Continuity of Care

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

Summer 2000

prepared by

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Revised 21st December 2000, 15th March 2001, minor editorial revisions May 2001

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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 provider continuity 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)*

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

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.

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.

Continuity of patient care	Case management	Care planning
Team care	Seamless care	Multi professional working
Multi agency working	Inter agency working	Inter professional working
Interpersonal continuity	Key workers	Care experience
Care process	Expectations	Check ups
Periodic health checks	Discontinuity	Information
Gaps	Transitions	Longitudinal
Interfaces	Satisfaction	Advocacy

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

- **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 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 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’.

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

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 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

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/relational 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

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 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 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 heath 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.

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.

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.

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.

Part C Discussion and recommendations

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

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

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

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

Definition of elements of continuity of care

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

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

To achieve this central element the service needs:

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

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

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

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

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

Recommendations for research priorities

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

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.

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.

Part D List of appendices

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

Appendix 1

Summary table of studies

Cardiovascular and Diabetes: Table 1

Author Title Journal, date	Study design	Intervention	Aim	Patient group	Setting	Outcomes – in relation to continuity of care	Length of follow-up	Rating: • Relevance • Evidence • Concept
Close, H. and Proctor, S. Coping strategies used by hospitalised stroke patients: implications for continuity and management of care *J Adv Nursing*, 1999	Qualitative Interviews with 9 patients and 8 carers	n/a	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	Patients recovering from a stroke	General hospital medical wards	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	n/a	• 2 • 2 • 2
Ekman, I. *et al* Feasibility of a nurse - monitored, outpatient	RCT 158 patients randomised	Nurse-monitored outpatient shared care	To ease transition after hospitalisation	Elderly patients with moderate to severe heart	Sweden, Göteborg 1/2 interface	Failed to detect a difference in hospital admissions or days in hospital	6 months	• 2 • 5 • 2

care programme for elderly patients with moderate to severe, chronic heart failure *Eur Heart J,* 1998	into 2 groups (a) shared care (b) usual care	programme	from an inpatient rehabilitation unit by enabling patients to recognise and monitor symptoms of deterioration	failure		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)		

Cardiovascular and Diabetes: Table 2

Author Title Journal, date	Study design	Intervention	Aim	Patient group	Setting	Outcomes – in relation to continuity of care	Length of follow-up	Rating: • Relevance • Evidence • Concept
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 life style 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

Piette, J.D., Weinberger, M. and McPhee, S. The effect of automated calls with telephone nurse follow-up on patient-centered outcomes of diabetes care *Medical Care*, 2000	RCT	Automated disease management calls with nurse follow-up on diabetic patients	To assess the impact of automated disease management calls with nurse follow-up on diabetic patients	Patients with type 2 diabetes, a multilingual population of patients who are poor and with inadequate health insurance	General medicine clinics	Greater satisfaction with continuity of care (English speakers only)	12 months	• 4 • 5 • 3

Cardiovascular and Diabetes: Table 3

Author Title Journal, date	Study design	Intervention	Aim	Patient group	Setting	Outcomes – in relation to continuity of care	Length of follow-up	Rating: • Relevance • Evidence • Concept
Preston, R. M. Ethnography: studying the fate of health promotion in coronary families. *J Adv Nursing*, 1997	Qualitative Interviews with 12 adults	Health education material	To what extent health information advice given by community cardiac support nurses was translated into everyday domestic setting	'Coronary family groups'	Home	Focus on lay beliefs of coronary heart disease and how information is used by the family	n/a	
Rawl, S.M. *et al.* Effectiveness of a nurse-managed follow-up program for rehabilitation patients after discharge *Rehab Nursing*, 1998	RCT	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)	To ease transition after hospitalisation and improve health outcome	Age range 21 to 89 years Majority of patients were recovering from a CVA or orthopaedic condition	Hospital and community	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) $p<0.001$	4 months	• 4 • 5 • 4
Thompson, D.R., Ersser, S.J. and	Qualitative Interviews	n/a	To explore any patterns	Patients recovering	Home	Most appropriate person to provide	n/a	• 1 • 2

Webster, R.A. The experiences of patients and partners 1 month after heart attack *J Adv Nursing*, 1995	with 20 patients and their partners		in the experiences of patients and their partners 1 month after first heart attack	from a heart attack, and their partners		advice and support is not clear, patients expressed a preference for family doctor; however, not always satisfied with information provided		• 1
Widén Holmqvist, L. *et al.* A randomised controlled trial of rehabilitation at home after stroke in southwest Stockholm *Stroke*, 1998	RCT	Home rehabilitation substituting for hospital-based rehabilitation	To evaluate rehabilitation at home after early supported discharge from hospital	Patients recovering from a stroke	Home or hospital, day care/ outpatient care	Increase in active participation in the planning of rehabilitation programme for patients allocated to home rehabilitation	3 months	• 3 • 4 • 3

Cancer: Table 1

Author Title Journal, Date	Study design	Intervention	Aim	Patient group	Setting	Length of follow-up	Outcomes – in relation to continuity of care	Conclusion	Rating: • Relevance • Evidence • Concept
Addington-Hall, H..J. *et al.* Randomised controlled trial of effects of coordinating care for terminally ill cancer patients *BMJ*, 1992	RCT standard vs. co-ordinators	Two nurse co-ordinators	To measure the effects of co-ordinating NHS and voluntary services	554 cancer patients not expected to survive 1 year	Secondary care	1 year	Interviewed patients and carers at home Physical and psychological morbidity Satisfaction Carer problems	Few differences – slight advantages	• 5 • 5 • 2
Boman, L. *et al.* Two models of care as evaluated by a group of women operated on for breast cancer with regard to their perceived well-being *Euro Journal Cancer Care*, 1999	Non-RCT	Seeing the same staff + better structure + firm operation date + shorter hospital stay	Evaluate the models of breast cancer care	Patients undergoing surgery for breast cancer 29 established care 115 continuity care	2^0 Care	1 year	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	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	• 4 • 3 • 2

Cancer: Table 2

Author Title Journal, Date	Study design	Intervention	Aim	Patient group	Setting	Length of follow-up	Outcomes – in relation to continuity of care	Conclusion	Rating: • Relevance • Evidence • Concept
Jarrett, N.J., Payne, S.A. and Wiles, R.A. Terminally ill patients' and lay-carers' perceptions and experiences of community-based services *J Adv Nursing,* 1999	Qualitative interview	9 terminally ill patients and 12 lay-carers interviewed concerning 12 patients	Experience and perceptions of terminal care	9 terminally ill patients and 12 lay-carers	Urban, at home, intermediate; 1/2 CoC; SouthamptonUK	n/a	Three emerging themes were: • role perceptions and domains of responsibility • economic and practical problems • CoC and communication 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	Recommend • info (e.g. booklet) describing roles of professionals • special attempt to improve provider continuity • fairer distribution of resources according to need	• 3 • 3 • 3
Johansson, B. *et al.* Intensified primary	RCT 2 Intensified	Intensified Primary	Compare Intensified	391 newly diagnosed	$2^0 + 1^0$ care	6 months	Hospital Anxiety & Depression Scale	Large increase in contacts and	• 4

cancer care: a randomized study of home care nurse contacts *J Adv Nursing*, 1999	Primary Care IPC (+rehab) 1 rehab only 1 standard care	Care (IPC) = •quick referral to home care nurse (HCN) •inform GP •hospital records copied to PCT •project group (oncology) supervision of HCNS	Primary Care vs. controls	cancer patients, Sweden			(HADS) 18-item Q. re contacts in primary care including patients' views N contacts with home care nurse	significant satisfaction (Cost not stated)	• 3 • 2

Cancer: Table 3

Author Title Journal, Date	Study design	Intervention	Aim	Patient group	Setting	Length of follow-up	Outcomes – in relation to continuity of care	Conclusion	Rating: • Relevance • Evidence • Concept
O’Malley, A. *et al.* Continuity of care and the use of breast and cervical cancer screening services in a multiethnic community *Arch Internal Med*, 1997	Telephone survey Structured interviews Stratified sample by ZIP code and racial group	Health care usage and social demographic, health status, insurance, ‘acculturalisation’ Utilisation rates of clinical breast scan, mammography, Papanicolaou smears 1 ever screened 2 recently screened according to guidelines	To examine how CoC affects its use of breast and cervical cancer screening in multiethnic patients	1420 multiethnic black/Hispanic (62% response) 7 groups, New York, USA		n/a	Utilisation rates of: • clinical breast exam • mammography • Pap smears including: 1 ever screened 2 recently screened according to guidelines	More CoC, more uptakes of screening Biggest effect was in women in the lowest uptakes	• 5 • 3 • 4
Smeenk, F.W.J.M. *et al.* Transmural care. A new approach in the care for terminal cancer patients: its	Quasi-experimental Controlled trial – allocated according to	Specialised support for 1 care team by nurse co-ordinator +	To test special home care programme in reducing readmission	Terminal cancer patients in Holland S79 +C37 =	2/ 1 interface supplement-ary	1 month Only 45 patients followed up with QOL	1^0 – Readmission (n days in hospital) ↑ $p<0.01$ – Quality of life	Benefit on all four measures Authors argue that the continuity (i.e. communication	• 4 • 4 • 4

effects on re-hospitalization and quality of life *Patient Education & Counselling*, 1998	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) ↑ (NS) – Survival time ↑ (NS)	$1^0/2^0$) was all important Very little extra service (8 requests only)	

Cancer: Table 4

Author Title Journal, Date	Study design	Intervention	Aim	Patient group	Setting	Length of follow-up	Outcomes – in relation to continuity of care	Conclusion	Rating: • Relevance • Evidence • Concept
Smith, S.D. *et al.* Encounters with doctors: quantity and quality *Palliative Medicine*, 1999	Qualitative survey	n/a	Examine patients' recollections recording their encounters with doctors during cancer care Examine the value of these encounters Determine total no. of doctors encountered	50 cancer patients, in Lothian, Scotland	Not stated	n/a	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	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	• 4 • 3 • 3

							delayed referral		
van Harteveld, J.T.M., Mistiaen, P.J.M.L. and Dukkers van Emden, D.M. Home visits by community nurses for cancer patients after discharge from hospital: an evaluation study of the continuity visit *Cancer Nursing*, 1997	Survey of health care	3 outreach visits by community nurse Patient evaluation questionnaires Nurse evaluation questionnaires Nurse focus groups	To evaluate post-discharge home visits	Cancer patients not indicated for community nurses of discharge 337 offered 168 accepted 112 received	8 hospitals in Amsterdam $2^0 \rightarrow 1^0$	6/12 months	Number and type of patient Physical, psychosocial problems Support and information Course of needs for six months Patient and carer (nurse) opinion	Most patients and staff liked it (NB: uncontrolled satisfaction study; it suggests inadequate discharge planning)	• 4 • 2 • 2

Care of Older People: Table 1.1

Author Title Journal, Date	Study design	Intervention	Aim	Patient group	Setting	Length of follow-up
Anttilla , S.K. *et al.* Cost-effectiveness of an innovative four-year post- discharge programme for elderly patients *Scand J Public Health*, 2000	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.* Consultative geriatric assessment for	RCT 1 geriatric	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

ambulatory patients. A randomized trial in a health maintenance organization. *JAMA*, 1990	assessment 2 2nd opinion internist 3 traditional service		assessment and limited follow-up			
Jackson, M.F. Discharge planning: issues and challenges for gerontological nursing. A critique of the literature *J Adv Nurs*, 1994	n/a	n/a	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	n/a	n/a	n/a
Klop, R. van Wijmen, F.C.B. and Philipsen, H. Patients' rights and the admission and discharge process *J Adv Nurs*, 1991	Qualitative interviews of patients and their professional carers	None – descriptive study	To find out the meaning of discharge (from hospital) for patients and for carers	Hospital discharge patients needing home care 11 patients + GP+ comm. nurse + hospital nurse + specialist	2^0 – 1^0 Netherlands	3 months

Care of Older People: Table 1.2

Author Title Journal, Date	Outcomes – in relation to continuity of care	Conclusion	Rating: • Relevance • Evidence • Concept
Anttilla , S.K. *et al.* Cost-effectiveness of an innovative four-year post- discharge programme for elderly patients *Scand J. Public Health*, 2000	Difference in the use of institutional care before and after the project Measurement of costs	Continuity somewhat better maintained in the intervention group, but no indication of how continuity was conceptualised or measured (presumably longitudinal perhaps with informational)	• 3 • 2 • 2
Epstein, A.M. *et al.* Consultative geriatric assessment for ambulatory patients. A randomized trial in a health maintenance organization. *JAMA*, 1990	Use of medical services and costs Health status Patient satisfaction	Showed little benefit in health status in intervention groups. Suggestion that lack of continuity post-assessment may explain disappointing outcome	• 3 • 4 • 2
Jackson, M.F. Discharge planning: issues and challenges for gerontological nursing. A critique of the literature *J Adv Nurs*, 1994	n/a	1 Difficult to prove that new discharge planning affects health status by improving CoC 2 Mixed conclusions re impact of discharge planning in CoC 3 Lack of ?? new DP improves quality of life Useful literature review on difficult aspects of discharge planning outcomes, but little specifically on CoC	• 3 • 3 • 2
Klop, R. van Wijmen, F.C.B. and Philipsen, H. Patients’ rights and the admission and discharge process *J Adv Nurs*, 1991	• What patients were told (very little) • Their tendency to ask questions	Patients more passive than expected Very little information given	• 2 • 2 • 2

Care of Older People: Table 2.1

Author Title Journal, Date	Study design	Intervention	Aim	Patient group	Setting	Length of follow-up
Lough, M.A. Ongoing work of older adults at home after hospitalization *J Adv Nurs*, 1996	Semi-structured interviews within 2 weeks of hospitalisation Analysed using grounded theory approach	None	To describe hospital to home transition process as experienced by elders with congestive heart failure (CHF)	Adults of 65+ after hospitalisation and discharge for CHF 25 patients (12 male; 13 female) Range 66–91 years. Mean age 71	Adults at home after discharge from a hospital in a large metropolitan community in the USA	Unclear – readmission rate checked at 3 months Some know to have died within a year
McWilliam, C. From hospital to home: elderly patients' discharge experiences *Family Medicine*, 1992	Qualitative semi-structured interviews and observation of discharge planning process	None	To describe experience of elderly patients	12 elderly patients (aged 65+) and their carers and professionals	Urban Ontario, Canada	10 days
McWilliam, C.L. and Sangster, J.F. Managing patient discharge to home: the challenges of achieving quality of care *Int J Qual Health Care*, 1994	Qualitative study 1 observation of discharge process 2 review of patient records 3 in-depth and semi-	n/a	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	21 older people aged 65+. Also purposeful sample of informal and professional care givers	Primary/ secondary interface, urban and rural London, Ontario	Up to 12 weeks

	structured interviews of patients, carers and expert informants					
Naylor, M.D. *et al.* Comprehensive discharge planning and home follow-up of hospitalised elders: a randomised clinical trial *JAMA*, 1999	Comprehensive Discharge Planning protocol RCT: 177 intervention group, 186 control group	48-hour visits by hospital; at least 2 home visits; telephone available; individual discharge plan	To examine the effectiveness of advanced practice nurse-controlled discharge planning and some follow up intervention for elders at risk of hospital readmission	363 elderly men, aged 75	2 urban hospitals Philadelphia, USA	2, 6, 12, 24 weeks post-discharge

Care of Older People: Table 2.2

Author Title Journal, Date	Outcomes – in relation to continuity of care	Conclusion	Rating: • Relevance • Evidence • Concept
Lough, M.A. Ongoing work of older adults at home after hospitalization *J Adv Nurs*, 1996	Qualitative study which identified 3 key processes in transition from hospital to home, for people with chronic illness: • managing the illness • caregivers' lives • quality of life challenges	Key finding: patients needed a post-hospital plan which provided them with ongoing information, additional resources and supportive assistance	• 3 • 2 • 2
McWilliam, C. From hospital to home: elderly patients' discharge experiences *Family Medicine*, 1992	n/a	Need better communication and co-ordination of discharge process (GP highlights problem of integrating family physician into discharge planning) Very interesting study of psychological factors involved in discharge process, but nothing new in terms of problems involved	• 3 • 4 • 2
McWilliam, C.L. and Sangster, J.F. Managing patient discharge to home: the challenges of achieving quality of care *Int J. Qual Health Care*, 1994	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	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	• 3 • 4 • 2
Naylor, M.D. *et al.* Comprehensive discharge planning and home follow-up of hospitalised elders: a randomised clinical trial *JAMA*, 1999	Readmission, time to first readmission, acute care after discharge; costs, functional status, depression and patient satisfaction	Discharge planning and home care for at-risk elders; reduced readmission, increased time to readmission, and reduced costs *Comment:* Demonstrates how individualised discharge	• 2 • 3 • 1

		planning and follow-up has significant effect on readmission rates for at-risk elderly patients, and on health care costs	

Care of Older People: Table 3.1

Author Title Journal, Date	Study design	Intervention	Aim	Patient group	Setting	Length of follow-up
Naylor, M.D. *et al.* Patient problems and advanced practice nurse interventions during transitional care *Public Health Nursing*, 2000	Secondary analysis of care logs written by Advanced Practice Nurses (APNs), Coded using Omaha system	n/a	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	124 elderly (65+) 37% African-American	$1^0/2^0$ interface Philadelphia, USA	n/a
Parkes, J. and Shepperd, S.A. Systematic review of discharge planning Cochrane Library Issue 4, 2000	Systematic review of RCTs	Discharge planning	Cochrane review			
Simpson, R.G., Scothern, G. and Vincent, M. Survey of carer satisfaction with the quality of care delivered to in-patients suffering from dementia *J Adv Nurs*, 1995	Single interview including structured questions yielding qualitative data and open questions analysed with grounded theory approach	n/a	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	Cases of patients with dementia (41), discharged from hospital after assessment/emergency admission/respite care	2^0 care and $1^0/2^0$ interface Urban Leicester, UK	n/a

van Achterberg, T. *et al.* Coordination of care: effects on the continuity and quality of care *Int J Nurs Stud*, 1996	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	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	3 rural/urban communities in Limberg, Netherlands	1 year

Care of Older People: Table 3.2

Author Title Journal, Date	Outcomes – in relation to continuity of care	Conclusion	Rating: • Relevance • Evidence • Concept
Naylor, M.D. *et al.* Patient problems and advanced practice nurse interventions during transitional care *Public Health Nursing*, 2000	Problems primarily physiological or relating to health behaviours. Majority of interventions connect to two main problems: co-ordination and discharge planning	Limited and pedestrian analysis. Raises more questions than it answers about elderly people discharged from hospital	• 1 • 3 • 1
Parkes, J. and Shepperd, S.A. Systematic review of discharge planning Cochrane Library Issue 4, 2000	small reduction in hospital length of stay for some groups	No difference in health outcomes, increased patient satisfaction	• 3 • 5 • 2
Simpson, R.G., Scothern, G. and Vincent, M. Survey of carer satisfaction with the quality of care delivered to in-patients suffering from dementia *J Adv Nurs*, 1995		Gaps in information exchange between staff/carers Interesting study but yet another revealing gaps in information between staff and carers	• 1 • 4 • 1
van Achterberg, T. *et al.* Coordination of care: effects on the continuity and quality of care *Int J Nurs Stud*, 1996	Interdisciplinary, Interpersonal Pre-structured interviews used to assess effects of coordination on client satisfaction	Improved interpersonal continuity but hardly any effect on client satisfaction Other interventions can be more appropriate for the improvement of client care	• 4 • 3 • 4

Care of Older People: Table 4.1

Author Title Journal, Date	Study design	Intervention	Aim	Patient group	Setting	Length of follow-up
von Sternberg, T. *et al.* Post-hospital sub-acute care: an example of a managed care model *J American Geriatrics Soc*, 1997	2 groups – Transitional Care Centres (TCCs) and standard contents Monitored and postal survey *Not* randomised	TCC model and standard nursing home contracts and venues	To describe Transitional Care Centres and to compare experiences and outcomes of enrolees compared with control enrolees who received customary continuity care through contract services.	253 elderly patients receiving TC	$1^0/2^0$ interface Bloomington, Minnesota, USA	n/a
Wasson, J.H. *et al.* Continuity of outpatient medical care in elderly men: A randomized trial *JAMA*, 1984	RCT	Study group (66%) see the same physician each time Control group (33%) have normal care but including measures to ensure patients did not see the same physician	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	776 males aged 55+ years	Ambulant patients attending Veterans Administration outpatient general medical clinics in Vermont (USA)	18 months

Care of Older People: Table 4.2

Author Title Journal, Date	Outcomes – in relation to continuity of care	Conclusion	Rating: • Relevance • Evidence • Concept
von Sternberg, T. *et al.* Post-hospital sub-acute care: an example of a managed care model *J American Geriatrics Soc*, 1997	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
Wasson, J.H. *et al.* Continuity of outpatient medical care in elderly men: A randomized trial *JAMA*, 1984	Resource use: • 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

Mental health: Table 1.1

Author Title Journal, Date	Study design	Intervention	Aim	Patient group	Setting
Bachrach, L.L. Continuity of care for chronic mental patients: a conceptual analysis *Am J of Psychiatry*, 1981	n/a	Discussion paper	To consider different dimensions of continuity in relation to psychiatric population.	Severe and chronic mental health problems	USA
Bindman, J. *et al.* Integration between primary and secondary services in the care of the severely mentally ill: patients' and general practitioners' views *Brit J Psychiatry*, 1997	Survey qualitative and quantitative methods combined	Not an intervention study	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?	Patients with SMI and two or more admissions. Ethnicity stated and focused on	Two inner London psychiatric sectors
Bindman, J. *et al.* Continuity of care and clinical outcome: a prospective cohort study *Social Psychiatry & Psych Epidemiology*, 2000	Prospective cohort study	CPA key-working	To test whether • CPA associated c better continuity • continuity is associated with improved patient outcomes • continuity is poorer for black African or Caribbean patients	The first 100 consenting patients approached randomly from a sample of 342 patients with defined severe mental illness	South London. Patients interviewed in a range of locations inc. home, clinic, hospital and prison

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

Mental Health: Table 1.2

Author Title Journal, Date	Outcomes – in relation to continuity of care	Rating: • Relevance • Evidence • Concept
Bachrach, L.L. Continuity of care for chronic mental patients: a conceptual analysis *Am J of Psychiatry*, 1981	No evaluation involved. Thoughtful and well informed (83 references) discussion of the meaning and dimensions of continuity	• 5 • 1 • 5
Bindman, J. *et al.* Integration between primary and secondary services in the care of the severely mentally ill: patients' and general practitioners' views *Brit J Psychiatry*, 1997	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	• 4 • 3 • 5
Bindman, J. *et al.* Continuity of care and clinical outcome: a prospective cohort study *Social Psychiatry & Psych Epidemiology*, 2000	No significant relationship between continuity and patient outcomes. Continuity improved over time under CPA. Continuity similar for black and white patients	• 5 • 4 • 5
Bjoerkman, T. *et al.* What is important in psychiatric outpatient care? Quality of care from the patient's perspective *Int J Qual Health Care*, 1995	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	• 2 • 5 • 2
Brekke, J.S. *et al.* Intensity and continuity of services and functional outcomes in the rehabilitation of persons with schizophrenia *Psychiatric Services*, 1999	Service continuity had more influence on symptoms than intensity of contact. Intensity had more influence on hospitalisation and psychosocial functioning at 12 months	• 5 • 3 • 5

Mental health: Table 2.1

Author Title Journal, Date	Study design	Intervention	Aim	Patient group	Setting
Brindis, C., Pfeffer, R. and Wolfe, A. A case management program for chemically dependent clients with multiple needs *J Case Management*, 1995	Audit/service description Qualitative findings referred to in abstract but not evident in text	Varying forms of case management on 3 sites (not compared) Innovative information system alerted case managers to need for action	To evaluate project aimed at strengthening links between drug treatment and other services	310 drug-dependent, mostly male, low income, many homeless. Ethnicity identified for each site	USA Three San Francisco drug dependency clinics participating in linkage service
Godley, S.H. *et al.* Case management services for adolescent substance abusers *J Subst Abuse Treat.*, 1994	Service description, involving some measured outcomes	3-stage drug treatment programme: screening, residential and continuing care phases. Care delivered within case management model	To describe functions of case managers during three phases of treatment programme	509 adolescent drug abusers requiring residential treatment 85% white	US Illinois Residential and community drug treatment service
Hall, S.M. *et al.* Continuity of care and Desipramine in primary cocaine abusers *J Nerv Ment. Dis.*, 1994	2x2 experimental study: drug versus placebo (blind) Treatment continuity versus standard care	Enhanced continuity: outpatient groups started during hospital stay. Same counsellor through in- and outpatient settings. Desipramine/placebo given	To investigate relative efficacy of enhanced continuity/ desipramine, compared to placebo and standard care	94 male cocaine-dependent veterans. 85% African -American	USA, San Francisco Substance abuse inpatient unit/ aftercare

Herman, D. *et al.* A critical time intervention with mentally ill homeless men: impact on psychiatric symptoms *J Nerv Ment. Dis.*, 2000	RCT (subsidiary to larger study of homelessness)	Critical Time Intervention (CTI) transitional intensive service, developed as continuity tool	To compare effects of CTI on negative and positive symptoms of schizophrenia and general psychopathology to standard service.	76 homeless men with psychotic disorders (57 for some analyses). Majority African-American/ Latino	USA New York men's shelter/ community housing
Holloway, F. *et al.* Case management: a critical review of the outcome literature Cochrane Library, 2000	Critical review	Case management	To examine the effects of case management	21 studies reviewed.	
Hoult, J. *et al.* Psychiatric hospital versus community treatment: the results of a randomised trial *Aust & NZ J of Psychiatry*, 1983	RCT	Community treatment team offered 24hr crisis intervention, medication support, family intervention, psycho-education, skills training	To compare community treatment to episodic hospital/OP care – effects on bed use, costs, clinical outcome, burden on others, patient/family satisfaction	120 patients (3/4 psychotic) presenting for admission Ethnicity not referred to	Australia, Sydney Urban state psych hospital/community

Mental Health: Table 2.2

Author Title Journal, Date	Outcomes – in relation to continuity of care	Rating: • Relevance • Evidence • Concept
Brindis, C., Pfeffer, R. and Wolfe, A. A case management program for chemically dependent clients with multiple needs *J Case Management*, 1995	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	• 1 • 2 • 2
Godley, S.H. *et al.* Case management services for adolescent substance abusers *J Subst. Abuse Treat.*, 1994	Case management activities identified. Favourable rate of abstinence (compared to earlier studies)	• 2 • 1 • 3
Hall, S.M. *et al.* Continuity of care and Desipramine in primary cocaine abusers *J Nerv. Ment. Dis.*, 1994	Desipramine had no effect on drug use Increased CoC increased abstinence rates and treatment attendance at no higher cost than standard care	• 5 • 4 • 4
Herman, D. *et al.* A critical time intervention with mentally ill homeless men: impact on psychiatric symptoms *J Nerv. Ment. Dis.*, 2000	CoC intervention achieved significant reduction in negative symptoms. No impact on positive symptoms/general psychopathology	• 5 • 5 • 4
Holloway, F. *et al.* Case management: a critical review of the outcome literature Cochrane Library, 2000	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	• 3 • 5 • 3
Hoult, J. *et al.* Psychiatric hospital versus community treatment: the results of a randomised trial *Aust. & NZ J. of Psychiatry*, 1983	Intervention reduced hospitalisation (8.4 days vs. 53.5 days) costs (by 26%). It increased patient/family satisfaction without increasing burden on relatives/community	• 4 • 5 • 4

Mental health: Table 3.1

Author Title Journal, Date	Study design	Intervention	Aim	Patient group	Setting
Johnson, S. *et al.* Continuity of care for the severely mentally ill: concepts and measures *Soc Psychiatry Psychiatr Epidemiol,* 1997	n/a	Discussion paper	Review theoretical definitions of continuity of care for the mentally ill Discuss work which has attempted to operationalise these	Mentally ill	General
Kopelowicz, A., Wallace, C.J. and Zarate, R. Teaching psychiatric in-patients to re-enter the community: a brief method of improving the continuity of care. *Psychiatric Services*, 1998	RCT	16 x 45-min training sessions, teaching patients relapse prevention, how to access and use services, psycho education	To compare effects of a structured training programme, designed to prepare patients for community re-entry, with equivalent occupational therapy	59 inpatients with psychotic diagnosis 61% ethnic minority	USA, California Acute psychiatric in-patient unit of a university affiliated state hospital
Malla, A.K. *et al.* An integrated medical and psychosocial treatment program for psychotic disorders: patient characteristics and outcome *Can J Psychiatry*, 1998	Longitudinal outcome survey (uncontrolled)	Community programme offering integrated interventions: medication, social skills training, stress management, family psycho-intervention, within case management model	To evaluate process and outcomes of case management programme	Patients with psychotic disorders and associated social problems No reference to ethnicity	Canada Community

Marshall , M., Lockwood, A. and Gath, D. Social services case management for long-term mental disorders: a randomised controlled trial *Lancet*, 1995	RCT	Assessment of need, liaison with carers, monitoring clients' progress, practical assistance	To evaluate effectiveness of case management (additional to standard service)	80 clients SMI and homeless history Ethnicity not referred to	UK Oxford social services CM team
Marshall, M. *et al.* Case management for people with severe mental disorders Cochrane Library, 2000	Cochrane Review	Case management	Comparison of case management to standard care, indicated by workers staying in contact with clients, psychiatric admissions, clinical and social outcomes and costs	11 studies reviewed. Patients with severe metal illness.	International

Mental Health: Table 3.2

Author Title Journal, Date	Outcomes – in relation to continuity of care	Rating: • Relevance • Evidence • Concept
Johnson, S. *et al.* Continuity of care for the severely mentally ill: concepts and measures *Soc Psychiatry Psychiatr Epidemiol,* 1997	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	• 5 • 1 • 5
Kopelowicz, A., Wallace, C.J. and Zarate, R. Teaching psychiatric in-patients to re-enter the community: a brief method of improving the continuity of care. *Psychiatric Services*, 1989	Early outpatient attendance improved by intervention (85% v 37% attendance) (small study, short follow-up)	• 5 • 4 • 5
Malla, A.K. *et al.* An integrated medical and psychosocial treatment program for psychotic disorders: patient characteristics and outcome *Can J Psychiatry*, 1998	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	• 3 • 3 • 4
Marshall , M., Lockwood, A. and Gath, D. Social services case management for long-term mental disorders: a randomised controlled trial *Lancet*, 1995	Additional case management achieved a reduction in deviant behaviour. No other significant differences between groups	• 3 • 5 • 2
Marshall, M. *et al.* Case management for people with severe mental disorders Cochrane Library, 2000	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	• 3 • 5 • 3

Mental health: Table 4.1

Author Title Journal, Date	Study design	Intervention	Aim	Patient group	Setting
Morgan, D. Psychiatric cases: an ethnography of the referral process *Psychol Med*,1989	Qualitative: ethnographic	n/a	To investigate how patients are selected by GPs for referral	106 consenting patients from a total of 182 new referrals in a six-month period	UK, Kent, Two psychiatric clinics in a provincial psychiatric hospital
Muijen, M. *et al.* Home based care and standard hospital care for patients with a severe mental illness: a randomised controlled trial *BMJ*, 1992	RCT	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	Replication in UK of other investigations comparing intensive home treatment to hospital	Patients with SMI needing hospital admission High proportion Afro-Caribbean, reflecting community	UK inner city
Olfson, M. *et al.* Linking inpatients with schizophrenia to outpatient care *Psychiatric Services*, 1998	Survey. Part of longitudinal outcome study. Outcomes compared for two matched (but not randomised) groups. Assessment at baseline and 3 months	Telephone or face-to-face contact with outpatient physician prior to discharge	To study effect of pre-discharge outpatient clinician contact on short-term course of patients with schizophrenia and compliance with aftercare	Inpatients with psychotic diagnosis due for discharge to unfamiliar clinician Ethnicity stated – black patients over-represented	USA, New York Four general hospitals/community
Paykel, E.S. *et al.* Community psychiatric nursing for neurotic patients: a controlled trial *Brit J Psychiatry*, 1982	RCT	CPNs main care agent, 78%contact at home, psychological interventions. Activities of control group workers not specified	Compare supportive home visiting by CPNs to routine outpatient care	Neurotic diagnosis, mostly female and middle-aged. Newly discharged /referred to outpatients Ethnicity not referred to	London hospital/ outpatient

Ramana, R. *et al.* Medication received by patients with depression following the acute episode: adequacy and relation to outcome *Brit J Psychiatry*, 1999	Retrospective survey	Not an intervention study	To assess adequacy of anti-depressant treatment and measure patient compliance	Clinically depressed, mostly female No reference to ethnicity	UK Cambridgeshire Health Authority Primary Care

Mental Health: Table 4.2

Author Title Journal, Date	Outcomes – in relation to continuity of care	Rating: • Relevance • Evidence • Concept
Morgan, D. Psychiatric cases: an ethnography of the referral process *Psychol Med*,1989	42% patients focused on physical complaints. Doctor–patient relationship deteriorates if referral period longer. 3 referral patterns. Barriers to smooth referral discussed	• 3 • 3 • 1
Muijen, M. *et al.* Home based care and standard hospital care for patients with a severe mental illness: a randomised controlled trial *BMJ*, 1992	Care by Daily Living Team reduced hospital stay by 80%. Increased patient and staff satisfaction, slight improvement in psychopathology/functioning	• 4 • 5 • 4
Olfson, M. *et al.* Linking inpatients with schizophrenia to outpatient care *Psychiatric Services*, 1998	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	• 4 • 4 • 4
Paykel, E.S. *et al.* Community psychiatric nursing for neurotic patients: a controlled trial *Brit J Psychiatry*, 1982	Higher patient satisfaction and discharge from care (identified as associated with personal continuity). No differences in symptoms, social adjustment, burden on family	• 4 • 5 • 3
Ramana, R. *et al.* Medication received by patients with depression following the acute episode: adequacy and relation to outcome *Brit J Psychiatry*, 1999	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	• 1 • 3 • 1

Mental health: Table 5.1

Author Title Journal, Date	Study design	Intervention	Aim	Patient group	Setting
Repper, J., Ford, R. and Cooke, A. How can nurses build trusting relationships with people who have severe and long-term mental health problems? Experiences of case managers and their clients *J Adv Nursing*, 1994	Qualitative Guided interviews with 17 case managers and 16 selected clients	n/a	To identify approaches and tactics used by case managers to develop and maintain relationships with clients	SMI 85% psychotic Ethnicity not stated	England Six case management demonstration services
Tansella, M. *et al.* Episodes of care for first–ever psychiatric patients: a long-term case-register in a mainly urban area. *Brit J Psychiatry*, 1995	Longitudinal case register study	Psychiatric case register used to monitor and evaluate care	To assess length and frequency of episodes of care provided by community-based services following Italian psychiatric reform and hospital closures	1423 new psychiatric patients	Italy South Verona Community Psychiatric Service (mixed community and hospital facilities)
Teague, G.B., Drake, R.E. and Ackerson, T.H. Evaluating use of continuous treatment teams for persons with mental illness and substance abuse. *Psychiatric Services*, 1995	Mixed qualitative/ quantitative survey	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)	To evaluate fidelity to an assertive outreach model (Program in Assertive Community Treatment (PACT) model) in seven community health centres	Not clear	USA, New Hampshire

Tessler, R.C. Continuity of care and client outcome *Psychosocial Rehab J*, 1987	Retrospective comparison of two time periods. Assessments at 1–3 and 4–6 months	Intake clinician following patient through admission and co-ordinating discharge plans	To identify and measure breaks in care and examine their effects on patient outcome	112 psychiatric patients. Mostly white and schizophrenic	USA Massachusetts State psychiatric hospital/ community mental health system
Tessler, R. and Hayes-Mason, J. Continuity of care in the delivery of mental health services *Am J Psychiatry*, 1979	Prospective survey	Not an intervention study	To predict compliance with aftercare and to look at the impact of patient characteristics on community tenure	146 psychiatric inpatients	USA Massachusetts State Hospital

Mental Health: Table 5.2

Author Title Journal, Date	Outcomes – in relation to continuity of care	Rating: • Relevance • Evidence • Concept
Repper, J., Ford, R. and Cooke, A. How can nurses build trusting relationships with people who have severe and long-term mental health problems? Experiences of case managers and their clients *J Adv Nursing*, 1994	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	• 2 • 2 • 2
Tansella, M. *et al.* Episodes of care for first–ever psychiatric patients: a long-term case-register in a mainly urban area. *Brit J Psychiatry*, 1995	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	• 1 • 3 • 2
Teague, G.B., Drake, R.E. and Ackerson, T.H. Evaluating use of continuous treatment teams for persons with mental illness and substance abuse. *Psychiatric Services*, 1995	6/7 sites successful in implementing assertive outreach model. Patient outcomes not looked at. Claim that continuous treatment teams more successful in treating substance abuse than case management not backed by evidence	• 2 • 2 • 1
Tessler, R.C. Continuity of care and client outcome *Psychosocial Rehab J*, 1987	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	• 5 • 3 • 5
Tessler, R. and Hayes-Mason, J. Continuity of care in the delivery of mental health services *Am J Psychiatry*, 1979	Patients with highest aftercare compliance more likely to be married, schizophrenic and feel hopeless. No evidence found that aftercare reduced hospitalisation	• 4 • 3 • 5

Mental health: Table 6.1

Author Title Journal, Date	Study design	Intervention	Aim	Patient group	Setting
Tyrer, P.J. and Remington, M. Controlled comparison of day-hospital and outpatient treatment for neurotic disorders *Lancet*, 1979	RCT Blind assessments at 4 and 8 months	Outpatients seen by psychiatrists for as long as necessary/ day hospital offering clinical, occupational therapy, art therapy, psychology/ general hospital day unit psychotherapeutic treatment	To compare outcomes of psychiatric outpatient care, day hospital and day unit care.	106 patients with neurotic disorders referred by GPS	UK, Southampton $1^0/2^0$ care
Tyrer, P.J. *et al.* A randomized controlled study of close monitoring of vulnerable psychiatric patients *Lancet*, 1995	RCT	Fortnightly contact by CPA key-worker. Transfer to key-worker in another area if patient moved	To test the effectiveness of the Care Programme Approach in preventing patients from losing contact with care services and to reduce admissions	393 vulnerable community-based psychiatric patients No reference to ethnicity	UK inner city
Tyrer, P.J. *et al.* Randomised controlled trial of two models of care for discharged psychiatric patients *BMJ*, 1998	RCT	Integrated care by multidisciplinary team: common case records, team supervision, and information sharing reviews. Caseload 25 Limited information about service available to controls	Compare clinical and cost outcomes of intervention to aftercare coordinated by hospital-based team	155 patients with SMI ready for discharge Ethnicity not referred to	UK Two inner city and one outer London sites

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	Cochrane Review	Community treatment by integrated multidisciplinary mental health teams	To evaluate the effects of community mental health treatment	Five studies reviewed. Patients with severe mental illness or personality disorders.	3 studies set in UK, one in Australia, one in Canada
Ware, N.C. *et al.* An ethnographic study of the meaning of continuity of care in mental health services *Psychiatric Services*, 1999	Ethnographic study Field observation and open ended interviews of 16 users and 16 service providers	n/a	To develop a standardized measure, to be used in further research, through investigating the meaning of continuity of care for users and providers	16 self-selected volunteers, users of community mental health centres with SMI Ethnicity stated	USA Four community mental health centres

Mental Health: Table 6.2

Author Title Journal, Date	Outcomes – in relation to continuity of care	Rating: • Relevance • Evidence • Concept
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

Primary care: Table 1.1

Author Title Journal, Date	Study design	Intervention	Aim	Patient group	Setting	Length of follow-up
Becker, M.H., Drachman, R.H. and Kirscht, J.P. A field experiment to evaluate various outcomes of continuity of physician care *Am J of Public Health*, 1974	RCT	Two similar clinics set up In one, patients see same physician. In the control: • random allocation of patients to clinics • random allocation of staff too	To examine the effects of delivery of ambulatory care for children from low-income families by two methods: • traditional, episodic clinic • clinic structured to provide continuity of physician	Black child patients (115/125) 125 mothers Mothers interviewed in Baltimore	USA, Baltimore Primary Care Urban (OP)	9–12 months
Del-Mar, C.B. and Wright, R.G. 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? *Aust J Pub Health*, 1995	Prospective randomised interview study	Randomised by practice Study group had redesigned form including patient's address for direct notification	To reduce loss of follow-up by direct information	Women of reproductive age. Number not stated but large (all results in 42 practices for 26 weeks)	Australia Primary care with input form secondary care	
Fleming, G.V. and Andersen, R.M. The Municipal Health Services Programme: improving access to primary care without increasing expenditures *Medical Care*, 1986	Two-phase survey baseline and f/u	Charity-funded special health scheme for inner cities	Evaluate a comprehensive health programme for low-income inner city patients designed to improve access and continuity while reducing costs and maintaining quality	Low-income patients in Municipal Health Services Programme (MHSP) in five contrasting inner cities Various ethnicities	USA Primary and secondary – urban	1 year

Flocke, S.A. Measuring attributes of primary care: development of a new instrument *J Family Practice*, 1997	Development and field test of 20-item questionnaire	Tests new instrument against 9-item satisfaction scale	To measure 7 aspects of primary care and observe association with patient satisfaction	4454 consultations from 138 Ohio primary care physicians	USA, Ohio Mixed Primary Care	n/a

Primary care: Table 1.2

Author Title Journal, Date	Outcomes – in relation to continuity of care	Conclusion	Rating: • Relevance • Evidence • Concept
Becker, M.H., Drachman, R.H. and Kirscht, J.P. A field experiment to evaluate various outcomes of continuity of physician care *Am J of Public Health*, 1974	Staff satisfaction on a number of dimensions and perception of patients Ancillary staff (but not physicians) felt better autonomy in study clinic Patient satisfaction much higher in study group but mothers more dependent and said they might consult more System worked better for study group: • more time with physician, shorter waiting times • better attendance of repeat visits • greater disclosure of personal problems	Ability to develop continuing relationship is good and satisfying in itself Beneficial mutual reinforcement	• 5 • 5 • 4
Del-Mar, C.B. and Wright, R.G. 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? *Aust J Pub Health*, 1995	Loss to follow-up of women with CIN	Control group 23% loss (95% CI 11–39%) Study group 0% loss (0-7%) Very promising	• 5 • 5 • 3
Fleming, G.V. and Andersen, R.M. The Municipal Health Services Programme: improving access to primary care without increasing expenditures *Medical Care*, 1986	Were MHSP recruiting poor people without appropriate access? Yes – somewhat Were utilisation patterns improved? Yes – more PC and less Emergency Room OPD More regular physical exams? (proxy for preventive care in 1983!) Yes Better continuity? No – worse than private physician Satisfaction better? No – less Costs less? No less – less than public but greater than private	Overall more OP and less IP expenses for MHSP programme NB: 1 Researchers reveal that Randomised Allocation essential to unpick causal relationships! 2 relevance to costs	• 4 • 3 • 3

	sector		
Flocke, S.A. Measuring attributes of primary care: development of a new instrument *J Family Practice*, 1997	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

Primary care: Table 2.1

Author Title Journal, Date	Study design	Intervention	Aim	Patient group	Setting	Length of follow-up
Flocke, S.A., Stange, K.C. and Zyzanski, S.J. The impact of insurance type and forced discontinuity on the delivery of primary care *J Family Practice*, 1997	Cross-sectional survey – direct observation + records + exit quest	Patient reported forced change of core plan (insurance) in past two years	Effect of insurance mandated disruption on quality of primary care	1839 consultations in 138 practices; all patients on two-day observational periods who were in insurance plans	Primary care	2 years retro-spective
Freeman, G.K. Receptionists, appointment systems and continuity of care *Journal of RCGP*, 1989	Observational survey supplemented by brief, structured interviews	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 543 appointments made by 22 receptionists	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	543 patients;	UK Four general practices in southern England	n/a
Freeman, G.K. and Richards, S.C. Practice observed. How much personal care in four group practices? *BMJ*, 1990	Cross-sectional retrospective record survey	Inspection of records Doctors identified by their handwriting	To establish amount of CoC in general practice	776 patients attending randomly selected consulting seniors who had been registered at least 2 years and consulted at least	UK Four general practices in southern England	2 years+ retrospective

				12 times		
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. *BJGP*, 1993	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

Primary care: Table 2.2

Author Title Journal, Date	Outcomes – in relation to continuity of care	Conclusion	Rating: • Relevance • Evidence • Concept
Flocke, S.A., Stange, K.C. and Zyzanski, S.J. The impact of insurance type and forced discontinuity on the delivery of primary care *J Family Practice*, 1997	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 *Journal of RCGP*, 1989	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? *BMJ*, 1990	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. *BJGP*, 1993	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. Patents 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

Primary care: Table 3.1

Author Title Journal, Date	Study design	Intervention	Aim	Patient group	Setting	Length of follow-up
Freeman, G.K. and Richards, S.C. Personal continuity and the care of patients with epilepsy in general practice *BJGP*, 1994	Cross-sectional survey	Perceived care of epilepsy Whether they have discussed key personal issues: • stopping medication • stigma • concealment • to whom would they address their most important questions? Compared with recorded CoC	Testing whether patients seeing the same doctor were more likely to discuss personally important aspects of their illness	99 adults with epilepsy	UK Four general practices in southern England	2 years+ retrospective
Hjortdahl, P. Continuity of care: general practitioners' knowledge about and sense of responsibility toward their patients *Family Practice*, 1992	Survey	How long and how dense does previous contact need to be to make significant difference to: • knowledge? • sense of responsibility?	Study relation between CoC and GPs' accumulated knowledge Study relation between CoC and GPs' sense of responsibility	3918 consultations from 133 GPs	Norway National sample of general practices	n/a
Hjortdahl, P. and Borchgrevink, C.F. Continuity of care: influence of general practitioners' knowledge	Cross-sectional survey	GPs rated their knowledge of patients history on a 5-point scale	To examine relation between GP's knowledge and use of all resources: • use of tests and X-rays	3918, all ages	Norway National sample of 133 GPs	n/a

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

Author Title Journal, Date	Outcomes – in relation to continuity of care	Conclusion	Rating: • Relevance • Evidence • Concept
Freeman, G.K. and Richards, S.C. Personal continuity and the care of patients with epilepsy in general practice *BJGP*, 1994	Number of doctors seen – UPC compared with demographic chart	UPC low in group practices, especially children	• 3 • 3 • 4
Hjortdahl, P. Continuity of care: general practitioners' knowledge about and sense of responsibility toward their patients *Family Practice*, 1992	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 *BMJ*, 1991	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

Author Title Journal, Date	Study design	Intervention	Aim	Patient group	Setting	Length of follow-up
Hjortdahl, P. and Laerum, E. Continuity of care in general practice; effect on patient satisfaction *BMJ*, 1992	Survey of GP evaluations inked onto pt. Q's for same consultation		Evaluate influence of CoC on patient satisfaction	3044 white patients, all ages	Norway National sample of 133 GPs	n/a Duration only significant if over 5 years
Howie, J.G.R. *et al.* Quality at general practice consultations: cross-sectional survey *BMJ*, 1999	Survey of consecutive consultations over two weeks	Pre consultation questionnaire included how well patient knew the doctor. Stopwatch timing of consultations Post-consultation questionnaire assessed patient enablement index (PEI)	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)	25,994 consultations	UK 53 general practices in four contrasting UK regions	n/a
Kibbe, D.C., Bentz, E. and McLaughlin, C.P. Continuous quality improvement for continuity of care *J Family Practice*, 1993	Audit cycle repeated survey after intervention	• Collect data • Analyse problems • Make changes, train staff • Second data collection • Review	To improve provider continuity by Continuous Quality Improvement (CQI) Five problem areas identified (especially receptionist training)	125 1^0 care patients	USA, North Carolina Primary care	Up to one year

Primary care: Table 4.2

Author Title Journal, Date	Outcomes – in relation to continuity of care	Conclusion	Rating: • Relevance • Evidence • Concept
Hjortdahl, P. and Laerum, E. Continuity of care in general practice; effect on patient satisfaction *BMJ*, 1992	Satisfaction most strongly associated with "My personal doctor". Intensity not related to satisfaction	Personal care is a highly significant factor in improving quality and satisfaction	• 4 • 3 • 5
Howie, J.G.R. *et al.* Quality at general practice consultations: cross-sectional survey *BMJ*, 1999	Enablement score was most closely associated with duration of consultation and with knowing the doctor well	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.	• 4 • 4 • 5
Kibbe, D.C., Bentz, E. and McLaughlin, C.P. Continuous quality improvement for continuity of care *J Family Practice*, 1993	UPC Recorded separately according to: health maintenance chronic illness acute care all three	64% rise in UPC (highly significant) Authors admit that interaction not necessarily the cause of this change	• 5 • 4 • 4

Primary care: Table 5.1

Author Title Journal, Date	Study design	Intervention	Aim	Patient group	Setting	Length of follow-up
Rubenstein, L.V. *et al.* Evaluation of the VA's pilot program in institutional reorganization toward primary and ambulatory care: Part I, changes in process and outcomes of care *Academic Medicine*, 1996	Surveys Baseline Implementation Early and late	PACE (primary Ambulatory Care and Education Program) 1 Continuity: same physician and better records 2 Proactive care: reminders 3 Mental health: resource, staff, education 4Humanistic care: communication skills training 5Access: telephone triage; short waiting times; rapid allocation of extras to appointments. [6 Technical quality: not implemented here]	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	Veterans attending who had already attended at least once Approx 1500	USA ,California Primary care	1 year
Taira, D.A. *et al.* Asian-American patient ratings of physician primary care performance	Survey – questionnaire (PCAS)	Last 20 patients seen by each physician	Compare Asian-American patient rating of primary care with those of Whites, Latinos and African-Americans	Patients (adults) registered with one university hospital (and consulting) primary care	USA , Boston Primary care	n/a

J Gen Int Medicine, 1997				practice		
Wasson, J. *et al.* Telephone care as a substitute for routine clinic follow-up *JAMA*, 1992	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 1^0 care, but average patient lived 80km from clinic	2 years

Primary care: Table 5.2

Author Title Journal, Date	Outcomes – in relation to continuity of care	Conclusion	Rating: • Relevance • Evidence • Concept
Rubenstein, L.V. *et al.* Evaluation of the VA's pilot program in institutional reorganization toward primary and ambulatory care: Part I, changes in process and outcomes of care *Academic Medicine*, 1996	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
Taira, D.A. *et al.* Asian-American patient ratings of physician primary care performance *J Gen Int Medicine*, 1997	PCAS (Primary care Assessment Survey) 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 *JAMA*, 1992	OP consultations ↓ IP admissions ↓ medication ↓ duration of stay ↓ tests (blood chem.) ↓ ICU ↓ costs ↓ hospital costs ↓ total costs ↓ All these reductions highly significant	28% reduction in costs	• 5 • 5 • 4

Maternity: Table 1.1

Author Title Journal, Date	Study design	Intervention	Aim	Patient group	Setting	Length of follow-up
Binstock, M.A. and Wolde-Tsadik, G. Alternative prenatal care. Impact of reduced visit frequency, focused visits and continuity of care *J Reprod Med.*, 1995	CCT	Visits from study team and provision of patient education handouts	To investigate impact of alternative prenatal care program for low risk women	Low risk women receiving prenatal care (n=549)	Community	
Brown, S. and Lumley, J. Changing childbirth: lessons from an Australian survey of 1336 women *B J of Obs & Gyn*, 1998	Mailed cross sectional survey 6–7 months post partum	Shared care system, birthing centres vs: • private care • hospital-led care	Views of women using new care options vs. old • extent of greater CoC • whether this enhanced women's experience	1336 women	Australia Maternity – various	Approx. 550 days
Giles, W. *et al.* Antenatal care of low-risk obstetric patients by midwives. A randomised controlled trial *Med J Aust*, 1992	RCT	Midwife-led clinic vs. obstetrician-led hospital care (Patients see obstetrician at booking, 30/40 and 40/40)	To assess practicality, patient acceptability and salary costs of a/n care of low-risk patients by midwives	Maternity; not stated	Australia $1^0/2^0$ interface	Not stated
Hodnett, E.D. Continuity of caregivers for care	Cochrane systematic review	Continuity of care through same caregiver or a small	Assess continuity of care during pregnancy, childbirth and puerperium	Pregnant women (2 studies n=1815 women)	Across primary and secondary care	To childbirth

during pregnancy and childbirth *Cochrane Library*, 2000		group from pregnancy				
Hodnett, E.D. and Roberts, I. Home based social support for socially disadvantaged mothers *Cochrane Library*, 2000	Cochrane Review	Additional home-based support for socially disadvantaged mothers and their children	To assess the effects of programmes offering additional home-based support for women and their children	Socially disadvantaged women who have recently given birth	Community 11 studies with 2992 families	Up to 4 years

Maternity: Table 1.2

Author Title Journal, Date	Outcomes – in relation to continuity of care	Rating • Relevance • Evidence • Concept
Binstock, M.A. and Wolde-Tsadik, G. Alternative prenatal care. Impact of reduced visit frequency, focused visits and continuity of care *J Reprod Med*, 1995	Higher levels of patient satisfaction regarding continuity of care in the intervention group	• 3 • 4 • 3
Brown, S. and Lumley, J. Changing childbirth: lessons from an Australian survey of 1336 women *B J of Obs & Gyn*, 1998	Most women have had no previous contact with their intra-partum midwife except in rural areas Knowing midwife makes independent contribution to satisfaction	• 3 • 3 • 2
Giles, W. *et al.* Antenatal care of low-risk obstetric patients by midwives. A randomised controlled trial *Med J Aust*, 1992	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]	(• 4?) (• 4?) (• 3?)
Hodnett, E.D. Continuity of caregivers for care during pregnancy and childbirth *Cochrane Library*, 2000	Women receiving the intervention were less likely to be admitted, have drugs for pain relief during labour, have an episiostomy, 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	• 4 • 5 • 4
Hodnett, E.D. and Roberts, I. Home based social support for socially disadvantaged mothers *Cochrane Library*, 2000	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	• 3 • 4 • 3

Maternity: Table 2.1

Author Title Journal, Date	Study design	Intervention	Aim	Patient group	Setting	Length of follow-up
Hundley, V.A. *et al.* Satisfaction and the 3 C's: continuity, choice and control. Women's views from a randomised controlled trial of midwife-led care *B J of Obs & Gyn*, 1997	RCT	Midwife managed delivery unit	To explore differences in women's satisfaction with care in midwife managed unit compared with consultant led labour ward.	Low risk women receiving antenatal care (n=2844)	Scotland Aberdeen Maternity Hospital, Grampian	
McCourt, C. *et al.* Evaluation of one to one midwifery: women's responses to care *Birth*, 1998	Prospective comparative study	One-to-one midwifery care	To compare one-to-one care with conventional care	Women receiving maternity services (treatment n=728; control n=675)	UK, West London	
Page, L. *et al.* Clinical interventions and outcomes of one to one midwifery practice *J Reprod Med*, 1999	Prospective comparative study	One-to-one midwifery care	To compare one-to-one care with conventional care	Women receiving maternity services (treatment n=728; control n=675)	UK, West London	
Rowley, M.J. *et al.* Continuity of care by a midwife team versus routine care during pregnancy and birth: a randomised trial	RCT	Team care with six midwives	To compare continuity of care from a midwife team with routine care from a variety of doctors and midwives.	Women receiving care during pregnancy and birth (treatment n=405, control n=409)	Clinic	

Med J Aust, 1995						
Shah, K. *et al.* Evaluation of the home-based maternal record: a WHO collaborative study *Bulletin WHO*, 1993	Pre- and post-intervention design	Home-based maternal record (HBMR)	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	Women who were 2–8 months pregnant	This article summarised findings from 13 centres in eight countries: Egypt, India, Pakistan, Philippines, Senegal, Sri Lanka, Democratic Yemen, Zambia	15–24 months

Maternity: Table 2.2

Author Title Journal, Date	Outcomes – in relation to continuity of care	Rating • Relevance • Evidence • Concept
Hundley, V.A. *et al.* Satisfaction and the 3 C's: continuity, choice and control. Women's views from a randomised controlled trial of midwife-led care *B J of Obs & Gyn*, 1997	Failed to detect a difference in satisfaction with overall experience. Highlights difficulties in measuring quality of service provision	• 5 • 5 • 3
McCourt, C. *et al.* Evaluation of one to one midwifery: women's responses to care *Birth*, 1998	Women are more satisfied with one-to-one model of care	• 5 • 5 • 4
Page, L. *et al.* Clinical interventions and outcomes of one to one midwifery practice *J Reprod Med*, 1999	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.	• 5 • 5 • 4
Rowley, M.J. *et al.* Continuity of care by a midwife team versus routine care during pregnancy and birth: a randomised trial *Med J Aust*, 1995	Continuity of care was part of intervention, women allocated to intervention reported increased satisfaction	• 3 • 4 • 3
Shah, K. *et al.* Evaluation of the home-based maternal record: a WHO collaborative study *Bulletin WHO*, 1993	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	• 5 • 4 • 4

Maternity: Table 3.1

Author Title Journal, Date	Study design	Intervention	Aim	Patient group	Setting	Length of follow-up
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	RCT	Antenatal care by midwives and GPs according to a care plan and protocols for managing complications.	To compare routine antenatal care provided by GPs and midwives with obstetrician-led shared care	Low-risk women receiving antenatal care (n=1765)	Scotland 51 general practices linked to 9 Scottish maternity hospitals	310 days (delivery +6 weeks
Waldenstrom, U. and Turnbull, D. A systematic review comparing continuity of midwifery care with standard maternity services *B J of Obs and Gyn*, 1998	Cochrane systematic review	Care provided by a midwife or small group of midwives	Assess continuity of care from early pregnancy to childbirth	Pregnant women (seven RCTs, n=9148 women)	Across primary and secondary care	To childbirth

Maternity: Table 3.2

Author Title Journal, Date	Outcomes – in relation to continuity of care	Rating • Relevance • Evidence • Concept
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

Author Title Journal, Date	Study design	Intervention	Aim	Patient group	Setting	Length of follow-up
Kao, A.C. *et al.* Patients' trust in their physicians. Effects of choice, continuity and payment method *J Gen Int Med*, 1998	Telephone questionnaire	Trust questionnaire (modified from Anderson, L.A. (1990) *Psychol. Rep.* **67**:1091–100)	To evaluate extent to which physician choice, continuity (length of patient–physician relationship) and perceived physical payment method predict trust	Insured patients (adults with at least one consultation in previous year) 292 out of 410 eligible patients (71%)	USA. Atlanta 1^0 Care	n/a
Lee, L.H., Levine, J.A. and Schultz, H.J. Utility of a standardised sign-out card for new medical interns *J Gen Int Med*, 1996	Random allocation of interns (resident doctors) to intervention or control teams	Use of a structured 'sign-out' (i.e. hand-over) record at shift changes (day–night)	To improve patient care by aiding transfer of relevant clinical information between shift-working doctors	252 questionnaires from interns Medicine, Minnesota, USA	USA, Rochester, Minnesota Secondary care: inpatient cardiovascular medicine	1 day (next morning)
Parkerton, P.H. Part-time practice and physician performance: continuity in primary care Conference abstract, 2000	Survey of administration and study departments	Physician availability and continuity Practice structure (team size, HC size etc.)	The relationship between part-time practice and physician physical performance	Group health medical centres 194 physicians	USA, Washington State Primary care	n/a
Wallace, K. and Soloman, J. Quality of epilepsy treatment and services: the views of women with epilepsy	18 women in three focus groups, further focus groups with six epilepsy women. Recruitment was	n/a	Assess views of epilepsy patients and nurse specialists on how epilepsy R might be improved	Female patients with epilepsy attending OP	UK Primary and secondary	n/a

Seizure, 1999	leaflets at OP (National Hospital) and by Epilepsy Support Network Nurses from hospitals around England					

Miscellaneous: Table 1.2

Author Title Journal, Date	Outcomes – in relation to continuity of care	Conclusion	• Rating • Relevance • Evidence • Concept
Kao, A.C. *et al.* Patients' trust in their physicians. Effects of choice, continuity and payment method *J Gen Int Med*, 1998	Length of relationship Knowledge of payment method	Awareness of payment method was poor Trust is associated with: • more choice of physician • length of relationship (and with trusting the managed care organisation)	• 3 • 2 • 2
Lee, L.H., Levine, J.A. and Schultz, H.J. Utility of a standardized sign-out card for new medical interns *J Gen Int Med*, 1996	Bad handover recorded at subsequent questionnaire	Significantly fewer bad handovers in intervention group NB: validity problems: non-blinded, confounding	• 4 • 3 • 4
Parkerton, P.H. Part-time practice and physician performance. Continuity in primary care Conference abstract, 2000	Part-time satisfaction, cancer success, diabetic management Costs Usual Provider Continuity index (UPC) length of association (team tenure, i.e. length of practice in study site; this was significant for periods exceeding three years)	Part-time physicians associated with: • better cancer screening • diabetes • higher costs • lower UPC • higher length of knowing physician Costs rise as FTE drops below 0.7 The authors like 'sustained practice availability'	• 5 • 2 • 2
Wallace, K and Soloman, J. Quality of epilepsy treatment and services: the views of women with	Areas of concern: •continuity – mainly seeing same doctor each time in OP – also $1^0/2^0$ communication	Recommends management changes to ensure greater provision of CoC in OP	• 3 • 3 • 2

epilepsy *Seizure*, 1999	(information) • rushed consultations • information provision, e.g. contraception, pregnancy • clinical competence and skills, including hospital, GP and A&E • outcomes of treatment		

Appendix 2

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.

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

VARIABLE	DATA	*Study ID*
Source: Author Title *Journal* date; **vol**:pages		
INCLUDED STUDY		
Aims		
Definition of continuity of care used in paper (state if no definition used)		
Setting (e.g. 1°, 2°, 1°/2° interface urban, intermediate, rural etc.)		
Country		
Patient group Ethnicity Number of patients		
Design		
Intervention (for example this may include the way a service or staff are organised, national or local policy)		
Outcomes measured including: • outcome measured, for example quality of care, and • how this is measured, e.g. by loss of contacts or death rate		
Length of follow-up (days)		
Conclusion Benefit/no benefit/disbenefit from continuity intervention		

Additional references from paper that we have not already identified				
Rating low = 1 best = 5	relevant	evidence	concept	

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 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*

> *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

(Notes 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.

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 multidiscipline, 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/anonymous 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

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

Numerous references (Currell, 1990; Green, Price and Renfrew, 1998; Green, Renfrew and Curtis, 2000). For definition see T. Murphy-Black (1993).

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.

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

References

Addington-Hall, H.J., MacDonald, L.D., Anderson, H.R., Chamberlain, J., Freeling, P., Bland, J.M. and Raftery, J. 1992. Randomised controlled trial of effects of coordinating care for terminally ill cancer patients. *BMJ* 305: 1317–22

Allott, M. and Robb, M. 1998. *Understanding health and social care*. London: Sage

Anttilla, S.K., Huhtala, H.S., Pekurinen, M.J. and Pitkäjärvi, T.K. 2000. Cost-effectiveness of an innovative four-year post-discharge programme for elderly patients. *Scandinavian Journal of Public Health* 28:41–6

Audit Commission. 1998. *First Class Delivery: A National Survey of Women's Views of Maternity Care*

Bachrach, L.L. 1981. Continuity of care for chronic mental patients: a conceptual analysis. *Am J Psychiatry* 138**:**1449–56

Baker, R. and Streatfield, J. 1995. What type of general practice do patients prefer? Exploration of practice characteristics influencing patient satisfaction. *Br J Gen Pract* 45:654–6

Beagan, B.L. 2000. Mutualising differences. *Soc Sci Med* 51:1253–65

Becker, M.H., Drachman, R.H. and Kirscht, J.P. 1974. A field experiment to evaluate various outcomes of continuity of physician care. *Am J Public Health* 64:1062–70

Bindman, J., Johnson, S., Szmukler, G., Wright, S., Kuipers, E., Thornicroft, G., Bebbington, P. and Leese, M. 2000. Continuity of care and clinical outcome: a prospective cohort study. *Social Psychiatry and Psychiatric Epidemiology* 35:242–47

Bindman, J., Johnson, S., Wright, S., Szmukler, G., Bebbington, P., Kuipers, E. and Thornicroft, G. 1997. Integration between primary and secondary services in the care of the severely mentally ill: patients' and general practitioners' views. *British Journal of Psychiatry* 171**:**169–74

Binstock, M.A. and Wolde-Tsadik, G. 1995. Alternative prenatal care. Impact of reduced visit frequency, focused visits and continuity of care. *Journal of Reproductive Medicine* 40**:**507–12

Bjoerkman, T., Hansson, L., Svensson, B. and Berglund, I. 1995. What is important in psychiatric outpatient care? Quality of care from the patient's perspective. *Int J Qual Health Care* 7:355–62

Boman, L., Bjorvell, H., Langius, A. and Cedermark, B. 1999 Two models of care as evaluated by a group of women operated on for breast cancer with regard to their perceived well-being. *Eur .J Cancer Care Engl* 8:87–96

Brekke, J.S., Ansel, M., Long, J., Slade, E. and Weinstein, M. 1999. Intensity and continuity of services and functional outcomes in the rehabilitation of persons with schizophrenia. *Psychiatr Serv* 50:248–56

Brindis, C., Pfeffer, R. and Wolfe, A. 1995. A case management program for chemically dependent clients with multiple needs. *J Case Manag* 4:22–8

Brown, S. and Lumley, J. 1998. Changing childbirth: lessons from an Australian survey of 1336 women. *Br J Obstet Gynaecol* 105:143–55

Clark, H. and Dyer, S. 1996. The assessment process for older people leaving hospital. *Joseph Rowntree Foundation Online,* July

Close, H. and Proctor, S. 1999. Coping strategies used by hospitalised stroke patients: implications for continuity and management of care. *Journal of Advanced Nursing* 29:138–44

Cook, R.I., Render, M. and Woods, D.D. 2000. Gaps in the continuity of care and progress on patient safety. *BMJ* 320:791–94

Currell, R. 1990. The organisation of midwifery care. In *Midwifery practice – antenatal care: a research based approach*, eds J. Alexander, V. Levy and S. Roch. London: Macmillan Press

Del-Mar, C.B. and Wright, R.G. 1995. 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? *Aust J Pub Health* 19**:**211–13

Ekman, I., Andersson, B., Ehnfors, M., Matejka, G., Persson, B. and Fagerberg, B. 1998. Feasibility of a nurse-monitored, outpatient-care programme for elderly patients with moderate-to-severe, chronic heart failure *Eur Heart J* 19:1254–60

Epstein, A.M., Hall, J.A., Fretwell, M., Feldstein, M., DeCiantis, M.L., Tognetti, J., Cutler C., Constantine M., Besdine R., Rowe J. and McNeil B.J. 1990. Consultative geriatric assessment for ambulatory patients. A randomized trial in a health maintenance organization. *JAMA* 263:538–44

Farquhar, M., Camilleri-Ferrante, C. and Todd, C. 1996. *An Evaluation of Midwifery Teams in West Essex: Final Report.* University of Cambridge: Institute of Public Health

Farquhar, M., Camilleri-Ferrante, C. and Todd, C. 1998. Working with team midwifery – health visitors' views of one team midwifery scheme. *Journal of Advanced Nursing* 27:546–52

Farquhar, M., Camilleri-Ferrante, C. and Todd, C. 2000a. Continuity of care in Maternity Services: women's views of one team midwifery scheme. *Midwifery* 16:35–47

Farquhar, M., Camilleri-Ferrante, C. and Todd, C. 2000b. General practitioners' views of working with team midwifery (Brief Report). *British Journal of General Practice* 50:211–13

Fleissig, A., Glasser, B. and Lloyd, M. 1999. Encouraging out-patients to make the most of their first hospital appointment: To what extent can a written prompt help patients get the information they want? *Patient Education and Counselling* 38:69–79

Fleming, D.M. 2000. Continuity of care: a concept revisited. *European J Gen Prac* 6:140–5

Fleming, G.V. and Andersen, R.M. 1986. The Municipal Health Services Program: improving access to primary care without increasing expenditures*. Medical Care* 24:565–79

Flocke, S.A. 1997. Measuring attributes of primary care: development of a new instrument. *J Fam Pract* 45:64–74

Flocke, S.A., Stange, K.C. and Zyzanski, S.J. 1997. The impact of insurance type and forced discontinuity on the delivery of primary care. *J Fam Pract* 45:129–35

Frank, A.F. 2000. Illness and autobiographical work. *Qual Sociology* 23:135–56

Frankenberg, R. 1987. Cycle, trajectory or pilgrimage. In *Rethinking the life cycle*, ed. A. Bryman. London: McMillan

Freeman, G.K. 1989. Receptionists, appointment systems and continuity of care. *Journal of the Royal College of General Practitioners* 39:145–7

Freeman, G.K. and Hjortdahl, P. 1997. What future of continuity of care in general practice? *BMJ* 314:1870–3

Freeman, G.K. and Richards, S.C. 1990. Practice observed. How much personal care in four group practices? *BMJ* 301:1028–30

Freeman, G.K. and Richards, S.C. 1993. Is personal continuity of care compatible with free choice of doctor? Patients' views on seeing the same doctor. *British Journal of General Practice* 43:493-497

Freeman, G.K. and Richards, S.C. 1994. Personal continuity and the care of patients with epilepsy in general practice. *British Journal of General Practice* 44:395–9

Fulop, N., Allen, P., Clarke, A. and Black, N. (in press) Issues in studying the organisation and delivery of health services. In *Studying the Organisation and Delivery of Health Service*. London: Routledge

Garcia, J. (1995) Continuity of care in context: What matters to women? In *Effective Group Practice in Midwifery: Working With Women*, ed. L. Page, 96–105. Oxford: Blackwell

Giles, W., Collins, J., Ong, F. and MacDonald, R. 1992. Antenatal care of low risk obstetric patients by midwives. A randomised controlled trial. *Med J Aust* 157:158–61

Godley, S.H., Godley, M.D., Pratt, A. and Wallace, J.L. 1994. Case management services for adolescent substance abusers: a program description. *J Subst Abuse Treat* 11:309–17

Green, J.M., Price, P. and Renfrew, M.J. 1998. *Continuing to Care: The organization of midwifery services in the UK: a structured review of the evidence*. Books for Midwives Press

Green, J.M., Renfrew M.J. and Curtis, P.A. 2000. Continuity of carer: what matters to women? A review of the evidence. *Midwifery* 16(3):186–96

Greenhalgh, T. and Hurwitz, B. (eds) 1998. *Narrative Based Medicine: Dialogue and discourse in clinical practice*. London: BMJ Books

Hall, S.M., Tunis, S., Triffleman, E., Banys, P., Westely Clark, H., Tusel, D., Stewart, P. and Presti, D. 1994. Continuity of care and Desipramine in primary cocaine abusers. *J Nerv Ment Dis* 182:570–5

Herman, D., Opler, L., Felix, A., Valencia, E., Wyatt, R.J. and Susser, E. 2000. A critical time intervention with mentally ill homeless men: impact on psychiatric symptoms. *J Nerv Ment Dis* 188:135–40

Heslop, L., Elsom, S. and Parker, N. 2000. Improving continuity of care across psychiatric and emergency services: combining patient data within a participatory action research framework. *Journal of Advanced Nursing* 31:135–43

Hibberd, P.A. 1998. The primary secondary interface – cross boundary teamwork. *Journal of Clinical Nursing* 7:274–82

Hjortdahl, P. 1992. Continuity of care: general practitioners' knowledge about, and sense of responsibility toward their patients. *Family Practice* 9:3–8

Hjortdahl, P. and Borchgrevink, C.F. 1991. Continuity of care: influence of general practitioners' knowledge about their patients on use of resources in consultations. *BMJ* 303:1181–4

Hjortdahl, P. and Laerum, E. 1992. Continuity of care in general practice: effect on patient satisfaction. *BMJ* 304:1287–90

Hodnett, E.D. 2000a. Caregiver support for women during childbirth (Cochrane Review*)* In *The Cochrane Library*, Issue 3. Oxford: Update Software

Hodnett, E.D. 2000b. Continuity of caregivers for care during pregnancy and childbirth (Cochrane Review). In *The Cochrane Library*, Issue 3. Oxford: Update Software

Hodnett, E.D. and Roberts, I. 2000. Home based social support for socially disadvantaged mothers (Cochrane review). In *The Cochrane Library*, Issue 3. Oxford: Update Software

Holloway, F., Oliver, N., Collins, E. and Carson, J. 1995. Case management: a critical review of the outcome literature. *European Psychiatry* 10:113–28

Hoult, J., Reynolds, I., Charbonneau-Powis, M., Weekes, P. and Briggs, J. 1983. Psychiatric hospital versus community treatment: the results of a randomised trial. *Austral NZ J Psychiatry* 17:160–7

Howie, J.G.R., Heaney, D.J., Maxwell, M., Walker, J.J., Freeman, G.K. and Rai, H. 1999. Quality of general practice consultations: cross sectional survey. *BMJ* 319: 738–43

Hundley, V.A., Milne, J.M., Glazener, C.M.A. and Mollison, J. 1997. Satisfaction and the three C's: continuity, choice and control. Women's views from a randomised controlled trial of midwife-led care. *Br J Obstet Gynaecol* 104:1273–80

Jackson, M.F. 1994. Discharge planning: issues and challenges for gerontological nursing. A critique of the literature. *J Adv Nursing* 19:492–502

Jarrett, N.J., Payne, S.A. and Wiles, R.A. 1999. Terminally ill patients' and lay-carers' perceptions and experiences of community-based services. *J Adv Nurs* 29:476–83

Johansson, B., Berglund, G., Glimelius, B., Holmberg, L. and Sjoden, P.O. 1999. Intensified primary cancer care: a randomized study of home care nurse contacts. *J Adv Nurs* 30:1137–46

Johnson, S., Prosser, D., Bindman, J. and Szmukler, G. 1997. Continuity of care for the severely mentally ill: concepts and measures. *Soc Psychiatry Psychiatr Epidemiol* 32:137–42

Jolly, K., Bradley, F., Sharp, S., Smith, H. and Mant, D. 1998. Follow-up care in general practice of patients with myocardial infarction or angina pectoris: initial results of the SHIP trial. Southampton Heart Integrated Care Project. *Family Practice* 15:548–55

Jung, H.P., Wensing, M., de Wilt, A., Olesen, F. and Grol, R. 2000. Comparison of patients' preferences and evaluations regarding aspects of general practice care. *Family Practice* 17:236–42

Kao, A.C., Green, D.C., Davis, N.A., Koplan, J.P. and Cleary, P.D. 1998. Patients' trust in their physicians. Effects of choice, continuity and payment method. *J Gen Intern Med* 13:681–6

Kaplan, S.H., Greenfield, S. and Ware, J.E. 1989. Assessing the effects of physician–patient interactions on the outcomes of chronic disease. *Medical Care* 27:110–27

Kibbe, D.C., Bentz, E. and McLaughlin, C.P. 1993. Continuous quality improvement for continuity of care. *Journal of Family Practice* 36:304–8

Klop, R., van Wijmen, F.C.B. and Philipsen, H. 1991. Patients' rights and the admission and discharge process*. Journal of Advanced Nursing* 16:408–12

Kopelowicz, A., Wallace, C.J. and Zarate, R. 1998. Teaching psychiatric inpatients to re-enter the community: a brief method of improving the continuity of care. *Psychiatr Serv* 49:1313–16.

Lee, L.H., Levine, J.A. and Schultz, H.J. 1996. Utility of a standardized sign-out card for new medical interns. *J Gen Intern Med* 11:753–5

Lough, M.A. 1996. Ongoing work of older adults at home after hospitalization. *J Adv Nurs* 23:804–9

McCourt, C., Page, L., Hewison, J. and Vail, A. 1998. Evaluation of one to one midwifery: women's responses to care. *Birth* 25:73–80

McWhinney, I.R. 2000. Being a general practitioner: what it means. *European J Gen Prac* 6:135–9

McWilliam, C. 1992. From hospital to home: elderly patients' discharge experiences. *Family Medicine* 24:457–67

McWilliam, C.L. and Sangster, J.F. 1994. Managing patient discharge to home: the challenges of achieving quality of care. *Int J Qual Health Care* 6:147–61

Malla, A.K., Norman, R.M.G., McLean, T.S., Cheng, S., Rickwood, A., McIntosh, E., Cortese, L., Diaz, K. and Voruganti, L.P. 1998. An integrated medical and psychosocial treatment program for psychotic disorders: patient characteristics and outcome. *Can J Psychiatry* 43:698–705

Marshall, M., Gray, A., Lockwood, A. and Green, R. 2000. Case management for people with severe mental disorders (Cochrane Review). In *The Cochrane Library,* Issue 3. Oxford: Update Software

Marshall, M., Lockwood, A. and Gath, D. 1995. Social services case-management for long-term mental disorders: a randomised controlled trial. *Lancet* 345:409–12

Meyer, J. 2000. Using qualitative methods in health related action research. *BMJ* 320:178–81

Morgan, D. 1989. Psychiatric cases: an ethnography of the referral process. *Psychol Med* 19:743–53

Morgan, M., Fenwick, N., McKenzie, C. and Wolfe, C.D. 1998. Quality of midwifery led care: assessing the effects of different models of continuity for women’s satisfaction. *Quality in Health Care* 7(2):77–82

Muijen, M., Marks, I., Connolly, J. and Audini, B. 1992. Home based care and standard hospital care for patients with severe mental illness: a randomised controlled trial. *BMJ* 304:749–54

Murphy, E., Dingwall, R., Greatbach, D., Parker, S. and Watson, P. 1998. Qualitative research methods in health technology assessment: a review of the literature. *Health Technology Assessment* 2(16)

Murphy-Black, T. 1993. *Identify the Key Features of Continuity of Care in Midwifery*, Report prepared for the Scottish Office Home & Health Department. University of Edinburgh: Nursing Research Unit

Naylor, M.D., Bowles, K.H. and Brooten, D. 2000. Patient problems and advanced practice nurse interventions during transitional care. *Public Health Nursing* 17:94–102

Naylor, M.D., Brooten, D., Campbell, R., Jacobsen, B.S., Mezey, M.D., Pauly, M.V. and Schwartz, J.S. 1999. Comprehensive discharge planning and home follow-up of hospitalised elders: a randomised clinical trial. *JAMA* 281:613–20

Noyes, J. 1999. Voices and choices: Young people who use assisted ventilation: their health and social care and education. London: Joseph Rowntree Foundation/HMSO

Olfson, M., Mechanic, D., Boyer, C.A. and Hansell, S. 1998. Linking inpatients with schizophrenia to outpatient care. *Psychiatr Serv* 49:911–17

O'Malley, A., Mandelblatt, J., Gold, K., Cagney, K.A. and Kerner, J. 1997. Continuity of care and the use of breast and cervical cancer screening services in a multiethnic community. *Archives of Internal Medicine*157:1462–70

Page, L. *et al.* 1999. Clinical interventions and outcomes of one to one midwifery practice. *Journal of Reproductive Medicine* 21:243–8

Pantilat, S.Z., Alpers, A.J.D. and Wachter, R.M. 1999. A new doctor in the house – ethical issues in hospitalist systems. *JAMA* 282:171-4

Parkerton, P.H. 2000. Part-time practice and physician performance. Continuity in primary care. Conference abstract. University of Michigan

Parkes, J. and Shepperd, S.A. 2000. Systematic review of discharge planning (Cochrane Review). In *The Cochrane Library*, Issue 4. Oxford: Update Software

Paykel, E.S., Mangen, S.P., Griffith, J.H. and Burns, T.P. 1982. Community psychiatric nursing for neurotic patients: a controlled trial. *Br J Psychiatry* 140:573–8

Payne, S., Hardey, M., Powell, J., Hawker, S. and Kerr, C. 2000. *Delivering Care Across Boundaries: the communication of information about elderly people between health and social care practitioners*, Report prepared for NHSE South-East Regional Office

Piette, J.D., Weinberger, M. and McPhee, S.J. 2000. The effect of automated calls with telephone nurse follow-up on patient-centered outcomes of diabetes care: a randomized, controlled trial. *Med Care* 38:218–30

Porter, S. and Ryan, S. 1996. Breaking the boundaries between nursing and sociology: a critical realist ethnography of the theory-practice gap. *J Adv Nurs* 24:413–20

Preston, R.M. 1997. Ethnography: studying the fate of health promotion in coronary families. *J Adv Nurs* 25:554–61

Ramana, R., Paykel, E.S., Surtees, P.G., Melzer, D. and Mehta, M.A. 1999. Medication received by patients with depression following the acute episode: adequacy and relation to outcome. *British Journal of Psychiatry* 174:128–34

Ratcliffe, J. and Buxton, M. 1999. Patients' preferences regarding the process and outcomes of life-saving technology. An application of conjoint analysis to liver transplantation. *Int J Technol Assess Health Care* 15:340–51

Rawl, S.M., Easton, K.L., Kwiatkowski, S., Zemen, D. and Burczyk, B. 1998. Effectiveness of a nurse-managed follow-up program for rehabilitation patients after discharge. *Rehabil Nurs* 23:204–9

Repper, J., Ford, R. and Cooke, A. 1994. How can nurses build trusting relationships with people who have severe and long term mental health problems? Experiences of case managers and their clients. *Journal of Advanced Nursing* 19:1096–104

Rowley, M.J., Hensley, M.J., Brinsmead, M.W. and Wlodarczyk, J.H. 1995. Continuity of care by a midwife team versus routine care during pregnancy and birth: a randomised trial. *Med J Aust* 163:289–93

Rubenstein, L.V., Yano, E.M., Fink, A., Lanto, A.B., Simon, B., Graham, M. and Robbins, A.S. 1996. Evaluation of the VA's pilot program in institutional reorganization toward primary and ambulatory care: Part I, changes in process and outcomes of care. *Academic Medicine* 71:772–83

Russell, S. 1999. Reducing readmissions to the intensive care unit. *Heart and Lung* 28:365–72

Sachs, L. 1989. Misunderstanding of therapy. *Culture Medicine & Psychiatry* 13:335–49

Sawyer, S.M., Collins, N., Bryan, D., Brown, D., Hope, M.A. and Bowes, G. 1998. Young people with spina bifida: transfer from paediatric to adult health care. *J Paediatr Child Health* 34:414–17

Shah, P.M., Selwyn, B.J., Shah, K., Kumar, V. and Collaborators 1993. Evaluation of the home-based maternal record: a WHO collaborative study. *Bull World Health Organ* 71:535–48

Simpson, R.G., Scothern, G., Vincent, M. 1995. Survey of carer satisfaction with the quality of care delivered to in-patients suffering from dementia. *J Adv Nurs* 22:517–27

Smeenk, F.W.J.M., de Witte, L.P., van Haastregt, J.C.M., Schipper, R.M., Biezemans, H.P.H. and Crebolder, H.F.J.M. 1998. Transmural care. A new approach in the care for terminal cancer patients: its effects on re-hospitalization and quality of life. *Patient Education & Counseling* 35:189–99

Smith, S.D., Nicol, K.M., Devereux, J. and Cornbleet, M.A. 1999. Encounters with doctors: quantity and quality. *Palliat Med* 13:217–23

Starfield, B. 1980. Continuous confusion. *Am J Public Health* 70:117–19

Sullivan, M.K. 1995. Facilitating Continuity of Care. *Nursing Clinics of North America* 30:221–30

Sundby, J., Olsen, A. and Schei, B. 1994. Quality of care for infertility patients. An evaluation of a plan for a hospital investigation. *Scand J Soc Med* 22:139–44

Taira, D.A., Safran, D.G., Seto, T.B., Rogers, W.H., Kosinski, M., Ware, J.E., Lieberman, N. and Tarlov, A.R. 1997. Asian-American patient ratings of physician primary care performance*. Journal of General Internal Medicine* 12:237–42

Tansella, M., Micciolo, R., Biggeri, A., Bisoffi, G. and Balestrieri, M. 1995. Episodes of care for first-ever psychiatric patients. A long-term case-register evaluation in a mainly urban area. *British Journal of Psychiatry* 167:220–27

Teague, G.B., Drake, R.E. and Ackerson, T.H. 1995. Evaluating use of continuous treatment teams for persons with mental illness and substance abuse. *Psychiatric Services* 46:689–95

Tessler, R.C. 1987. Continuity of care and client outcome. *Psychosocial Rehabilitation Journal* 11:39–53

Tessler, R. and Hayes-Mason, J. 1979. Continuity of care in the delivery of mental health services. *American Journal of Psychiatry* 136:1297–301

Thompson, D.R., Ersser, S.J. and Webster, R.A. 1995. The experiences of patients and their partners 1 month after a heart attack. *J Adv Nurs* 22:707–14

Todd, C., Farquhar, M. and Camilleri-Ferrante, C. 1998. Team midwifery – the views and job satisfaction of midwives. *Midwifery* 14:214–24

Tucker, J.S., Hall, M.H., Howie, P.W., Reid, M.E., Barbour, R.S., Florey, C. du V. and McIlwaine, G.M. 1996. 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* 312:554–9

Tyrer, P., Coid, J., Simmonds, S., Joseph, P. and Marriott, S. 2000. Community mental health teams (CMHTs) for people with severe mental illnesses and disordered personality (Cochrane Review). In *The Cochrane Library*, Issue 3. Oxford: Update Software

Tyrer, P., Evans, K., Gandhi, N., Lamont, A., Harrison-Read, P. and Johnson, T. 1998. Randomised controlled trial of two models of care for discharged psychiatric patients. *BMJ* 316:106–9

Tyrer, P., Morgan, J., van Horn, E., Jayakody, M., Evans, K., Brummell, R., White, T., Baldwin, D., Harrison-Read, P. and Johnson T. 1995. A randomized controlled study of close monitoring of vulnerable psychiatric patients. *Lancet* 345:756–9

Tyrer, P.J. and Remington, M. 1979. Controlled comparison of day-hospital and outpatient treatment for neurotic disorders*. Lancet* 1:1014–16 van Achterberg, T., Stevens, F.C.J., Crebolder, H.F.J.M., de Witte, L.P. and Philipsen, H. 1996. Coordination of care: effects on the continuity and quality of care. *Int J Nurs Stud* 33:638–50

van Harteveld, J.T.M., Mistiaen, P.J.M.L. and Dukkers van Emden, D.M. 1997. Home visits by community nurses for cancer patients after discharge from hospital; an evaluation study of the continuity visit. *Cancer Nursing* 20:105–14

von Sternberg, T., Hepburn, K., Cibuzar, P., Convery, L., Dokken, B., Haefemeyer, J., Rettke, S., Ripley, J., Vosenau, V., Rothe, P., Schurle, D. and Won-Savage, R. 1997. Post-hospital sub-acute care: an example of a managed care model. *J Am Geriatr Soc* 45:87–91

Waldenstrom, U. 1998. Continuity of carer and satisfaction. *Midwifery* 14:207–13

Waldenstrom, U. and Turnbull, D. 1998. A systematic review comparing continuity of midwifery care with standard maternity services. *Br J Obstet Gynaecol* 105:1160–70

Wallace, K. and Soloman, J. 1999. Quality of epilepsy treatment and services: the views of women with epilepsy. *Seizure* 8:81–7

Ware, N.C., Tugenberg, T., Dickey, B. and McHorney, C.A. 1999. An ethnographic study of the meaning of continuity of care in mental health services. *Psychiatr Serv* 50:395–400

Wasson, J., Gaudette, C., Whaley, F., Sauvigne, A., Baribeau, H. and Welch, G. 1992. Telephone care as a substitute for routine clinic follow-up. *JAMA* 267:1788–93

Wasson, J.H., Sauvigne, A.E., Mogielnicki, R.P., Frey, W.G., Sox, C.H., Gaudette, C. and Rockwell, A. 1984. Continuity of outpatient medical care in elderly men. A randomized trial. *JAMA* 252:2413–17

Widén Holmqvist, L., von Koch, L., Kostulas, V., Holm, M., Widsell, G., Tegler, H., Johansson, K., Almazán, J. and de Pedro-Cuesta, J. 1998. A randomized controlled trial of rehabilitation at home after stroke in southwest Stockholm. *Stroke* 29:591–7

Wilson, R., Krefting, L., Sutcliffe, P. and Van-Bussel, L. 1994. Native Canadians relocating for renal dialysis. Psychosocial and cultural issues. *Can Fam Physician* 40:1934–41

Wyke, S., Myles, S., Popay, J., Scott, J., Campbell, A. and Girling, J. 1999. Total purchasing community and continuing care: lessons for future policy developments in the NHS in Health and Social Care in the Community. *Health and Social Care in the Community* 7:394–407

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Addendum

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

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