

Continuity of Care

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

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prepared by

George Freeman and Sasha Shepperd
Division of Primary Care & Population Health Sciences
Imperial College School of Medicine

Ian Robinson and Kathryn Ehrich
Centre for the Study of Health
Brunel University

Sally Richards
Department of Social Work Studies
University of Southampton

assisted by

Patty Pitman and Harriet Sand
Imperial College School of Medicine

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Address for correspondence

Professor George K Freeman
Department of Primary Health Care & General Practice
Imperial College School of Medicine, Charing Cross Campus
The Reynold's Building
St Dunstan's Road
London W6 8RP

Email: g.freeman@ic.ac.uk

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

Continuity of Care

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*)

Continuity of Care

- 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.

Continuity of Care

- 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.

Continuity of Care

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

Disclaimer

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Addendum

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