nd (N=43) no co-ordinator
- Co-ordinator (effectively a key worker) designated time with patient’s existing network
  - Could be a professional carer or a non-professional carer
- Interviews used to assess effects of intervention
- To find out ways in which appointment of care co-ordinators affects continuity of care and whether care co-ordination affects satisfaction with care

**Participants:**
- People who were 60+, suffering from a chronic disease, had at least 2 professional/non-professional care givers, and who lived independently
- 108 patients recruited; 72 completed study

**Setting:**
- 3 rural/urban communities in Limberg, Netherlands

**Duration:**
- 1 year
## Continuity of Care

### Care of Older People: Table 3.2

<table>
<thead>
<tr>
<th>Author</th>
<th>Outcomes – in relation to continuity of care</th>
<th>Conclusion</th>
<th>Rating:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Naylor, M.D. et al.</td>
<td>Problems primarily physiological or relating to health behaviours. Majority of interventions connect to two main problems: co-ordination and discharge planning</td>
<td>Limited and pedestrian analysis. Raises more questions than it answers about elderly people discharged from hospital</td>
<td>1, 3, 1</td>
</tr>
<tr>
<td>Parkes, J. and Shepperd, S.A.</td>
<td>small reduction in hospital length of stay for some groups</td>
<td>No difference in health outcomes, increased patient satisfaction</td>
<td>3, 5, 2</td>
</tr>
<tr>
<td>Simpson, R.G., Scothern, G. and Vincent, M.</td>
<td>Gaps in information exchange between staff/carers Interesting study but yet another revealing gaps in information between staff and carers</td>
<td>1, 4, 1</td>
<td></td>
</tr>
<tr>
<td>van Achterberg, T. et al.</td>
<td>Interdisciplinary, Interpersonal Pre-structured interviews used to assess effects of coordination on client satisfaction</td>
<td>Improved interpersonal continuity but hardly any effect on client satisfaction Other interventions can be more appropriate for the improvement of client care</td>
<td>4, 3, 4</td>
</tr>
</tbody>
</table>
## Care of Older People: Table 4.1

<table>
<thead>
<tr>
<th>Author</th>
<th>Study design</th>
<th>Intervention</th>
<th>Aim</th>
<th>Patient group</th>
<th>Setting</th>
<th>Length of follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>von Sternberg, T. et al.</td>
<td>2 groups – Transitional Care Centres (TCCs) and standard contents&lt;br&gt;Monitored and postal survey&lt;br&gt;Not randomised</td>
<td>TCC model and standard nursing home contracts and venues</td>
<td>To describe Transitional Care Centres and to compare experiences and outcomes of enrollees compared with control enrollees who received customary continuity care through contract services.</td>
<td>253 elderly patients receiving TC</td>
<td>1&lt;sup&gt;0&lt;/sup&gt;/2&lt;sup&gt;0&lt;/sup&gt; interface&lt;br&gt;Bloomington, Minnesota, USA</td>
<td>n/a</td>
</tr>
<tr>
<td>Wasson, J.H. et al.</td>
<td>RCT</td>
<td>Study group (66%) see the same physician each time&lt;br&gt;Control group (33%) have normal care but including measures to ensure patients did not see the same physician</td>
<td>To determine the impact of provider continuity on the course of patients’ illnesses and to see if previous studies with paediatric patients and/or physicians in training could be generalised</td>
<td>776 males aged 55+ years</td>
<td>Ambulant patients attending&lt;br&gt;Veterans Administration&lt;br&gt;outpatient general medical clinics in Vermont (USA)</td>
<td>18 months</td>
</tr>
<tr>
<td>Author</td>
<td>Title</td>
<td>Outcomes – in relation to continuity of care</td>
<td>Conclusion</td>
<td>Rating:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>------------------------</td>
<td>------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------</td>
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</tr>
</tbody>
</table>
| von Sternberg, T. et al. | Post-hospital sub-acute care: an example of a managed care model       | 1 average length of stay  
2 post-discharge status via phone calls at 3 & 6 months  
3 rehospitalisation rates  
4 satisfaction of primary care physicians  
5 patient rehabilitation via | Benefit claimed for information, but as continuity is unexplained this is difficult to assess. Also, comparison with maintenance group is patchy | • 1  
• 2  
• 2 |
• emergency admissions  
• hospital days intensive care days  
• tests etc.  
Patient satisfaction with  
• continuity  
• education  
• thoroughness  
Staff satisfaction | More patient satisfaction  
Shorter hospitalisations  
Fewer emergency admissions  
No difference in medication use or in health status | • 5  
• 5  
• 3 |
## Continuity of Care

### Mental health: Table 1.1

<table>
<thead>
<tr>
<th>Author</th>
<th>Study design</th>
<th>Intervention</th>
<th>Aim</th>
<th>Patient group</th>
<th>Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bachrach, L.L.</td>
<td>n/a</td>
<td>Discussion paper</td>
<td>To consider different dimensions of continuity in relation to psychiatric population.</td>
<td>Severe and chronic mental health problems</td>
<td>USA</td>
</tr>
<tr>
<td>Binding, J. et al.</td>
<td>Survey qualitative and quantitative methods combined</td>
<td>Not an intervention study</td>
<td>To measure communication and joint working between GPs and psychiatric teams. To elicit patient satisfaction and nature of contact with GPs. Does unsatisfactory GP contact lead to early disengagement with psychiatric services for black clients?</td>
<td>Patients with SMI and two or more admissions. Ethnicity stated and focused on</td>
<td>Two inner London psychiatric sectors</td>
</tr>
<tr>
<td>Bindman, J. et al.</td>
<td>Prospective cohort study</td>
<td>CPA key-working</td>
<td>To test whether • CPA associated with better continuity • continuity is associated with improved patient outcomes • continuity is poorer for black African or Caribbean patients</td>
<td>The first 100 consenting patients approached randomly from a sample of 342 patients with defined severe mental illness</td>
<td>South London. Patients interviewed in a range of locations inc. home, clinic, hospital and prison</td>
</tr>
</tbody>
</table>
### Continuity of Care

<table>
<thead>
<tr>
<th>Study Authors/Title</th>
<th>Methodology</th>
<th>Interventions</th>
<th>Study Outcomes</th>
<th>Sample Size</th>
<th>Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bjoerkman, T. et al. What is important in psychiatric outpatient care? Quality of care from the patient's perspective <em>Int J Qual Health Care, 1995</em></td>
<td>Qualitative/quantitative 2-stage study</td>
<td>n/a</td>
<td>To map characteristics of ideal psychiatric outpatient treatment from patients' perspective</td>
<td>94/84 psychiatric outpatients</td>
<td>Psychiatric outpatient clinic</td>
</tr>
<tr>
<td>Brekke, J.S. et al. Intensity and continuity of services and functional outcomes in the rehabilitation of persons with schizophrenia <em>Psychiatric Services, 1999</em></td>
<td>Prospective study (not controlled) outcomes assessed at 6 and 12 months</td>
<td>Frequent contact (reducing over 6 months), on-site monitoring of medication, crisis management, vocational services 5x weekly, socialisation services 7x weekly</td>
<td>To examine the relationship between intensity and longitudinal continuity and functional patient outcome</td>
<td>41 patients with psychotic diagnosis, predominantly young male. Equal white/ethnic minority</td>
<td>USA, location not specified Psychosocial rehabilitation clubhouse</td>
</tr>
</tbody>
</table>
## Continuity of Care

### Mental Health: Table 1.2

<table>
<thead>
<tr>
<th>Author</th>
<th>Title</th>
<th>Outcomes – in relation to continuity of care</th>
<th>Rating:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bachrach, L.L.</td>
<td>Continuity of care for chronic mental patients: a conceptual analysis</td>
<td>No evaluation involved. Thoughtful and well informed (83 references) discussion of the meaning and dimensions of continuity</td>
<td>5 1 5</td>
</tr>
<tr>
<td></td>
<td>Am J of Psychiatry, 1981</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bindman, J. et al.</td>
<td>Integration between primary and secondary services in the care of the severely mentally ill: patients’ and general practitioners’ views</td>
<td>Poor continuity found between GPs and psychiatrists. Patients prefer GPs not to be involved in psychiatric care but satisfied with GPs. GP perception that they had less involvement with black patients not confirmed by patient perspective Recommendations made for improving continuity</td>
<td>4 3 5</td>
</tr>
<tr>
<td></td>
<td>Brit J Psychiatry, 1997</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bindman, J. et al.</td>
<td>Continuity of care and clinical outcome: a prospective cohort study</td>
<td>No significant relationship between continuity and patient outcomes. Continuity improved over time under CPA. Continuity similar for black and white patients</td>
<td>5 4 5</td>
</tr>
<tr>
<td></td>
<td>Social Psychiatry &amp; Psych Epidemiology, 2000</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bjoerkmann, T. et al.</td>
<td>What is important in psychiatric outpatient care? Quality of care from the patient’s perspective</td>
<td>Continuity of care identified as one of eight content categories. Highest number of statements concerned accessibility. Patients’ ratings of treatment characteristics focused on staff–patient relationships. Accessibility, costs and continuity had not appeared as content categories in a previous inpatient study</td>
<td>2 5 2</td>
</tr>
<tr>
<td></td>
<td>Int J Qual Health Care, 1995</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brekke, J.S. et al.</td>
<td>Intensity and continuity of services and functional outcomes in the rehabilitation of persons with schizophrenia</td>
<td>Service continuity had more influence on symptoms than intensity of contact. Intensity had more influence on hospitalisation and psychosocial functioning at 12 months</td>
<td>5 3 5</td>
</tr>
<tr>
<td></td>
<td>Psychiatric Services, 1999</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Author</td>
<td>Study design</td>
<td>Intervention</td>
<td>Aim</td>
</tr>
<tr>
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<td>-----</td>
</tr>
<tr>
<td>Brindis, C., Pfeffer, R. and Wolfe, A.</td>
<td>Audit/service description Qualitative findings referred to in abstract but not evident in text</td>
<td>Varying forms of case management on 3 sites (not compared) Innovative information system alerted case managers to need for action</td>
<td>To evaluate project aimed at strengthening links between drug treatment and other services</td>
</tr>
<tr>
<td>Godley, S.H. <em>et al.</em></td>
<td>Service description, involving some measured outcomes</td>
<td>3-stage drug treatment programme: screening, residential and continuing care phases. Care delivered within case management model</td>
<td>To describe functions of case managers during three phases of treatment programme</td>
</tr>
<tr>
<td>Hall, S.M. <em>et al.</em></td>
<td>2x2 experimental study: drug versus placebo (blind) Treatment continuity versus standard care</td>
<td>Enhanced continuity: outpatient groups started during hospital stay. Same counsellor through in- and outpatient settings. Desipramine/placebo given</td>
<td>To investigate relative efficacy of enhanced continuity/ desipramine, compared to placebo and standard care</td>
</tr>
<tr>
<td>Study</td>
<td>Design</td>
<td>Intervention</td>
<td>Comparison</td>
</tr>
<tr>
<td>-------</td>
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</tr>
<tr>
<td>Herman, D. et al.</td>
<td>RCT</td>
<td>Critical Time Intervention (CTI) transitional intensive service</td>
<td>To compare effects of CTI on negative and positive symptoms of schizophrenia and general psychopathology to standard service.</td>
</tr>
<tr>
<td>Holloway, F. et al.</td>
<td>Critical review</td>
<td>Case management</td>
<td>To examine the effects of case management</td>
</tr>
<tr>
<td>Hoult, J. et al.</td>
<td>RCT</td>
<td>Community treatment team offered 24hr crisis intervention, medication support, family intervention, psycho-education, skills training</td>
<td>To compare community treatment to episodic hospital/OP care – effects on bed use, costs, clinical outcome, burden on others, patient/family satisfaction</td>
</tr>
<tr>
<td>Author</td>
<td>Title</td>
<td>Outcomes – in relation to continuity of care</td>
<td>Rating:</td>
</tr>
<tr>
<td>--------</td>
<td>-------</td>
<td>--------------------------------------------</td>
<td>---------</td>
</tr>
<tr>
<td>Brindis, C., Pfeffer, R. and Wolfe, A.</td>
<td>A case management program for chemically dependent clients with multiple needs</td>
<td>Unresolved client problems documented by a computerised information system. Claim that case management shown to be instrumental in facilitating access to needed services not backed by evidence</td>
<td>1 2 2</td>
</tr>
<tr>
<td>Godley, S.H. et al.</td>
<td>Case management services for adolescent substance abusers</td>
<td>Case management activities identified. Favourable rate of abstinence (compared to earlier studies)</td>
<td>2 1 3</td>
</tr>
<tr>
<td>Hall, S.M. et al.</td>
<td>Continuity of care and Desipramine in primary cocaine abusers</td>
<td>Desipramine had no effect on drug use Increased CoC increased abstinence rates and treatment attendance at no higher cost than standard care</td>
<td>5 4 4</td>
</tr>
<tr>
<td>Herman, D. et al.</td>
<td>A critical time intervention with mentally ill homeless men: impact on psychiatric symptoms</td>
<td>CoC intervention achieved significant reduction in negative symptoms. No impact on positive symptoms/general psychopathology</td>
<td>5 5 4</td>
</tr>
<tr>
<td>Holloway, F. et al.</td>
<td>Case management: a critical review of the outcome literature</td>
<td>Differing effects for all outcomes: decrease in hospital usage reported in 11 cases, increase in two, seven showed no difference. CM has some impact on use of other services, symptomatology, satisfaction, engagement Different models of CM need to be compared</td>
<td>3 5 3</td>
</tr>
<tr>
<td>Hoult, J. et al.</td>
<td>Psychiatric hospital versus community treatment: the results of a randomised trial</td>
<td>Intervention reduced hospitalisation (8.4 days vs. 53.5 days) costs (by 26%). It increased patient/family satisfaction without increasing burden on relatives/community</td>
<td>4 5 4</td>
</tr>
</tbody>
</table>
## Mental health: Table 3.1

<table>
<thead>
<tr>
<th>Author</th>
<th>Title</th>
<th>Study design</th>
<th>Intervention</th>
<th>Aim</th>
<th>Patient group</th>
<th>Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Johnson, S. et al.</td>
<td>Continuity of care for the severely mentally ill: concepts and measures</td>
<td>n/a</td>
<td>Discussion paper</td>
<td>Review theoretical definitions of continuity of care for the mentally ill</td>
<td>Mentally ill</td>
<td>General</td>
</tr>
<tr>
<td></td>
<td><em>Soc Psychiatry Psychiatr Epidemiol</em>, 1997</td>
<td></td>
<td></td>
<td>Discuss work which has attempted to operationalise these</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kopelowicz, A., Wallace, C.J. and Zarate, R.</td>
<td>Teaching psychiatric in-patients to re-enter the community: a brief method of improving the continuity of care.</td>
<td>RCT</td>
<td>16 x 45-min training sessions, teaching patients relapse prevention, how to access and use services, psycho education</td>
<td>To compare effects of a structured training programme, designed to prepare patients for community re-entry, with equivalent occupational therapy</td>
<td>59 inpatients with psychotic diagnosis 61% ethnic minority</td>
<td>USA, California Acute psychiatric in-patient unit of a university affiliated state hospital</td>
</tr>
<tr>
<td>Malla, A.K. et al.</td>
<td>An integrated medical and psychosocial treatment program for psychotic disorders: patient characteristics and outcome</td>
<td>Longitudinal outcome survey (uncontrolled)</td>
<td>Community programme offering integrated interventions: medication, social skills training, stress management, family psycho-intervention, within case management model</td>
<td>To evaluate process and outcomes of case management programme</td>
<td>Patients with psychotic disorders and associated social problems No reference to ethnicity</td>
<td>Canada Community</td>
</tr>
<tr>
<td>Marshall, M., Lockwood, A. and Gath, D.</td>
<td>RCT</td>
<td>Assessment of need, liaison with carers, monitoring clients’ progress, practical assistance</td>
<td>To evaluate effectiveness of case management (additional to standard service)</td>
<td>80 clients SMI and homeless history</td>
<td>UK Oxford social services CM team</td>
<td></td>
</tr>
<tr>
<td>----------------------------------------</td>
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<td>-------------------------------------------------</td>
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<td></td>
</tr>
<tr>
<td>Social services case management for long-term mental disorders: a randomised controlled trial <em>Lancet</em>, 1995</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Marshall, M. <em>et al.</em></th>
<th>Cochrane Review</th>
<th>Case management</th>
<th>Comparison of case management to standard care, indicated by workers staying in contact with clients, psychiatric admissions, clinical and social outcomes and costs</th>
<th>11 studies reviewed. Patients with severe mental illness.</th>
<th>International</th>
</tr>
</thead>
<tbody>
<tr>
<td>Case management for people with severe mental disorders <em>Cochrane Library</em>, 2000</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Continuity of Care

### Mental Health: Table 3.2

<table>
<thead>
<tr>
<th>Author</th>
<th>Title</th>
<th>Outcomes – in relation to continuity of care</th>
<th>Rating:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Johnson, S. <em>et al.</em></td>
<td>Continuity of care for the severely mentally ill: concepts and measures</td>
<td>Continuity of care has had a central place in theory but limited application. Obstacles include confusion of definition and the confounding influence of individual patient characteristics. However, new research promises to be productive in finding a link between continuity process and individual outcome</td>
<td>5, 1, 5</td>
</tr>
<tr>
<td>Kopelowicz, A., Wallace, C.J. and Zarate, R.</td>
<td>Teaching psychiatric in-patients to re-enter the community: a brief method of improving the continuity of care.</td>
<td>Early outpatient attendance improved by intervention (85% v 37% attendance) (small study, short follow-up)</td>
<td>5, 4, 5</td>
</tr>
<tr>
<td>Malla, A.K. <em>et al.</em></td>
<td>An integrated medical and psychosocial treatment program for psychotic disorders: patient characteristics and outcome</td>
<td>Case management resulted in fewer and briefer admissions (than pre-program-entry), high levels of client/relative/service provider satisfaction, fewer relapses not leading to admission</td>
<td>3, 3, 4</td>
</tr>
<tr>
<td>Marshall, M., Lockwood, A. and Gath, D.</td>
<td>Social services case management for long-term mental disorders: a randomised controlled trial</td>
<td>Additional case management achieved a reduction in deviant behaviour. No other significant differences between groups</td>
<td>3, 5, 2</td>
</tr>
<tr>
<td>Marshall, M. <em>et al.</em></td>
<td>Case management for people with severe mental disorders</td>
<td>Five RCTs identified an increase in contact with patients by CMHTs. Psychiatric admissions doubled. No differences in clinical or social outcomes, other than finding from one study showing improved compliance. Uncertain evidence of increased costs</td>
<td>3, 5, 3</td>
</tr>
</tbody>
</table>
## Mental health: Table 4.1

<table>
<thead>
<tr>
<th>Author</th>
<th>Study design</th>
<th>Intervention</th>
<th>Aim</th>
<th>Patient group</th>
<th>Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Morgan, D.</td>
<td>Qualitative: ethnographic</td>
<td>n/a</td>
<td>To investigate how patients are selected by GPs for referral</td>
<td>106 consenting patients from a total of 182 new referrals in a six-month period</td>
<td>UK, Kent; Two psychiatric clinics in a provincial psychiatric hospital</td>
</tr>
<tr>
<td>Muijen, M. et al.</td>
<td>RCT</td>
<td>Daily Living Team offered intensive support at home as an alternative to hospital – intervention included key working, frequent contact, and practical assistance. Controls only offered outpatient appointments</td>
<td>Replication in UK of other investigations comparing intensive home treatment to hospital</td>
<td>Patients with SMI needing hospital admission</td>
<td>UK inner city</td>
</tr>
<tr>
<td>Olffson, M. et al.</td>
<td>Survey</td>
<td>Telephone or face-to-face contact with outpatient physician prior to discharge</td>
<td>To study effect of pre-discharge outpatient clinician contact on short-term course of patients with schizophrenia and compliance with aftercare</td>
<td>Inpatients with psychotic diagnosis due for discharge to unfamiliar clinician</td>
<td>USA, New York; Four general hospitals/community</td>
</tr>
<tr>
<td>Paykel, E.S. et al.</td>
<td>RCT</td>
<td>CPNs main care agent, 78% contact at home, psychological interventions. Activities of control group workers not specified</td>
<td>Compare supportive home visiting by CPNs to routine outpatient care</td>
<td>Neurotic diagnosis, mostly female and middle-aged. Newly discharged /referred to outpatients</td>
<td>London hospital/outpatient</td>
</tr>
<tr>
<td>Ramana, R. et al.</td>
<td>Retrospective survey</td>
<td>Not an intervention study</td>
<td>To assess adequacy of anti-depressant treatment and measure patient compliance</td>
<td>Clinically depressed, mostly female</td>
<td>UK Cambridgeshire Health Authority Primary Care</td>
</tr>
<tr>
<td>------------------</td>
<td>----------------------</td>
<td>---------------------------</td>
<td>----------------------------------------------------------------</td>
<td>-----------------------------------</td>
<td>-----------------------------------------------</td>
</tr>
<tr>
<td>Medication received by patients with depression following the acute episode: adequacy and relation to outcome</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><em>Brit J Psychiatry</em>, 1999</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Mental Health: Table 4.2

<table>
<thead>
<tr>
<th>Author</th>
<th>Title</th>
<th>Outcomes – in relation to continuity of care</th>
<th>Rating:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Morgan, D.</td>
<td>Psychiatric cases: an ethnography of the referral process</td>
<td>42% patients focused on physical complaints. Doctor–patient relationship deteriorates if referral period longer. 3 referral patterns. Barriers to smooth referral discussed</td>
<td>• 3 • 3 • 1</td>
</tr>
<tr>
<td></td>
<td><em>Psychol Med</em>, 1989</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Muijen, M. et al.</td>
<td>Home based care and standard hospital care for patients with a severe mental illness: a randomised controlled trial</td>
<td>Care by Daily Living Team reduced hospital stay by 80%. Increased patient and staff satisfaction, slight improvement in psychopathology/functioning</td>
<td>• 4 • 5 • 4</td>
</tr>
<tr>
<td></td>
<td><em>BMJ</em>, 1992</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Olfson, M. et al.</td>
<td>Linking inpatients with schizophrenia to outpatient care</td>
<td>Contact group more likely to keep O/P appointments, showed reduction in hostility/suspicion and depression. Trend (ns) towards improved medication compliance and reduced homelessness. No effect on emergency room use or social functioning</td>
<td>• 4 • 4 • 4</td>
</tr>
<tr>
<td></td>
<td><em>Psychiatric Services</em>, 1998</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Paykel, E.S. et al.</td>
<td>Community psychiatric nursing for neurotic patients: a controlled trial</td>
<td>Higher patient satisfaction and discharge from care (identified as associated with personal continuity). No differences in symptoms, social adjustment, burden on family</td>
<td>• 4 • 5 • 3</td>
</tr>
<tr>
<td></td>
<td><em>Brit J Psychiatry</em>, 1982</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ramana, R. et al.</td>
<td>Medication received by patients with depression following the acute episode: adequacy and relation to outcome</td>
<td>30% patients did not receive adequate longer-term treatment. Reported compliance 70%. Most common reason for not using antidepressants, patient refusal. Relapses not particularly associated with inadequate treatment</td>
<td>• 1 • 3 • 1</td>
</tr>
<tr>
<td></td>
<td><em>Brit J Psychiatry</em>, 1999</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Author</td>
<td>Study design</td>
<td>Intervention</td>
<td>Aim</td>
</tr>
<tr>
<td>--------</td>
<td>--------------</td>
<td>--------------</td>
<td>-----</td>
</tr>
<tr>
<td>Repper, J., Ford, R. and Cooke, A.</td>
<td>Qualitative Guided interviews with 17 case managers and 16 selected clients</td>
<td>n/a</td>
<td>To identify approaches and tactics used by case managers to develop and maintain relationships with clients</td>
</tr>
<tr>
<td>Tansella, M. et al.</td>
<td>Longitudinal case register study</td>
<td>Psychiatric case register used to monitor and evaluate care</td>
<td>To assess length and frequency of episodes of care provided by community-based services following Italian psychiatric reform and hospital closures</td>
</tr>
<tr>
<td>Teague, G.B., Drake, R.E. and Ackerson, T.H.</td>
<td>Mixed qualitative/quantitative survey</td>
<td>Interviews and records of staff and patients (ethnographic element) used to rate fidelity to a model service (continuous treatment, small caseloads, in vivo treatment, team care)</td>
<td>To evaluate fidelity to an assertive outreach model (Program in Assertive Community Treatment (PACT) model) in seven community health centres</td>
</tr>
<tr>
<td>Tessler, R.C.</td>
<td>Retrospective comparison of two time periods. Assessments at 1–3 and 4–6 months</td>
<td>Intake clinician following patient through admission and co-ordinating discharge plans</td>
<td>To identify and measure breaks in care and examine their effects on patient outcome</td>
</tr>
<tr>
<td>--------------</td>
<td>-------------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Tessler, R. and Hayes-Mason, J.</td>
<td>Prospective survey</td>
<td>Not an intervention study</td>
<td>To predict compliance with aftercare and to look at the impact of patient characteristics on community tenure</td>
</tr>
</tbody>
</table>
### Mental Health: Table 5.2

<table>
<thead>
<tr>
<th>Author</th>
<th>Title</th>
<th>Journal, Date</th>
<th>Outcomes – in relation to continuity of care</th>
<th>Rating:</th>
<th>• Relevance</th>
<th>• Evidence</th>
<th>• Concept</th>
</tr>
</thead>
<tbody>
<tr>
<td>Repper, J., Ford, R. and Cooke, A.</td>
<td>How can nurses build trusting relationships with people who have severe and long-term mental health problems? Experiences of case managers and their clients</td>
<td><em>J Adv Nursing</em>, 1994</td>
<td>Worker–client relationships identified as pivotal to service delivery. Philosophical approach of workers claimed to lead to success in meeting client need – not backed by evidence</td>
<td>2•</td>
<td>2</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Tansella, M. et al.</td>
<td>Episodes of care for first–ever psychiatric patients: a long-term case-register in a mainly urban area.</td>
<td><em>Brit J Psychiatry</em>, 1995</td>
<td>Patterns of service use decline over time but no comparison to other services, other than comment that many patients would previously have spent time in hospital. No clear evidence to back up authors’ claim that the aim of psychiatric services to prioritise CoC has been achieved</td>
<td>1•</td>
<td>3</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Tessler, R.C.</td>
<td>Continuity of care and client outcome</td>
<td><em>Psychosocial Rehab J</em>, 1987</td>
<td>Intervention achieved better linkage to recommended services, increased patient acceptance. Fulfilment of treatment plan associated with improved community adjustment and reduction in complaints about patients</td>
<td>5•</td>
<td>3</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Tessler, R. and Hayes-Mason, J.</td>
<td>Continuity of care in the delivery of mental health services</td>
<td><em>Am J Psychiatry</em>, 1979</td>
<td>Patients with highest aftercare compliance more likely to be married, schizophrenic and feel hopeless. No evidence found that aftercare reduced hospitalisation</td>
<td>4•</td>
<td>3</td>
<td>5</td>
<td></td>
</tr>
</tbody>
</table>
### Mental health: Table 6.1

<table>
<thead>
<tr>
<th>Author</th>
<th>Study design</th>
<th>Intervention</th>
<th>Aim</th>
<th>Patient group</th>
<th>Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tyrer, P.J. and Remington, M.</td>
<td>RCT</td>
<td>Outpatients seen by psychiatrists for as long as necessary/ day hospital offering clinical, occupational therapy, art therapy, psychology/ general hospital day unit psychotherapeutic treatment</td>
<td>To compare outcomes of psychiatric outpatient care, day hospital and day unit care.</td>
<td>106 patients with neurotic disorders referred by GPS</td>
<td>UK, Southampton 10/20 care</td>
</tr>
<tr>
<td>Tyrer, P.J. <em>et al.</em></td>
<td>RCT</td>
<td>Fortnightly contact by CPA key-worker. Transfer to key-worker in another area if patient moved</td>
<td>To test the effectiveness of the Care Programme Approach in preventing patients from losing contact with care services and to reduce admissions</td>
<td>393 vulnerable community-based psychiatric patients No reference to ethnicity</td>
<td>UK inner city</td>
</tr>
<tr>
<td>Tyrer, P.J. <em>et al.</em></td>
<td>RCT</td>
<td>Integrated care by multidisciplinary team: common case records, team supervision, and information sharing reviews. Caseload 25 Limited information about service available to controls</td>
<td>Compare clinical and cost outcomes of intervention to aftercare coordinated by hospital-based team</td>
<td>155 patients with SMI ready for discharge Ethnicity not referred to</td>
<td>UK Two inner city and one outer London sites</td>
</tr>
</tbody>
</table>
### Continuity of Care

<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Study Type</th>
<th>Methodology</th>
<th>Purpose</th>
<th>Location and Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tyrer, P.J. <em>et al.</em></td>
<td>Cochrane Review</td>
<td>Community treatment by integrated multidisciplinary mental health teams</td>
<td>To evaluate the effects of community mental health treatment</td>
<td>Five studies reviewed. Patients with severe mental illness or personality disorders. 3 studies set in UK, one in Australia, one in Canada</td>
</tr>
<tr>
<td>Ware, N.C. <em>et al.</em></td>
<td>Ethnographic study</td>
<td>Field observation and open ended interviews of 16 users and 16 service providers</td>
<td>To develop a standardized measure, to be used in further research, through investigating the meaning of continuity of care for users and providers</td>
<td>16 self-selected volunteers, users of community mental health centres with SMI. Ethnicity stated. Four community mental health centres. USA.</td>
</tr>
<tr>
<td>Author</td>
<td>Title</td>
<td>Outcomes – in relation to continuity of care</td>
<td>Rating:</td>
<td></td>
</tr>
<tr>
<td>----------------------</td>
<td>----------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------------------------------</td>
<td>---------</td>
<td></td>
</tr>
</tbody>
</table>
| Tyrer, P.J. and Remington, M. | Controlled comparison of day-hospital and outpatient treatment for neurotic disorders  
*Lancet*, 1979 | More day patients discontinued treatment  
Greater patient satisfaction with O/P on range of measures including consistency of staff and treatment. More expensive psychotherapeutic care not justified as no difference in symptoms or social functioning | • 1   
• 5   
• 1 |
| Tyrer, P.J. *et al.* | A randomized controlled study of close monitoring of vulnerable psychiatric patients  
*Lancet*, 1995 | No difference in death rate. Fewer lost contacts in CPA group but admissions and bed usage increased | • 3   
• 5   
• 3 |
| Tyrer, P.J. *et al.* | Randomised controlled trial of two models of care for discharged psychiatric patients  
*BMJ*, 1998 | No difference in clinical outcome. Reduction in admissions for 2 inner London community team groups resulted in 14% reduction in costs. In outer London, for both groups, costs doubled as a result of bed shortage and ECR use | • 3   
• 5   
• 3 |
| Tyrer, P.J. *et al.* | Community Mental Health Teams (CMHTs) for people with severe mental illnesses and disordered personality  
*The Cochrane Library*, Issue 3, 2000 | No differences found in admission rates, length of stay or clinical outcomes. Increased patient satisfaction and possible suicide reduction | • 3   
• 5   
• 3 |
| Ware, N.C. *et al.* | An ethnographic study of the meaning of continuity of care in mental health services  
*Psychiatric Services*, 1999 | 6 mechanisms of continuity identified which enhance continuity of care: pinch-hitting, trouble shooting, smoothing transitions, creating flexibility, speeding the system up, contextualising, which could be used as indicators for a structured research interview | • 5   
• 5   
• 5 |
## Continuity of Care

### Appendix 1

#### Primary care: Table 1.1

<table>
<thead>
<tr>
<th>Author</th>
<th>Study design</th>
<th>Intervention</th>
<th>Aim</th>
<th>Patient group</th>
<th>Setting</th>
<th>Length of follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Becker, M.H., Drachman, R.H. and Kirscht, J.P.</td>
<td>RCT</td>
<td>Two similar clinics set up</td>
<td>To examine the effects of delivery of ambulatory care for children from low-income families by two methods:</td>
<td>Black child patients (115/125) 125 mothers Mothers interviewed in Baltimore</td>
<td>USA, Baltimore Primary Care Urban (OP)</td>
<td>9–12 months</td>
</tr>
<tr>
<td></td>
<td></td>
<td>In one, patients see same physician.</td>
<td>• traditional, episodic clinic • clinic structured to provide continuity of physician</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>In the control:</td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td></td>
<td>• random allocation of patients to clinics</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• random allocation of staff too</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Del-Mar, C.B. and Wright, R.G.</td>
<td>Prospective randomised interview study</td>
<td>Randomised by practice Study group had redesigned form including patient’s address for direct notification</td>
<td>To reduce loss of follow-up by direct information</td>
<td>Women of reproductive age. Number not stated but large (all results in 42 practices for 26 weeks)</td>
<td>Australia Primary care with input form secondary care</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Study group had redesigned form including patient’s address for direct notification</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fleming, G.V. and Andersen, R.M.</td>
<td>Two-phase survey baseline and f/u</td>
<td>Charity-funded special health scheme for inner cities</td>
<td>Evaluate a comprehensive health programme for low-income inner city patients designed to improve access and continuity while reducing costs and maintaining quality</td>
<td>Low-income patients in Municipal Health Services Programme (MHSP) in five contrasting inner cities Various ethnicities</td>
<td>USA Primary and secondary – urban</td>
<td>1 year</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Two-phase survey baseline and f/u</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Flocke, S.A.</td>
<td>Development and field test of 20-item questionnaire</td>
<td>Tests new instrument against 9-item satisfaction scale</td>
<td>To measure 7 aspects of primary care and observe association with patient satisfaction</td>
<td>4454 consultations from 138 Ohio primary care physicians</td>
<td>USA, Ohio Mixed Primary Care</td>
<td>n/a</td>
</tr>
</tbody>
</table>

*J Family Practice, 1997*
## Continuity of Care

### Appendix 1

<table>
<thead>
<tr>
<th>Author</th>
<th>Title</th>
<th>Outcomes – in relation to continuity of care</th>
<th>Conclusion</th>
<th>Rating:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Becker, M.H., Drachman, R.H. and Kirscht, J.P.</td>
<td>A field experiment to evaluate various outcomes of continuity of physician care</td>
<td>Staff satisfaction on a number of dimensions and perception of patients&lt;br&gt;Ancillary staff (but not physicians) felt better autonomy in study clinic&lt;br&gt;Patient satisfaction much higher in study group but mothers more dependent and said they might consult more&lt;br&gt;System worked better for study group:&lt;br&gt;• more time with physician, shorter waiting times&lt;br&gt;• better attendance of repeat visits&lt;br&gt;• greater disclosure of personal problems</td>
<td>Ability to develop continuing relationship is good and satisfying in itself&lt;br&gt;Beneficial mutual reinforcement</td>
<td>• 5&lt;br&gt;• 5&lt;br&gt;• 4</td>
</tr>
<tr>
<td>Del-Mar, C.B. and Wright, R.G.</td>
<td>Notifying women of the results of their cervical smear tests by mail: does it result in a decreased loss to follow-up of abnormal smears?</td>
<td>Loss to follow-up of women with CIN</td>
<td>Control group 23% loss (95% CI 11–39%)&lt;br&gt;Study group 0% loss (0–7%)&lt;br&gt;Very promising</td>
<td>• 5&lt;br&gt;• 5&lt;br&gt;• 3</td>
</tr>
<tr>
<td>Fleming, G.V. and Andersen, R.M.</td>
<td>The Municipal Health Services Programme: improving access to primary care without increasing expenditures</td>
<td>Were MHSP recruiting poor people without appropriate access? Yes – somewhat&lt;br&gt;Were utilisation patterns improved? Yes – more PC and less Emergency Room OPD&lt;br&gt;More regular physical exams? (proxy for preventive care in 1983!) Yes&lt;br&gt;Better continuity? No – worse than private physician&lt;br&gt;Satisfaction better? No – less&lt;br&gt;Costs less? No less – less than public but greater than private</td>
<td>Overall more OP and less IP expenses for MHSP programme&lt;br&gt;NB:&lt;br&gt;1 Researchers reveal that Randomised Allocation essential to unpick causal relationships!&lt;br&gt;2 relevance to costs</td>
<td>• 4&lt;br&gt;• 3&lt;br&gt;• 3</td>
</tr>
</tbody>
</table>
### Continuity of Care

| Flocke, S.A. | Identifies and compares four aspects 'components' of primary care  
|             | Patient preference for regular physician  
|             | Interpersonal communication  
|             | Accumulated knowledge  
|             | Coordination of care  
|             | These are all more strongly associated with patient satisfaction than is usual provider continuity (UPC) | Satisfaction correlated poorly with seeing the same physician a lot.  
|             | Interpersonal communication and care co-ordination rated more highly than preference for a regular physician in NE Ohio. | 5  
|             | 3  
|             | 4 |

*J Family Practice, 1997*
<table>
<thead>
<tr>
<th>Author</th>
<th>Study design</th>
<th>Intervention</th>
<th>Aim</th>
<th>Patient group</th>
<th>Setting</th>
<th>Length of follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Flocke, S.A., Stange, K.C. and Zyzanski, S.J.</td>
<td>Cross-sectional survey – direct observation + records + exit quest</td>
<td>Patient reported forced change of core plan (insurance) in past two years</td>
<td>Effect of insurance mandated disruption on quality of primary care</td>
<td>1839 consultations in 138 practices; all patients on two-day observational periods who were in insurance plans</td>
<td>Primary care</td>
<td>2 years retrospective</td>
</tr>
<tr>
<td>Freeman, G.K.</td>
<td>Observational survey supplemented by brief, structured interviews</td>
<td>One personal list and three combined list practices. Receptionists observed mostly using telephone patients’ requests (1st and 2nd choices) for doctor and time (session) of appointment recoded – also agreed decision</td>
<td>1 observe receptionists working opportunities and what they do when patients first choice is not available 2 investigate receptionists’ beliefs about CoC and its priorities 3 compare beliefs with behaviour 4 assess impact of practice policies 5 assess influence of receptionists</td>
<td>543 patients; UK Four general practices in southern England</td>
<td>n/a</td>
<td></td>
</tr>
<tr>
<td>Freeman, G.K. and Richards, S.C.</td>
<td>Cross-sectional retrospective record survey</td>
<td>Inspection of records Doctors identified by their handwriting</td>
<td>To establish amount of CoC in general practice</td>
<td>776 patients attending randomly selected consulting seniors who had been registered at least 2 years and consulted at least</td>
<td>UK Four general practices in southern England</td>
<td>2 years retrospective</td>
</tr>
</tbody>
</table>

*Continuity of Care*

Appendix 1

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| Freeman, G.K. and Richards, S.C. | Interview survey | Patients were interviewed at home one week after an index consultation. One practice ran a strict personal list – the other two combined as shared lists | To elucidate patients’ views on CoC received and on seeing the same doctor | 111 patients | UK Three general practices in southern England | n/a |

Is personal continuity of care compatible with free choice of doctor? Patients’ views on seeing the same doctor. *BJGP*, 1993

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## Continuity of Care

### Appendix 1

<table>
<thead>
<tr>
<th>Author</th>
<th>Title</th>
<th>Outcomes – in relation to continuity of care</th>
<th>Conclusion</th>
<th>Rating:</th>
</tr>
</thead>
</table>
| Flocke, S.A., Stange, K.C. and Zyzanski, S.J. | The impact of insurance type and forced discontinuity on the delivery of primary care | Interpersonal communication  
Dr’s knowledge of patient.  
Coordination of CoC  
Patient’s preference to see regular physician  
UPC  
All these significantly worse with forced discontinuity | Convincing evidence that forced discontinuity is detrimental to patient measures of process and relationship  
An implementation study (albeit a negative one!) | 4  
3  
5 |
| Freeman, G.K.                  | Receptionists, appointment systems and continuity of care            | No significant benefit from seeing the same doctor  
Better discussion associated with patients reporting there was one or more doctors easy to talk to within practice | Communication skills and knowledge of psychosocial impact of epilepsy has greater priority than seeing the same doctor | 4  
3  
4 |
| Freeman, G.K. and Richards, S.C. | Practice observed. How much personal care in four group practices?  | Combined list practices attracted specific requests. Priority for individual doctors raised up to eightfold  
Receptionists had differing priorities  
If they prioritised CoC then some patients got this. If they did not then their patients always got their requested time rather than their requested doctor  
Overall, receptionists’ influence limited by practice policies | Unusual study advancing our understanding of the negotiating process | 5  
4  
4 |
| Freeman, G.K. and Richards, S.C. | Is personal continuity of care compatible with free choice of doctor? Patients’ views on seeing the same doctor. | Patients in personal list practice were happier and usually waited longer.  
They had no expectation of having a choice of doctors and had high longitudinal CoC. Patients in combined list practices were far more ‘streetwise’ and more willing to choose and criticise. Many were glad to be able to choose and then frustrated at difficulty of exercising their choice. | Patients are not willing to wait too long to see their usual doctor as a rule.  
There is no evidence that they should be compelled to do so, e.g. by personal lists. | 4  
3  
4 |
## Continuous Care

**Primary Care: Table 3.1**

<table>
<thead>
<tr>
<th>Author</th>
<th>Study design</th>
<th>Intervention</th>
<th>Aim</th>
<th>Patient group</th>
<th>Setting</th>
<th>Length of follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Freeman, G.K. and Richards, S.C.</td>
<td>Cross-sectional survey</td>
<td>Perceived care of epilepsy</td>
<td>Testing whether patients seeing the same doctor were more likely to discuss personally important aspects of their illness</td>
<td>99 adults with epilepsy</td>
<td>UK Four general practices in southern England</td>
<td>2 years+ retrospective</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Whether they have discussed key personal issues:</td>
<td></td>
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<td></td>
<td></td>
<td>• stopping medication</td>
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<td></td>
<td></td>
<td>• stigma</td>
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<td></td>
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<td>• concealment</td>
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<tr>
<td></td>
<td></td>
<td>• to whom would they address their most important questions?</td>
<td></td>
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</tr>
<tr>
<td></td>
<td></td>
<td>Compared with recorded CoC</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Hjortdahl, P.</td>
<td>Survey</td>
<td>How long and how dense does previous contact need to be to make significant difference to:</td>
<td>Study relation between CoC and GPs’ accumulated knowledge</td>
<td>3918 consultations from 133 GPs</td>
<td>Norway National sample of general practices</td>
<td>n/a</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• knowledge?</td>
<td>Study relation between CoC and GPs’ sense of responsibility</td>
<td></td>
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</tr>
<tr>
<td></td>
<td></td>
<td>• sense of responsibility?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hjortdahl, P. and Borchgrevink, C.F.</td>
<td>Cross-sectional survey</td>
<td>GPs rated their knowledge of patients history on a 5-point scale</td>
<td>To examine relation between GP’s knowledge and use of all resources: • use of tests and X-rays</td>
<td>3918, all ages</td>
<td>Norway National sample of 133 GPs</td>
<td>n/a</td>
</tr>
</tbody>
</table>
Continuity of Care

| ABOUT THEIR PATIENTS ON USE OF RESOURCES IN CONSULTATIONS BMJ, 1991 | GPs HAD TO RECORD: (a) IF THEY’D CONSIDERED USING IT (b) WAS THIS – CLINICAL PRESENTATION ALONE? – KNOWLEDGE OR LACK OF KNOWLEDGE? (c) DID THEY ACTUALLY USE IT? | • REFERRALS • EXPECTANT MANAGEMENT • PRESCRIPTIONS, CERTIFICATES • CONSULTATION TIME |  |  
|---|---|---|---|---|
### Primary care: Table 3.2

<table>
<thead>
<tr>
<th>Author</th>
<th>Title</th>
<th>Outcomes – in relation to continuity of care</th>
<th>Conclusion</th>
<th>Rating:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Freeman, G.K. and Richards, S.C.</td>
<td>Personal continuity and the care of patients with epilepsy in general practice</td>
<td>Number of doctors seen – UPC compared with demographic chart</td>
<td>UPC low in group practices, especially children</td>
<td>• 3 • 3 • 4</td>
</tr>
</tbody>
</table>
| Hjortdahl, P. | Continuity of care: general practitioners’ knowledge about and sense of responsibility toward their patients | Answer:  
- knowledge – at least six visits in last year or at least five years  
- responsibility – at least two visits or three months: i.e. much less | • Density was more significant that total duration  
• Sense of responsibility comes before knowledge  
• Unique study of this aspect of CoC | • 5 • 3 • 5 |
| Hjortdahl, P. and Borchgrevink, C.F. | Continuity of care: influence of general practitioners’ knowledge about their patients on use of resources in consultations | When GP uses previous knowledge of patient their use of:  
- time – less  
- tests – less  
- expectant management (wait and see) – more  
- prescriptions – more liberal  
- sick certificates – much more  
- referrals – more | NB:  
- subjective judgements  
- difficulty of using cross-sectional study for longitudinal phenomenon  
- highly relevant outcomes | • 5 • 3 • 5 |
## Primary care: Table 4.1

<table>
<thead>
<tr>
<th>Author</th>
<th>Study design</th>
<th>Intervention</th>
<th>Aim</th>
<th>Patient group</th>
<th>Setting</th>
<th>Length of follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hjortdahl, P. and Laerum, E.</td>
<td>Survey of GP evaluations inked onto pt. Q’s for same consultation</td>
<td>Evaluate influence of CoC on patient satisfaction</td>
<td>3044 white patients, all ages</td>
<td>Norway National sample of 133 GPs</td>
<td>n/a Duration only significant if over 5 years</td>
<td></td>
</tr>
<tr>
<td>Howie, J.G.R. <em>et al.</em></td>
<td>Survey of consecutive consultations over two weeks</td>
<td>Pre consultation questionnaire included how well patient knew the doctor. Stopwatch timing of consultations Post-consultation questionnaire assessed patient enablement index (PEI)</td>
<td>To measure quality of care at GP consultations To determine principle correlates associated with enablement including time and continuity (assessed as knowing the doctor well – relational)</td>
<td>25,994 consultations</td>
<td>UK 53 general practices in four contrasting UK regions</td>
<td>n/a</td>
</tr>
<tr>
<td>Kibbe, D.C., Bentz, E. and McLaughlin, C.P.</td>
<td>Audit cycle repeated survey after intervention</td>
<td>• Collect data • Analyse problems • Make changes, train staff • Second data collection • Review</td>
<td>To improve provider continuity by Continuous Quality Improvement (CQI) Five problem areas identified (especially receptionist training)</td>
<td>125 1^o^ care patients</td>
<td>USA, North Carolina Primary care</td>
<td>Up to one year</td>
</tr>
</tbody>
</table>
### Primary care: Table 4.2

<table>
<thead>
<tr>
<th>Author</th>
<th>Title</th>
<th>Journal, Date</th>
<th>Outcomes – in relation to continuity of care</th>
<th>Conclusion</th>
<th>Rating:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hjortdahl, P. and Laerum, E.</td>
<td>Continuity of care in general practice; effect on patient satisfaction</td>
<td><em>BMJ</em>, 1992</td>
<td>Satisfaction most strongly associated with “My personal doctor”. Intensity not related to satisfaction</td>
<td>Personal care is a highly significant factor in improving quality and satisfaction</td>
<td>• 4 • 3 • 5</td>
</tr>
<tr>
<td>Howie, J.G.R. <em>et al.</em></td>
<td>Quality at general practice consultations: cross-sectional survey</td>
<td><em>BMJ</em>, 1999</td>
<td>Enablement score was most closely associated with duration of consultation and with knowing the doctor well</td>
<td>It may be appropriate to reward doctors who have longer consultations, provide greater continuity of care and both enable more patients and enable patients more.</td>
<td>• 4 • 4 • 5</td>
</tr>
<tr>
<td>Kibbe, D.C., Bentz, E. and McLaughlin, C.P.</td>
<td>Continuous quality improvement for continuity of care</td>
<td><em>J Family Practice</em>, 1993</td>
<td>UPC Recorded separately according to: health maintenance chronic illness acute care all three</td>
<td>64% rise in UPC (highly significant) Authors admit that interaction not necessarily the cause of this change</td>
<td>• 5 • 4 • 4</td>
</tr>
</tbody>
</table>
## Primary care: Table 5.1

<table>
<thead>
<tr>
<th>Author</th>
<th>Study design</th>
<th>Intervention</th>
<th>Aim</th>
<th>Patient group</th>
<th>Setting</th>
<th>Length of follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rubenstein, L.V. et al.</td>
<td>Surveys Baseline Implementation Early and late</td>
<td>PACE (primary Ambulatory Care and Education Program)</td>
<td>Evaluate impact of reorganisation towards primary care on quality of primary ambulatory care (Improving primary CoC was top objective) • all care from PACE • particular physician at least twice a year</td>
<td>Veterans attending who had already attended at least once Approx 1500</td>
<td>USA, California Primary care</td>
<td>1 year</td>
</tr>
<tr>
<td>Taira, D.A. et al.</td>
<td>Survey – questionnaire (PCAS)</td>
<td>Last 20 patients seen by each physician</td>
<td>Compare Asian-American patient rating of primary care with those of Whites, Latinos and African-Americans</td>
<td>Patients (adults) registered with one university hospital (and consulting) primary care</td>
<td>USA, Boston Primary care</td>
<td>n/a</td>
</tr>
</tbody>
</table>
### Continuity of Care

| J Gen Int Medicine, 1997 | Balanced RCT | Telephone care (substitute for clinic visits) | To reduce medical care utilisation without harming health | 497 veterans (males over 54 years) | USA, New Hampshire 1<sup>st</sup> care, but average patient lived 80km from clinic | 2 years |

Wasson, J. et al.
Telephone care as a substitute for routine clinic follow-up
*JAMA*, 1992
## Continuity of Care

### Appendix 1

### Primary care: Table 5.2

<table>
<thead>
<tr>
<th>Author</th>
<th>Title</th>
<th>Outcomes – in relation to continuity of care</th>
<th>Conclusion</th>
<th>Rating:</th>
</tr>
</thead>
</table>
| Rubenstein, L.V. | Evaluation of the VA’s pilot program in institutional reorganization toward primary and ambulatory care: Part I, changes in process and outcomes of care | Interviewer administered questionnaire including several standard instruments Utilisation data [Note: utilisation outcomes – but cannot show cause and effect because it was not a trial] | 10% increase in seeing same physician  
15% increase in getting all or most care from team  
Satisfaction improved slightly (2%)  
More primary care and less Speciality Clinic visits  
Hospital admissions down 21% (all) and 26% (emergency) | • 4  
• 3  
• 3 |
Dimensions include communication, trust, interpersonal, how well doctor knows patient, access, technical skill etc.  
Study is a comparison: conclusions can only be tentative | Asian-Americans gave significantly lower ratings on all dimensions except longitudinal CoC which was recorded rather than rated (but only 25 patients or 5% of sample)  
Important because it is a rare inter-ethnic study | • 3  
• 3  
• 3 |
| Wasson, J. et al.| Telephone care as a substitute for routine clinic follow-up          | OP consultations ↓ IP admissions ↓ medication ↓ duration of stay ↓ tests (blood chem.) ↓ ICU ↓ costs ↓ hospital costs ↓ total costs ↓ | 28% reduction in costs | • 5  
• 5  
• 4 |
## Maternity: Table 1.1

<table>
<thead>
<tr>
<th>Author</th>
<th>Title</th>
<th>Study design</th>
<th>Intervention</th>
<th>Aim</th>
<th>Patient group</th>
<th>Setting</th>
<th>Length of follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Binstock, M.A. and Wolde-Tsadik, G.</td>
<td>Alternative prenatal care. Impact of reduced visit frequency, focused visits and continuity of care</td>
<td>CCT</td>
<td>Visits from study team and provision of patient education handouts</td>
<td>To investigate impact of alternative prenatal care program for low risk women</td>
<td>Low risk women receiving prenatal care (n=549)</td>
<td>Community</td>
<td></td>
</tr>
<tr>
<td>Brown, S. and Lumley, J.</td>
<td>Changing childbirth: lessons from an Australian survey of 1336 women</td>
<td>Mailed cross sectional survey 6–7 months post partum</td>
<td>Shared care system, birthing centres vs: • private care • hospital-led care</td>
<td>Views of women using new care options vs. old • extent of greater CoC • whether this enhanced women’s experience</td>
<td>1336 women</td>
<td>Australia Maternity – various</td>
<td>Approx. 550 days</td>
</tr>
<tr>
<td>Giles, W. et al.</td>
<td>Antenatal care of low-risk obstetric patients by midwives. A randomised controlled trial</td>
<td>RCT</td>
<td>Midwife-led clinic vs. obstetrician-led hospital care (Patients see obstetrician at booking, 30/40 and 40/40)</td>
<td>To assess practicality, patient acceptability and salary costs of a/n care of low-risk patients by midwives</td>
<td>Maternity; not stated</td>
<td>Australia 1°/2° interface</td>
<td>Not stated</td>
</tr>
<tr>
<td>Hodnett, E.D.</td>
<td>Continuity of caregivers for care</td>
<td>Cochrane systematic review</td>
<td>Continuity of care through same caregiver or a small</td>
<td>Assess continuity of care during pregnancy, childbirth and puerperium</td>
<td>Pregnant women (2 studies n=1815 women)</td>
<td>Across primary and secondary care</td>
<td>To childbirth</td>
</tr>
</tbody>
</table>
### Continuity of Care

<table>
<thead>
<tr>
<th>during pregnancy and childbirth</th>
<th>group from pregnancy</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Cochrane Library, 2000</em></td>
<td></td>
</tr>
</tbody>
</table>

#### Hodnett, E.D. and Roberts, I.  
Home based social support for socially disadvantaged mothers  
*Cochrane Library, 2000*

<table>
<thead>
<tr>
<th>Cochrane Review</th>
<th>Additional home-based support for socially disadvantaged mothers and their children</th>
<th>To assess the effects of programmes offering additional home-based support for women and their children</th>
<th>Socially disadvantaged women who have recently given birth</th>
<th>Community</th>
<th>Up to 4 years</th>
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</table>
### Continuity of Care

#### Maternity: Table 1.2

<table>
<thead>
<tr>
<th>Author</th>
<th>Title</th>
<th>Rating</th>
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<tbody>
<tr>
<td>Binstock, M.A. and Wolde-Tsadik, G.</td>
<td>Alternative prenatal care. Impact of reduced visit frequency, focused visits and continuity of care</td>
<td>• 3 • 4 • 3</td>
</tr>
<tr>
<td>Brown, S. and Lumley, J.</td>
<td>Changing childbirth: lessons from an Australian survey of 1336 women</td>
<td>• 3 • 3 • 2</td>
</tr>
<tr>
<td>Giles, W. et al.</td>
<td>Antenatal care of low-risk obstetric patients by midwives. A randomised controlled trial</td>
<td>(• 4?) (• 4?) (• 3?)</td>
</tr>
<tr>
<td>Hodnett, E.D.</td>
<td>Continuity of caregivers for care during pregnancy and childbirth</td>
<td>• 4 • 5 • 4</td>
</tr>
<tr>
<td>Hodnett, E.D. and Roberts, I.</td>
<td>Home based social support for socially disadvantaged mothers</td>
<td>• 3 • 4 • 3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Author</th>
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<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Higher levels of patient satisfaction regarding continuity of care in the intervention group</td>
<td>• 3</td>
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<tr>
<td></td>
<td>Most women have had no previous contact with their intra-partum midwife except in rural areas Knowing midwife makes independent contribution to satisfaction</td>
<td>• 3 • 3 • 2</td>
</tr>
<tr>
<td></td>
<td>Salary costs Practicality Acceptability to patients (= satisfaction) Salary costs down 28–68% Patients prefer continuity of midwife = better information [NB: only abstract available for review – cannot assess quality well here]</td>
<td>(• 4?) (• 4?) (• 3?)</td>
</tr>
<tr>
<td></td>
<td>Women receiving the intervention were less likely to be admitted, have drugs for pain relief during labour, have an episiotomy, and newborns less likely to require resuscitation. No differences in Apgar score, low birthweight, stillbirths or neonatal deaths. More likely to attend antenatal education and be pleased with antepartum care, and more likely to have a vaginal or perineal tear</td>
<td>• 4 • 5 • 4</td>
</tr>
<tr>
<td></td>
<td>Trend towards reduced child injury rates, failed to detect a difference for child abuse and neglect. Babies in additional support groups were more likely to have complete well child immunisations</td>
<td>• 3 • 4 • 3</td>
</tr>
</tbody>
</table>
## Maternity: Table 2.1

<table>
<thead>
<tr>
<th>Author</th>
<th>Study design</th>
<th>Intervention</th>
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<th>Setting</th>
<th>Length of follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hundley, V.A. <em>et al.</em>&lt;br&gt;Satisfaction and the 3 C’s: continuity, choice and control. Women’s views from a randomised controlled trial of midwife-led care&lt;br&gt; <em>B J of Obs &amp; Gyn</em>, 1997</td>
<td>RCT</td>
<td>Midwife managed delivery unit</td>
<td>To explore differences in women’s satisfaction with care in midwife managed unit compared with consultant led labour ward.</td>
<td>Low risk women receiving antenatal care (n=2844)</td>
<td>Scotland Aberdeen Maternity Hospital, Grampian</td>
<td></td>
</tr>
<tr>
<td>McCourt, C. <em>et al.</em>&lt;br&gt;Evaluation of one to one midwifery: women’s responses to care&lt;br&gt; <em>Birth</em>, 1998</td>
<td>Prospective comparative study</td>
<td>One-to-one midwifery care</td>
<td>To compare one-to-one care with conventional care</td>
<td>Women receiving maternity services (treatment n=728; control n=675)</td>
<td>UK, West London</td>
<td></td>
</tr>
<tr>
<td>Page, L. <em>et al.</em>&lt;br&gt;Clinical interventions and outcomes of one to one midwifery practice&lt;br&gt; <em>J Reprod Med</em>, 1999</td>
<td>Prospective comparative study</td>
<td>One-to-one midwifery care</td>
<td>To compare one-to-one care with conventional care</td>
<td>Women receiving maternity services (treatment n=728; control n=675)</td>
<td>UK, West London</td>
<td></td>
</tr>
<tr>
<td>Rowley, M.J. <em>et al.</em>&lt;br&gt;Continuity of care by a midwife team versus routine care during pregnancy and birth: a randomised trial</td>
<td>RCT</td>
<td>Team care with six midwives</td>
<td>To compare continuity of care from a midwife team with routine care from a variety of doctors and midwives.</td>
<td>Women receiving care during pregnancy and birth (treatment n=405, control n=409)</td>
<td>Clinic</td>
<td></td>
</tr>
<tr>
<td>Med J Aust, 1995</td>
<td>Pre- and post-intervention design</td>
<td>Home-based maternal record (HBMR)</td>
<td>One of the aims of this study was to assess if the HBMR promotes continuity of care throughout pregnancy, labour, delivery and the postpartum and interpregnancy periods</td>
<td>Women who were 2–8 months pregnant</td>
<td>This article summarised findings from 13 centres in eight countries: Egypt, India, Pakistan, Philippines, Senegal, Sri Lanka, Democratic Yemen, Zambia</td>
<td>15–24 months</td>
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</tr>
</tbody>
</table>
### Maternity: Table 2.2

<table>
<thead>
<tr>
<th>Author</th>
<th>Title</th>
<th>Outcomes – in relation to continuity of care</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hundley, V.A. <em>et al.</em></td>
<td>Satisfaction and the 3 C's: continuity, choice and control. Women's views from a randomised controlled trial of midwife-led care</td>
<td>Failed to detect a difference in satisfaction with overall experience. Highlights difficulties in measuring quality of service provision</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td><em>B J of Obs &amp; Gyn</em>, 1997</td>
<td></td>
<td>5</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>3</td>
</tr>
<tr>
<td>McCourt, C. <em>et al.</em></td>
<td>Evaluation of one to one midwifery: women's responses to care</td>
<td>Women are more satisfied with one-to-one model of care</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td><em>Birth</em>, 1998</td>
<td></td>
<td>5</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>4</td>
</tr>
<tr>
<td>Page, L. <em>et al.</em></td>
<td>Clinical interventions and outcomes of one to one midwifery practice</td>
<td>High degree of continuity for intervention group, measured by women seeing fewer staff, knew more of the staff they did see, high level of constant support in labour.</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td><em>J Reprod Med</em>, 1999</td>
<td></td>
<td>5</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>4</td>
</tr>
<tr>
<td>Rowley, M.J. <em>et al.</em></td>
<td>Continuity of care by a midwife team versus routine care during pregnancy and birth: a randomised trial</td>
<td>Continuity of care was part of intervention, women allocated to intervention reported increased satisfaction</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3</td>
</tr>
<tr>
<td>Shah, K. <em>et al.</em></td>
<td>Evaluation of the home-based maternal record: a WHO collaborative study</td>
<td>In terms of continuity of care in most study centres a higher proportion of women attended the antenatal clinics in the HBMR areas, and many used postnatal, interpregnancy and newborn care. They perceived their care to be improved compared with past experience. Study emphasised the importance of choosing an appropriate person to introduce the HBMR in the community and the need for training materials</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td><em>Bulletin WHO</em>, 1993</td>
<td></td>
<td>4</td>
</tr>
<tr>
<td></td>
<td></td>
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<th>Length of follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tucker, J.S. et al.</td>
<td>RCT</td>
<td>Antenatal care by midwives and GPs according to a care plan and protocols for managing complications.</td>
<td>To compare routine antenatal care provided by GPs and midwives with obstetrician-led shared care</td>
<td>Low-risk women receiving antenatal care (n=1765)</td>
<td>Scotland 51 general practices linked to 9 Scottish maternity hospitals</td>
<td>310 days (delivery +6 weeks)</td>
</tr>
<tr>
<td>Waldenstrom, U. and Turnbull, D.</td>
<td>Cochrane systematic review</td>
<td>Care provided by a midwife or small group of midwives</td>
<td>Assess continuity of care from early pregnancy to childbirth</td>
<td>Pregnant women (seven RCTs, n=9148 women)</td>
<td>Across primary and secondary care</td>
<td>To childbirth</td>
</tr>
</tbody>
</table>

**Study design:** RCT

**Intervention:**
- Antenatal care by midwives and GPs according to a care plan and protocols for managing complications.
- Care provided by a midwife or small group of midwives.
# Continuity of Care

## Maternity: Table 3.2

<table>
<thead>
<tr>
<th>Author</th>
<th>Outcomes – in relation to continuity of care</th>
<th>Rating</th>
</tr>
</thead>
</table>
| Tucker, J.S. *et al.*  
Should obstetricians see women with normal pregnancies? A multicentre randomised controlled trial of routine antenatal care by general practitioners and midwives compared with shared care led by obstetricians  
*BMJ*, 1996 | Measured continuity of care by number of carers patients had, and routine visits. Intervention reduced the number of carers (median five carers vs. seven, p<0.001) and number of routine visits (10.9 vs. 11.7, p<0.001) | 4, 5, 3 |
| Waldenstrom, U. and Turnbull, D.  
A systematic review comparing continuity of midwifery care with standard maternity services  
*B J of Obs and Gyn* 1998 | Continuity of midwifery care is associated with lower intervention rates than standard maternity care. Failed to detect a difference for maternal or fetal outcomes | 5, 5, 5 |
## Miscellaneous: Table 1.1

<table>
<thead>
<tr>
<th>Author</th>
<th>Title</th>
<th>Study design</th>
<th>Intervention</th>
<th>Aim</th>
<th>Patient group</th>
<th>Setting</th>
<th>Length of follow-up</th>
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</thead>
<tbody>
<tr>
<td>Kao, A.C. et al.</td>
<td>Patients’ trust in their physicians. Effects of choice, continuity and payment method</td>
<td>Telephone questionnaire</td>
<td>Trust questionnaire (modified from Anderson, L.A. (1990) <em>Psychol. Rep.</em> 67:1091–100)</td>
<td>To evaluate extent to which physician choice, continuity (length of patient–physician relationship) and perceived physical payment method predict trust</td>
<td>Insured patients (adults with at least one consultation in previous year) 292 out of 410 eligible patients (71%)</td>
<td>USA. Atlanta 1º Care</td>
<td>n/a</td>
</tr>
<tr>
<td>Lee, L.H., Levine, J.A. and Schultz, H.J.</td>
<td>Utility of a standardised sign-out card for new medical interns</td>
<td>Random allocation of interns (resident doctors) to intervention or control teams</td>
<td>Use of a structured ‘sign-out’ (i.e. hand-over) record at shift changes (day–night)</td>
<td>To improve patient care by aiding transfer of relevant clinical information between shift-working doctors</td>
<td>252 questionnaires from interns Medicine, Minnesota, USA</td>
<td>USA, Rochester, Minnesota Secondary care: inpatient cardiovascular medicine</td>
<td>1 day (next morning)</td>
</tr>
<tr>
<td>Parkerton, P.H.</td>
<td>Part-time practice and physician performance: continuity in primary care</td>
<td>Survey of administration and study departments</td>
<td>Physician availability and continuity Practice structure (team size, HC size etc.)</td>
<td>The relationship between part-time practice and physician physical performance</td>
<td>Group health medical centres 194 physicians</td>
<td>USA, Washington State Primary care</td>
<td>n/a</td>
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<tr>
<td>Wallace, K. and Soloman, J.</td>
<td>Quality of epilepsy treatment and services: the views of women with epilepsy</td>
<td>18 women in three focus groups, further focus groups with six epilepsy women. Recruitment was n/a</td>
<td>Assess views of epilepsy patients and nurse specialists on how epilepsy R might be improved</td>
<td>Female patients with epilepsy attending OP</td>
<td>UK Primary and secondary</td>
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<tr>
<td>Continuity of Care</td>
<td>Appendix 1</td>
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<td><strong>Seizure, 1999</strong></td>
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<td>leaflets at OP (National Hospital)</td>
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<td>and by Epilepsy Support Network</td>
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<td>Nurses from hospitals around England</td>
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### Miscellaneous: Table 1.2

<table>
<thead>
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<th>Conclusion</th>
<th>Rating</th>
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<tbody>
<tr>
<td>Kao, A.C. et al.</td>
<td>Length of relationship</td>
<td>Awareness of payment method was poor</td>
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<tr>
<td>Patients’ trust in their physicians. Effects of choice, continuity and payment method</td>
<td>Knowledge of payment method</td>
<td>Trust is associated with:</td>
<td>2</td>
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<tr>
<td><em>J Gen Int Med</em>, 1998</td>
<td></td>
<td>• more choice of physician</td>
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<td></td>
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<td>• length of relationship</td>
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<td></td>
<td></td>
<td>(and with trusting the managed care organisation)</td>
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<tr>
<td>Lee, L.H., Levine, J.A. and Schultz, H.J.</td>
<td>Bad handover recorded at subsequent questionnaire</td>
<td>Significantly fewer bad handovers in intervention group</td>
<td>4</td>
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<tr>
<td>Utility of a standardized sign-out card for new medical interns</td>
<td></td>
<td>NB: validity problems: non-blinded, confounding</td>
<td>3</td>
</tr>
<tr>
<td><em>J Gen Int Med</em>, 1996</td>
<td></td>
<td></td>
<td>4</td>
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<tr>
<td>Parkerton, P.H.</td>
<td>Part-time satisfaction, cancer success, diabetic management</td>
<td>Part-time physicians associated with:</td>
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<tr>
<td>Part-time practice and physician performance. Continuity in primary care</td>
<td>Costs</td>
<td>• better cancer screening</td>
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<tr>
<td>Conference abstract, 2000</td>
<td>Usual Provider Continuity index (UPC)</td>
<td>• diabetes</td>
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<td></td>
<td>length of association (team tenure, i.e. length of practice in study site; this was significant for periods exceeding three years)</td>
<td>• higher costs</td>
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<td>• lower UPC</td>
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<td></td>
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<td>• higher length of knowing physician</td>
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<td>Costs rise as FTE drops below 0.7</td>
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<tr>
<td></td>
<td></td>
<td>The authors like ‘sustained practice availability’</td>
<td></td>
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<tr>
<td>Wallace, K and Soloman, J.</td>
<td>Areas of concern:</td>
<td>Recommends management changes to ensure greater provision of CoC in OP</td>
<td>3</td>
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<tr>
<td>Quality of epilepsy treatment and services: the views of women with</td>
<td>•continuity – mainly seeing same doctor each time in OP – also 10/20 communication</td>
<td></td>
<td>3</td>
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<tr>
<td>Continuity of Care</td>
<td>Appendix 1</td>
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<td><strong>epilepsy</strong></td>
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<td><em>Seizure, 1999</em></td>
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<tr>
<td>(information)</td>
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<td>• rushed consultations</td>
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<tr>
<td>• information provision, e.g. contraception, pregnancy</td>
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<td>• clinical competence and skills, including hospital, GP and A&amp;E</td>
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<td>• outcomes of treatment</td>
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</tbody>
</table>
Ratings definitions for Continuity of Care Scoping Exercise

**Relevance (to policy and/or research)**

5  Continuity of care (CoC) clearly defined and related directly to outcome measures used. These include clinically useful changes in process other than patient satisfaction.
  Qualitative study which expands our understanding of CoC from patient’s viewpoint.

4  Attempts to make a definition of CoC with visible connection to outcomes.
   Valuable qualitative study perhaps from a novel aspect other than the patient but having impact on the patient.

3  Interesting findings which advance our understanding of CoC; however, study was not set up with this primary aim.
   Qualitative work less well focused on CoC and its meanings and effects.
   Promising preliminary work mapping future directions.

2  Promising preliminary work but with no definite findings.

1  No definition. Implicit or routine reference made to CoC in paper as part of a general positive attribute.

**Evidence (methodological quality)**

5  Well-designed randomised controlled trial.
   Rigorous qualitative study with well-described methods and critical discussion, placed in context of wider literature.

4  Well-designed controlled trial without randomisation.
   Qualitative work of high standard but perhaps with small numbers, less well described/rigorous method and less well contextualised in relevant literature.

3  Appropriately conducted study mapping future directions, with implicit but undeveloped findings.

3  Poorly defined methods and/or lack of power with conclusions going beyond the evidence.

1  Opinion pieces or anecdotal discussion.

**Concept (clarity of definition of continuity)**

5  Has awareness of challenges of defining CoC and in relating such to the health care scene. Well-argued new definitions or reassessment of old ones

4  Clearly described definition(s). Results clearly relate to definitions and move them forward.
Continuity of Care

3 Uses clear definition(s) and/or places results in context of definition.
2 Fuzzy definition. Lack of awareness of CoC as concept needing definition.
1 No definition and unclear relevance to CoC although CoC or its equivalent is stated but undeveloped. (Study included because of serendipitous relevance to our needs.)
## Data extraction sheet: Continuity of Care Scoping Exercise

If not clear on any of the items please insert ? and check

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<thead>
<tr>
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<th>DATA</th>
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<td><strong>INCLUDED STUDY</strong></td>
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<td><strong>Definition</strong></td>
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<td>of continuity of care used in paper</td>
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<td>(state if no definition used)</td>
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<td><strong>Setting</strong></td>
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<td>(e.g. 1°, 2°, 1°/2° interface</td>
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<td>urban, intermediate, rural etc.)</td>
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<td><strong>Country</strong></td>
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<td>Ethnicity</td>
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<td>Number of patients</td>
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<td><strong>Intervention</strong></td>
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<td>(for example this may include the</td>
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<td>way a service or staff are organised,</td>
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<td>national or local policy)</td>
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<td><strong>Outcomes measured</strong></td>
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<td>• outcome measured, for example</td>
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<td>quality of care, and</td>
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<td>• how this is measured, e.g. by loss</td>
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<td>of contacts or death rate</td>
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<tr>
<td><strong>Length of follow-up</strong> (days)</td>
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<tr>
<td><strong>Conclusion</strong></td>
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<tr>
<td>Benefit/no benefit/disbenefit from</td>
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<td>continuity intervention</td>
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### Continuity of Care

**Additional references**
from paper that we have not already identified

<table>
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<th>Rating</th>
<th>relevant</th>
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<td>low = 1</td>
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<tr>
<td>best = 5</td>
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</table>

**Excluded studies** (i.e. included from reading abstract, then excluded after reading full paper)
Appendix 3

Other evidence from organisations and individuals

A3.1 Voluntary organisations

We conducted a survey of a selection of voluntary organisations (identified through the Association of Medical Charities Handbook 2000 and the National Council of Voluntary Organisations).

List of voluntary organisations replying to scoping questions

- Action for Sick Children
- Age Concern
- British Colostomy Association
- British Epilepsy Association
- British Heart Foundation
- Chest, Heart & Stroke Northern Ireland
- Commission for Racial Equality
- Headway (National Head Injuries Association)
- Mencap
- Mental Health Foundation
- National Asthma Campaign
- National Autistic Society
- National Society for Epilepsy
- Patient Association
- RNIB
- Stroke Association

The sample of 55 organisations represented a range of long-term chronic conditions affecting physical and mental health, different age groups and ethnic minority groups. We asked each respondent to reply to three questions concerning their understanding of continuity, the aspects of concern to their members and any relevant material.

Of those organisations approached, 24 replied (44 per cent). Of these, eight (14.5 per cent) were unable to provide us with information we requested because their function was administrative or to support research. Sixteen of the organisations (67 per cent of replies) provided information (see box); their responses are summarised below.
**Q1** What do you understand by continuity of care?

Seamless working between different providers within a certain time period, accommodating the needs of patients and their families if the patient dies, or gives up direct care. It is important that providers have up-to-date information on the patient/client and are aware of their history and family details where appropriate. This will include prompt transfer of patients’ care plan between different services. Attention should be paid to the predictable transition from childhood to adulthood for patients with long-term conditions, for example epilepsy, autism. Continuity of care should be concerned about the needs and experiences of those who use the services, rather than organisational, legal and financial systems.

We interpret these replies as a plea for experienced continuity associated with increased attention to cross-boundary aspects including information transfer.

**Q2** What aspects of continuity of care concern the members of your organisation?

Of particular concern was the problem of effective communication between different professional groups for the benefit of the patient, changes in personnel, a lack of information on health and social care available from within the system and from other support services, and delays before support services make contact (cross-boundary and relational continuity).

Organisations also reported concern over gaps in the provision of care when patients are discharged from hospital. One organisation (Action for Sick Children) was concerned about poor communication between providers, and the inadequate information given to parents regarding telephone numbers, advice and support.

The Commission for Racial Equality highlighted the need to design services to meet the needs of all ethnic groups, so that services are delivered in a culturally appropriate way and outcomes and patient satisfaction are monitored.

For patients with conditions requiring care throughout their lifetime, for example epilepsy, concern was expressed at the varying quality of services across the country, particularly in terms of accessing specialist care.

Concern was expressed when patients had unusual needs that were not easy to classify in terms of service provision, for example autism, head injury.

Patients who experience a prolonged admission to hospital, for example those admitted to a psychiatric hospital, experience particular difficulties when returning home if no one has been overseeing general housekeeping, for example payment of bills, changes to benefits. Some of these patients may require education and training, for example those recovering from a brain injury.

**Q3** Do you have relevant material that we could access on the views of users of health care regarding continuity of care?

Many organisations provided us with detailed reports describing work they have either completed or that is ongoing in the field. Details of these reports are available from Dr Sasha Shepperd.
A3.2 NHS providers

We also approached a sample of NHS providers (identified by the SDO Programme) representing a community trust, a PCG, a district general hospital and a teaching hospital from each of the eight English Regions.

Six weeks later we had received one response from a Clinical Nurse Manager in an Accident and Emergency Department. The respondent defined continuity of care as the care of a patient from the initial consultation through to the endpoint. Aspects of concern included financial restraints and management issues that make it difficult for different organisations (PCGs, social services, and trusts) to operate on the same 'wavelength'.
Appendix 4

Contact with other health care researchers (I)

1 Canada: HSR Foundation

The SDO office most helpfully put George Freeman in touch with the Canadian Health Services Research Foundation which has been mounting a Continuity of Care programme with two rounds of bidding in 1999 and 2000. None of the studies is yet complete, but it has been possible to contact some of the project leads.

The spread of projects is highly relevant with an emphasis on primary care, cancer care, the severely mentally ill and people with dementia.

Primary care

In British Columbia, Morris Barer and Robert Reid are comparing provider continuity vs. practice continuity in the current context of multiple primary care provision including walk-in clinics and alternative out-of-hours care (longitudinal/personal vs. team/geographical continuity). After pilot studies to develop measurement tools they propose focusing on three problem groups, patients with:

- workplace injuries
- HIV/AIDS
- severe and persistent mental disorder.

Hui Lee in Sault Ste. Marie (Ontario) is linking continuity of care with quality in prevention as assessed through evidence-based health promotion.

Mental health

Carol Adair in Alberta is:

- developing and testing a standard measure of continuity in mental health services
- describing continuity in groups of severely mentally ill patients in three regions and its relationship to costs and outcomes
- testing a method of evaluating new services designed to improve care.

Ethnic minorities

Bruce Minore is working with ‘first nation’ (American Indians) in Northern Ontario to improve continuity for patients with oncology problems, diabetes and mental illness. Methods include a five-year retrospective record review, in-depth interviews and health services data on utilisation and costs.
**Dementia**

Louise Lemieux-Charles (Toronto) is using a case study approach to four care networks. Can the network model deliver continuity of care?

**Cancer care**

Timothy Whelan (Hamilton, Ontario) is also looking at networks – supportive care networks for cancer. The issues are:

1. has the restructured Ontario Cancer Agency delivered improved care by setting up networks?
2. the lack of knowledge of and access to supportive services for cancer patients.

Methods include cross-sectional randomised sample surveys in three regional networks supplemented by case studies. The key outcome is awareness of services.

Kevin Brazil (Hamilton, Ontario) is interested in care of the seriously (terminally) ill in the community. He plans to:

- describe receipt of care over time by interviewing family care givers on two occasions
- establish utilisation patterns from health ministry databases
- interview a sample of patients in depth.

**Long-term community care clients**

Christel Woodward (Hamilton, Ontario) is focusing on problems of continuity in home care for chronic adult clients of community care access centres.
2 Personal Care Study Group

This is a loose and informal interest group chaired by George Freeman. Several of the members are undertaking relevant work on continuity of care.

Nijmegen, Netherlands: Professor Wil van den Bosch and Dr Henk Schers

Professor van den Bosch writes:

We have started a project among 40 GPs, to identify which elements of continuity of care they consider most important for quality improvement. We use the Delphi method for this. We want to select the most important issues, in order to implement them into the instrument.

In parallel we study patient expectations and preferences about continuity. What is so special about a personal doctor? Can it be done by somebody else? Do patients expect home visits when they are hospitalised or discharged? For what symptoms do they want to see their personal doctor, and for what symptoms it is less important? Do they want to keep their own health files?

Recently we started the qualitative part of the study, in which 10–20 patients are interviewed, mainly to detect issues. Later, on the basis of these interviews, we will develop a questionnaire that will be handed out to approximately 1000 patients, in 40 practices. This will allow us to draw more quantitative conclusions. Some of the elements from this part of the study will be built into the instrument as well.

In a few years from now, the development of the computer-aided support is planned, in co-operation with software houses. We will study the effects of the instrument in a controlled trial in approximately 20 practices. Outcome measures will be the feasibility of the instrument, patient satisfaction and enablement, doctor satisfaction, and some other health outcomes. We hope to be able to improve continuity of care by this means and to maintain the high level of personal care experienced by patients in the Netherlands.

Oslo, Norway: Professor Per Hjortdahl

Professor Hjortdahl undertook a series of linked studies into continuity of care in general practice (see 'Primary care', main report) and more recently with EQuiP evaluating patient priorities and satisfaction (see below).

Currently he is keen to get involved in international projects related to how the new information technology is influencing the doctor–patient relationship.

The informed, empowered internet-patient: how well are we as general practitioners equipped to meet this new challenge? If not adequately, how should we prepare ourselves?

Leicester: Professor Richard Baker

Professor Baker has worked extensively on the assessment of quality in general practice. He developed a widely used satisfaction scale (Baker and Streatfield, 1995) and found that patients tended to be more satisfied with consultations in small practices and those which ran personal lists where the patients normally see the same doctor. He is currently involved in projects investigating the effect of trust on the patient–professional relationship and on relational continuity with Arch Mainous (Chapel Hill, NC, USA) and Sir Denis Pereira Gray (Exeter). He is conducting pilot
Continuity of Care

studies of the relationship between process measures and continuity for other conditions with Dr Kamlesh Khunti. He is also leading a qualitative study of what patients understand by personal care with Professors Mary Boulton (Oxford Brookes) and George Freeman.

Together with Professor Hjortdahl he is a member of the European general practice quality standards group EQuIP led by Professor Richard Grol (Nijmegen and Maastricht). In a comprehensive programme, EQuIP has developed a patient-centred European quality instrument – EUROPEP (Grol and Wensing). Seeing the same doctor at each visit (longitudinal continuity) was one of the original 38 items in EUROPEP. However, it was dropped when it was refined to its final 23-item form as it had less priority than other continuity elements including access to the GP on the telephone and preparation for what to expect from specialist or hospital care, as well as competing priorities including provision of quick access for urgent health problems (Jung et al., 2000).

National Primary Care R & D Centre, Manchester: Professors Bonnie Sibbald and Anne Rogers

Professor Sibbald writes:

Innovations such as NHS Direct and Drop-in Centres increase access to care by providing multiple points of entry to health care which bypass the patient’s registered GP. Similarly the substitution of GPs by other types of primary health care providers (e.g. nurses, pharmacists, counsellors) may enhance access to care, but permit GPs to be bypassed. We want to know whether the benefits of enhanced access to care offset the disadvantages of fragmentation of care. Related to this is the question of whether the overall cost-effectiveness of primary health care delivery is enhanced or diminished when GPs are substituted for providers with more specialised/less broad-based skills.

We have completed research into the substitution of GPs by pharmacists, nurses, and mental health professionals. This includes:

• ethnographic and other studies of the role of pharmacists as primary care providers
• a randomised controlled trial of substituting nurses for GPs in the treatment of patients wanting same-day appointments in general practice
• a case study of a nurse-led general practice
• a randomised controlled trial comparing usual GP care with psychological therapies provided by practice-based mental health professionals
• a systematic Cochrane review of the impact on GPs of attaching mental health professionals to their teams.

Ongoing work includes a Cochrane review of nurse–doctor substitution in primary care and a study assessing what patients want from a Drop-in Centre.

We have also examined the role of lay action in demand for primary care, and how the way in which primary care is delivered impacts on need and future service use. Our current research attempts to integrate the patient’s perspective into strategies designed to enhance access and manage demand in primary care. We are particularly interested in integrating self-management with flexible access arrangements and patient-centred consultations. This work includes the development and evaluation of a new ‘care package’ which combines a guided self-management manual (incorporating both lay and professional knowledge) for patients and their clinicians, open access via telephone consultations, and patient-initiated attendance at clinics. A further project will examine the way in which patients’ use of an internet facility based in general practice can be systematically incorporated into ongoing care and shared decision making.

We would like, in our future work, to identify the circumstances in which fragmentation of the GP role as the usual first point of access to health care has adverse consequences.
Continuity of Care

for patient health and well-being, and assess the resource implications of this. Just how we will do this, we don’t yet know.

National Primary Care R & D Centre, Manchester: Alison Chapple

Continuity of care in primary care today

(Note about patients’ perceptions of the importance of continuity of care in relation to the Wakefield walk-in centre study.)

During the in-depth interviews people commented on whether or not continuity of care was important for them and whether or not this would be a problem if they used a walk-in centre. There was a wide range of response.

• Some people said that continuity was important to them, particularly for serious illness such as breast cancer that ran in families.
• One woman said that she had a very sick child and would hate to have to explain everything again to a new person.
• Someone else said that it would be a disadvantage if the professional working at the walk-in centre did not have any notes about the history of the patient.
• However, some people said that a walk-in centre would be fine for minor ailments, because continuity of care was not so important for less serious illness.
• Others said they had to wait one to three weeks to see their own GPs anyway, and so there was little continuity of care at their own GPs surgery, so a walk-in centre would not make much difference.
• Some people said that they would welcome the chance to consult an unfamiliar health care professional at a walk-in centre if they had personal problems such as a sexually transmitted disease.

Edinburgh University Division of Community Health – General Practice: Bruce Guthrie and Sally Wyke

Continuity of care in general practice: how is it valued and is it equitably distributed?

Bruce Guthrie writes:

Continuity is a key feature of all formal definitions of general practice. Despite this central role, it is rarely clearly defined and often seems unconsidered in NHS reorganisation where other values such as efficiency, effectiveness and accessibility appear to be prioritised. Given the key role given to the concept of continuity in definitions of general practice and the risks posed to it by recent organisational change, it is important to better understand how it is valued, how it is traded off against other values, and the consequences for patient care of such trade-offs.

I am carrying out two studies.

• One is a qualitative study of the views of patients and GPs about what they consider important elements of general practice are. This will focus on how aspects of continuity are talked about and how they relate to other valued aspects of care such as access or efficiency. Theoretical sampling of doctors and patients is intended to select for variability in practice size, and for patients with and without chronic disease. I have just started the main part of this study.
• The second is a quantitative study of provider continuity (measures of how often patients see the same doctor) with a focus on the association with practice structure (e.g. list size, balance of full- and part-time doctors) and patient characteristics (e.g. age, sex, socioeconomic status, disease). I am currently recruiting for this and expect 30–40 practices to participate.

Montreal, Canada

We were already aware of Jeannie Haggerty’s work. Jeannie Haggerty and colleagues in the Groupe de recherche interdisciplinaire en santé (GRIS) are developing a primary care programme to evaluate the effect on continuity and health care outcomes of changes in primary care. These particularly include the secondary to primary care shift occurring simultaneously with a move from individual to group practice. The research group is notable for its close links with health services management and with medico-political colleagues. Jeannie Haggerty is particularly interested in the access/continuity trade-off.

EuroWONCA congress, Vienna: Continuity of Care day

George Freeman attended the recent European conference in July 2000 where a whole day was devoted to the theme of continuity in primary care. The keynote address by Fleming (RCGP Birmingham) reminded delegates that the days of the individual personal GP were numbered, albeit more urgently in some parts of Europe such as the UK than others such as Austria and Belgium. Instead there would be the primary care practice team. While there was plenty of evidence that this process is happening, apparently inexorably, there is almost none about its consequences.

During the day a number of studies were presented confirming patients’ preference for seeing the same doctor. There were two studies examining the experience of ethnic minorities, each suggesting that these patients were managing to access satisfactory care better than expected.

No major new work was presented but the day served to raise consciousness about the importance of the personal elements of care across Europe and to increase interest in future research collaboration. The two relevant keynote addresses have been published in the *European Journal of General Practice* (McWhinney, 2000; Fleming, 2000).
Appendix 5

Contact with other health care researchers (II)

BSA Medical Sociology Register Survey

A5.1 Medical sociology in Britain: a register of research and teaching

Following analysis of the register and selection of a sample of researchers who have worked on topics related to continuity of care, we sent an e-mail request for information with three questions to 20 people. Eight replied. A summary of replies is followed by a précis of individual replies and some additional references.

A5.2 Summary

Definitions emphasised a ‘seamless service’ – i.e. that movement between sectors or agencies responsible for care does not result in undue delays or interruptions in overall receipt of appropriate services – and co-ordinated delivery of different kinds of care delivered through multidisciplinary or multi-agency services. However, it was recognised that ‘continuity of care’ is an ambiguous term which can have a number of meanings. It is cited as an ‘ideal type’ for the health provider–recipient relationship, yet may involve paradoxes that make it achievable only in relation to specifically defined terms.

A5.3 Continuity of care in midwifery

This was addressed by four of the respondents, who noted that schemes designed to increase continuity of care (not carer) can increase the chances of women being delivered by a known midwife but at the same time reduce continuity of carer, which patients regret (see also 8.1). Considerable work has already been done in midwifery on new ways of organising services, identifying gaps in the evidence and making recommendations for future research, as well as gathering evidence on users’ perspectives. There is evidence on the beneficial effects of continuity of care in childbirth in relation to medical, psychosocial and behavioural outcomes and measures of patient satisfaction. However, methodological challenges include lack of clarity as to whether the effects can be attributed to greater continuity of care or to other aspects of midwifery care, and the difficulty of asking women to evaluate systems of care they have not received. The Department of Health held a research Colloquium in 2000 on the ‘best’ evidence on organising maternity care (including a substantial focus on continuity of care) with a view to informing policy and future R & D commissioning. The report from this colloquium, to be produced in the near future (see A5.6.8), should be consulted in relation to continuity of care in midwifery and to the critique of the use of inappropriate methods, e.g. randomised controlled trial designs which inadequately identify the interventions of which they claim to measure the effects.
Continuity of Care

A5.4

The remaining four replies pertained to other health and social care professionals and community groups/representatives. Topics identified for future research included:

- the need for changing clinical behaviour
- evaluation of multidisciplinary, cross-sector schemes to support disabled people, elderly infirm people, those with fluctuating and/or multiple health and social care needs in home/residential care, and children in the public ‘looked-after’ system.

A5.5

Process and context-based research approaches were advocated:

- to identify situations in which patients value continuity or conversely prefer no continuity/anonymouse care without the moral framework of a ‘caring’ provider
- on ways of overcoming barriers to co-operation, communication and therefore increasing continuity between services and between services and user groups in the community.

A5.6 Précis of replies to Kathryn Ehrich via e-mail

The following information includes the name and position of respondents and summarised responses (including some follow-up discussion) to an e-mail request for replies to three questions:

1. What do you understand by 'continuity of care'?
2. For what aspects (which settings, patients, health issues, processes) of continuity of care do you think there is good evidence, or need for further research?
3. Do you have relevant material we could access on the views of users of healthcare regarding continuity of care?

A5.6.1 Morag Farquhar

Research Nurse, Health Services Research Group, Institute of Public Health, University of Cambridge

Conducted an evaluation of a Midwifery Team scheme in West Essex (survey of 1482 users and staff).

Evidence

One of the aims of the scheme studied was to increase continuity of care (not carer), but also increases chances of women being delivered by a known midwife. Found that by introducing teams of seven (WTE) midwives to provide care throughout the antenatal/intrapartum and postnatal periods, where formerly two or three midwives had provided antenatal and postnatal care, with hospital midwives covering delivery, they actually reduced continuity of carer. Patients seemed to regret loss of continuity of carer in antenatal and postnatal periods despite increased chance of delivery by a known midwife. List of references from this author provided (Farquhar, Camilleri-Ferrante and Todd, 1996 and 1998; Todd, Farquhar and Camilleri-Ferrante, 1998; Farquhar, Camilleri-Ferrante and Todd, 2000a and 2000b).

A5.6.2 Alex Faulkner

Researcher, Research Support Unit in Health & Social Care, Cardiff University
Continuity of Care

Conducted a research prioritisation exercise in south-east Wales with health and social care professionals and community groups/representatives. Account of priorities available at http://www.cf.ac.uk/socsi/rsu under the heading ‘Research Prioritisation’.

Definition

Continuity in time and space. Co-ordination processes such as referral or planned care pathways or systems of planned follow-up care or re-referral/re-access for outpatients. Co-ordination practices such as multidisciplinary teamworking, cross-sector working, co-ordination/liaison/keyworker/advocacy roles in health and social care.

Evidence and further research

- Fairly good evidence of poor practice in referral communications between GPs and secondary care/specialists/consultants – this is well known and now seems to be an issue of changing clinical behaviour rather than more research.
- Evaluation of multidisciplinary cross-sector schemes to support disabled and/or elderly infirm people in home/residential care in independent living.
- Community care assessment techniques for service users with fluctuating illnesses and/or multiple health and social care needs.
- Multi-agency models for childcare, review of schemes to support/promote continuity for children in public care/foster care. Schemes to promote full range of health services for children and young people in the looked-after system.
- Some evidence on continuity of outpatient care – role of nurse-led schemes.
- Evaluation of alternative methods of follow-up apart from hospital visit, i.e. telephone, questionnaire, patient-directed re-referral systems (some evidence on shared care systems, e.g. in diabetes).
- Effectiveness/acceptability of patient-directed care management in a variety of chronic/fluctuating conditions – increasingly important.

A5.6.3 Brian Glasser

Patient Information Programme Officer and Honorary Lecturer, Royal Free Hampstead NHS Trust

Study on ‘patient lists’ (Fleissig, Glasser and Lloyd, 1999). Also may be useful to look at growing amount of work on narrative (e.g. Greenhalgh and Hurwitz, 1998).

A5.6.4 Jo Green

Senior Lecturer, Mother and Infant Research Unit, University of Leeds


A5.6.5 Judith Green

London School of Hygiene & Tropical Medicine

Definition

‘Within services’ (e.g. primary care) refers to continuity of provider, e.g. patients preferring same GP. See recent survey (J.M. Campbell, personal communication);
found patients of single-handed GPs rated ‘continuity’ better than those in larger practices.

‘Between services’ refers to notes being transferred, services fitting together and not getting lost in the system.

**Evidence and further research**

The ‘missing’ research would address the question: ‘In what situations do patients give accounts that focus on ‘continuity’?’ An ‘apple pie’ construct – more superficial research instruments would ‘reveal’ that patients valued it. In practice, aspects of continuity may be less important, and we need more ‘process’ research to identify this, e.g. new provisions such as walk-in centres may appeal because there is no ‘continuity’, just anonymous care without the moral framework of a ‘caring’ provider. There may be parallels with the concept of ‘community’ in the social capital literature.

**A5.6.6 Myfanwy Morgan**

*Reader in Sociology of Health, Department of Public Health Sciences, Kings College London*

**Definition**

Difference between continuity in terms of a single carer and continuity of care that may be provided by several professionals but involves seamless care based on communication and co-ordination between professionals.

**Evidence and further research**

Main work refers to midwifery (Morgan et al., 1998).

There is quite a lot of patient dissatisfaction for a number of conditions, regarding lack of continuity between hospital and GP, conflicting advice, need for greater co-ordination.

**A5.6.7 Fiona Poland**

*Senior Lecturer in Therapy Research, School of Occupational Therapy and Physiotherapy, University of East Anglia*

**Definition**

1. That users of services and their carers receive a ‘seamless service’ in which movement between sectors or agencies responsible for care does not result in undue delays or interruptions in their overall receipt of appropriate services.

2. A co-ordinated delivery of different kinds of care which ensures that there is an evenly co-ordinated, holistic delivery of multidisciplinary or multi-agency services.

**Evidence and further research**

There is plenty of evidence about the problems, processes and resources entailed by hospital discharge planning. There is much less evidence about becoming community-focused so as to maintain people independently at home in a way that is responsive to local needs and resources, and to prevent hospital readmissions and to maximise the level of independent living. More evidence needed about ways of overcoming barriers to co-operation and communication between services and between services and user groups in the community.
**Continuity of Care**

See Arthritis Care in-depth programme for users to enable more effective user intervention in managing the services they receive to optimise continuity of care.

**A5.6.8 Jane Sandall**

*Professor of Midwifery, Department of Midwifery, City University*

**Definition**

With reference to maternity care, 'continuity of care' is an ambiguous term. It can mean:

1. a stated commitment to a shared philosophy of care
2. a strict adherence to a common protocol for care
3. a system whereby those who are discharged from hospital are routinely referred to community services, or
4. the actual provision of care by the same caregiver or small group of caregivers throughout pregnancy, birth and the postnatal period.

Jane Sandall’s definition is the last of these. In maternity care this means seeing the same midwife or her partner from booking through to the final postnatal check. Continuity of care represents the ‘ideal type’ health provider–recipient relationship. For the care provider it adds meaning and job satisfaction to the normally fragmented care process. To the patient it feels as if the health professional may go the extra mile for you, if they know you and your circumstances.

In all these situations continuity of care aims to establish a relationship of trust and a personal relationship that goes beyond the stereotype of health professional and care recipient. However, in practice this means seeing a primary midwife for most visits and birth, with a partner midwife for back-up. In reality, continuity of acute hospital care is more likely to occur in private health care (obstetricians and midwives told us that this is one of the main satisfactions of private practice).

**Evidence**

There is robust evidence from meta-analyses that continuity of care in childbirth results in less operative vaginal delivery, low Apgar score, a shorter labour, less likelihood of need for pain relief, fewer Caesarian sections and better psychosocial outcomes (Hodnett, 2000a). This also shows that women who had continuity of care from a team of midwives were less likely to be admitted to hospital antenatally and more likely to attend antenatal education programs. They were also less likely to have drugs for pain relief during labour and their newborns were less likely to require resuscitation. No differences were detected in Apgar scores, low birthweight and stillbirths or neonatal deaths. While they were less likely to have an episiotomy, women receiving continuity of care were more likely to have either a vaginal or perineal tear. They were more likely to be pleased with their antenatal, intrapartum and postnatal care. Studies of continuity of care show beneficial effects. It is not clear whether these are due to greater continuity of care, or to midwifery care.

There is evidence that women prefer continuity of carer during pregnancy and childbirth, but this is a very difficult area methodologically to tackle. Women find it very difficult to evaluate a system of care they have not received Randomised controlled trials have provided inadequate evidence because they have not specified which part of the system has been identified as the intervention.
The Department of Health held a research Colloquium in 2000 pulling together the 'best' evidence on organising maternity care (which includes a substantial focus on continuity of care) with a view to informing policy and future R & D commissioning. The team producing the report is headed by Jo Garcia, at the National Perinatal Epidemiology Unit in Oxford.

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Further research in this area on women’s views: McCourt et al., 1998; Hundley et al., 1997; Hodnett, 2000a; Garcia, 1995; Audit Commission, 1998; Waldenstrom, 1998.
Appendix 6

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