Continuity of care in type 2 diabetes: patients', professionals' and carers' experiences and health outcomes

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

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prepared by

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Contributors

Smriti Naithani conducted all qualitative fieldwork, analysed the qualitative data and wrote first drafts describing the findings. Myfanwy Morgan advised on the conduct of the qualitative studies, supervised qualitative data analysis and contributed to the writing up of qualitative data. Martin Gulliford commented on the qualitative results and contributed to the writing up. All authors contributed to the development of the continuity-of-care questionnaires.

Smriti Naithani and Martin Gulliford designed the cohort study. Smriti Naithani led the fieldwork. Additional interviews and measurements were done by Emma Rooney at baseline and by Daniel Robotham and Sally Wood at follow-up. Smriti Naithani completed the clinical data extraction. Martin Gulliford analysed the quantitative data and drafted the report. Myfanwy Morgan and Smriti Naithani commented on the quantitative results and contributed to the writing up. All authors read and commented on the report.

Research ethics

The studies were approved by the Research Ethics Committee of Guy's Hospital. The project was approved, on behalf of Lambeth and Southwark Primary Care Trusts, by the Research Support Unit for the South London PCTs. All subjects gave written informed consent to participation.

Executive summary

Background and objectives

This project investigated the experience of health care of patients with type 2 diabetes mellitus. We asked 'What is continuity of care?', 'How can it be measured?' and 'Is continuity of care associated with better health outcomes for patients?'

We adapted the conceptual framework developed by Freeman and colleagues, identifying two ideals: continuity of care as a 'continuous caring relationship' between patient and professional, and continuity of care as the delivery of a 'seamless service'.

Aims and objectives

Mixed methods were used to evaluate and measure patients', carers' and providers' experiences of continuity of care in type 2 diabetes and to determine whether continuity of care was associated with clinical and patient outcomes. The study was set in two inner-London primary care trusts with young, mobile and ethnically diverse populations, high levels of deprivation and a number of existing models of diabetes care provision.

The specific objectives of the project were to:

1 hold in-depth interviews with diabetic patients in order to understand their values and experiences with respect to continuity in diabetes care;

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

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

4 conduct further qualitative work including the evaluation of the views and experiences of carers and South Asian patients;

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

Experienced continuity of care: patients' values and experiences

What we did: we held in-depth semi-structured interviews with 25 type 2 diabetic patients from 14 general practices. Interviews were transcribed and analysed thematically using a framework approach.

What we found: patients valued receiving regular reviews with clinical testing and provision of advice longitudinally over time. They valued a relationship with a named 'usual' professional who knew and understood them, was concerned and interested, and took time to listen and explain. Patients were more likely to trust and confide in a usual professional. Continuity was facilitated if patients could make and change appointments flexibly in response to changing needs or unexpected situations, or speak to their usual professional when they needed advice. Patients discussed questions of consistency and coordination between different members of staff, and between hospital and general practice or community settings. Patients who only received hospital-based care for their diabetes described less favourable experiences of seeing usual providers and less flexibility in adapting to changing needs.

What we conclude: these empirical data from patients are consistent with four dimensions of experienced continuity of care: longitudinal, relational, flexible and team and cross-boundary continuity.

Experienced continuity of care: development and evaluation of a new measure

What we did: we used the qualitative data to develop a 19-item measure of experienced continuity of care in type 2 diabetes mellitus (ECC-DM). The measure includes four sub-domains: longitudinal continuity (four items), flexible continuity (four items), relational continuity (six items) and team and cross-boundary continuity (five items). Scores ranged from 0 to 100. The measure was administered by interview in a survey of 209 type 2 diabetic subjects registered with 19 general practices.

What we found: the mean score was 62.1 (SD ±16.0). The average inter-item correlation was 0.343 and Cronbach's alpha was 0.908. Factor analysis revealed four factors which were generally consistent with the four sub-domains of continuity of care. The questionnaire was additionally tested in self-completion and telephone interview formats with satisfactory results. Test-retest reliability was good. Mean scores varied significantly (P=0.001) from 46 to 78 among patients registered with different general practices. Experienced continuity of care was lower for subjects who only received diabetes care from hospital-based clinics than for subjects who received diabetes care from their general practice (difference 13.7, 95% confidence interval 8.2 to 19.2, P<0.001). Patients gave higher continuity-of-care scores at general practices with a named lead doctor for diabetes (difference 8.2, 2.7 to 13.6, P=0.003).

What we conclude: the experienced continuity-of-care measure gives reliable, valid results and is easily applied. Patients' experiences of continuity depend on the organisation of care: if general practices have a named lead professional for diabetes then their patients generally experience better continuity of care; patients attending

hospital diabetes clinics for most of their diabetes care tend to experience lower continuity of care.

Continuity of care and clinical and patient outcomes

What we did: we conducted a cohort study of type 2 diabetic patients attending 19 general practices in two inner-London boroughs. Subjects were interviewed at home; the study questionnaire included the experienced continuity-of-care measure, the short-form 12 (SF-12) questionnaire, a measure of global satisfaction with care and confounding variables. Measurements were made of height, weight, blood pressure and glycated haemoglobin (HbA1c). Patients were followed-up with repeat interviews and measurements after 10 months. Analyses were adjusted for baseline values, age, sex, ethnicity, duration of diabetes, diabetes treatment, education, housing tenure and living alone.

What we found: interviews were obtained at baseline with 209/553 (38%) eligible subjects. Experienced continuity scores were obtained for 193 (85%) participants at baseline and 156 (75%) at follow-up. There were no differences in continuity scores or health measures between those followed-up and those lost to follow-up. Higher experienced continuity of care was associated with higher global satisfaction ratings. Experienced continuity of care was positively associated with number of consultations in the last 12 months, but negatively associated with the number of different individual professionals seen. Experienced continuity of care was not associated with HbA1c (coefficient for 10-unit increase in experienced continuity-of-care (ECC) score, −0.09%, −0.29 to 0.12, P=0.402). ECC scores were not associated with systolic or diastolic blood pressure, body weight, body mass index or physical or mental functioning.

What we conclude: experienced continuity of care encompasses patients' perceptions of the interpersonal aspects of their care and the degree of coordination of care. Dimensions of experienced continuity are therefore conceptually related to more traditional assessments of 'patient satisfaction'. Measurements of experienced continuity of care are associated with patients' global ratings of their overall satisfaction with care received.

In this health-care setting, experienced continuity of care is not associated with changes in glycated haemoglobin (HbA1c), blood pressure or body weight during approximately 10 months of follow-up; nor is experienced continuity of care associated with physical and mental functioning scores from the SF-12 questionnaire. Whereas a naïve model might suggest that experienced continuity should be associated with better health outcomes, experienced continuity may also be associated with disease progression and worse health. Discontinuities in care may be associated, at different times, with either improvement or deterioration in health measures.

Later qualitative work: carers and South Asian patients

What we did: in-depth interviews were held with seven carers of diabetic patients and 12 South Asian patients in order to understand their experiences with respect to continuity of care.

What we found: carers generally commented negatively on the quality of their relationships with health professionals. Carers perceived that professionals' reluctance to involve carers could result in a failure to fully appreciate patients' and carers' needs. This could be a particular problem with respect to mental health needs. South Asian patients generally expressed similar experiences and values with respect to continuity as other patients. Differences in language contributed to less favourable experiences of continuity of care, whereas services were sometimes not sufficiently flexible with respect to cultural differences, as for example in the provision of appropriate dietary advice.

What we conclude: differences in language, culture, disability or mental illness may contribute to difficulties in establishing and maintaining continuity of care.

Continuity in the delivery of care

What we did: we held interviews with 25 health professionals recruited from primary care and hospital-based diabetes services in order to understand their perceptions of continuity in the delivery of care. The data were used to develop a 28-item measure of continuity in the delivery of care. This was tested in a postal survey of staff in two primary care trusts and three hospitals.

What we found: professionals, like patients, endorsed the importance of regular reviews and checks with the development of systems to avoid loss to follow-up. Staff generally preferred to see the same patients at successive visits in order to develop a better understanding with the patient and deliver personally tailored care. Coordination between staff in the same setting and between different organisational settings were viewed as difficult issues. Flexibility in the delivery of services according to individual needs was considered to be an attribute of the system rather than a distinct dimension of continuity. The 28-item measure included the dimensions of longitudinal, relational, team, cross-boundary and informational continuity. The measure had good psychometric properties including excellent test-retest reliability. Continuity in the delivery of care was rated lower by hospital-based staff than by primary care professionals.

What we conclude: professionals' perceptions and values of continuity in the delivery of care generally endorse those described by patients. However, professionals generally showed greater awareness of organisational questions and the difficulties of delivering a 'seamless service'. These issues have been addressed in the development of

models of 'integrated care' and 'chronic disease management'. A questionnaire was developed to measure professionals' perceptions of continuity in the delivery of care. This has excellent psychometric properties.

Recommendations

1 Aspects of the patient experience that were identified by this research are important to consider in designing services for patients with diabetes and in assessing the quality of care.

2 Patients are vulnerable to experiences of loss of continuity when their health changes or when they move between health care organisations. It may be more difficult for some groups to establish and maintain continuity of care. Further research is required to develop and test interventions to enhance experiences of continuity through transitions in health and health care for different groups of patients.

3 Patients' experiences of continuity of care in diabetes should be monitored using the self-administered ECC-DM measure developed for this project. The instrument may also be used to evaluate the effectiveness of interventions to enhance continuity of care.

4 Further research is required to adapt the ECC-DM instrument into a form suitable for monitoring the experiences of patients with a range of chronic illnesses.

5 Organising care through an identified lead professional may enhance patients' experience of continuity of care.

6 Enhancing the patient experience of continuity of care is especially important for hospital-based services. Further research is required to develop and test interventions to enhance experiences of continuity of care in hospital-based clinics.

7 Assessment of professionals' views of continuity of care may be used to monitor service delivery and inform improvements in services.

8 Continuity of care is justified in terms of enhanced patient-centredness and acceptability of care rather than increased effectiveness. Experienced continuity of care should be valued because it represents, in the view of patients and professionals, the experience of more patient-centred care.

9 Additional research should investigate whether provider continuity is associated with patient safety or the frequency of serious adverse events.

Section 1 Introduction

1.1 Background

Chronic illnesses like diabetes mellitus impose a substantial burden on health services. There is much evidence to show that the organisation of services to deliver effective preventive clinical care has potential to improve patients' health outcomes in these conditions, yet the quality of clinical care is often sub-optimal.

Continuity of care is a term used to describe aspects of the quality of health care in a longitudinal, temporal domain. Primary care professionals regard continuity of care as a key attribute of service delivery in general practice, in contrast to the more fragmented nature of specialist consultation in hospital settings.

It has been suggested that continuity of care may lead to delivery of a higher quality of care, increased patient satisfaction and better health outcomes for patients. If confirmed, these observations could have important implications for the organisation and delivery of care for diabetes mellitus and other chronic illnesses. Uncertainty exists, however, because the concept of continuity of care is diffuse and poorly defined, few suitable measurement tools are available and empirical evidence is limited in scope and often drawn from contexts different than the UK National Health Service (NHS).

At the time this project was commissioned, policies were evolving to redesign health services so as to promote flexibility of access and to increase patient choice. In this context, the priority to be afforded to continuity of care was an important policy question, especially in the organisation and delivery of services outside hospitals. Questions requiring answers included What is continuity of care?, Can continuity of care be measured?, Is continuity of care associated with better health outcomes of care? and Is continuity of care a useful concept?

1.2 Objectives

This research aimed to study continuity of care in the context of the delivery of care for type 2 diabetes mellitus. We specifically aimed to:

1 evaluate patients' values and experiences with respect to continuity of care;

2 develop a reliable, valid, easily applied questionnaire measure of experienced continuity of care in type 2 diabetes;

3 evaluate health professional's values and experiences with respect to continuity of care and produce a questionnaire measure which may be used to monitor these;

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

5 evaluate the views of specific stakeholder groups including carers and South Asian patients.

1.3 Organisation of the report

In the next section of this report, we discuss the meaning, range and scope of the concept of continuity of care in order to develop a working definition. We go on to describe existing measures of continuity of care. In the third section we outline the epidemiology of type 2 diabetes mellitus and discuss current issues in the organisation and delivery of health services for the condition. The fourth section provides a review of earlier work on continuity of care in type 2 diabetes mellitus. The fifth section describes the aims and objectives of the project in more detail and describes the context in which the work was set. In the ensuing sections, we report and discuss our empirical findings, including:

- patients' experiences and values in relation to continuity of care;
- evidence for the reliability and validity of a new patient-based measure of experienced continuity of care in type 2 diabetes mellitus;
- professionals' experiences and values with respect to continuity of care including the development and evaluation of a new measure;
- evidence from a cohort study concerning the relationship between experienced continuity of care and patient health outcomes;
- views and experiences of carers and South Asian patients.

We conclude by making recommendations for future research. We also identify some important considerations for those responsible for organising and delivering services for patients with diabetes mellitus.

Section 2 The conceptual framework: meaning of continuity of care

Continuity of care is often cited as a 'cornerstone' (Cabana and Jee, 2004) or 'essential element' (Freeman *et al.*, 2003) of health care in general, or of primary care in particular, but the meaning of continuity of care is debated, the concept is hard to measure and its value is uncertain. Several definitions of continuity of care have been proposed but these have been criticised as vague and over-inclusive. There are problems of measurement because existing measures do not capture aspects of continuity which are relevant to current definitions of the term. Some authors have suggested that continuity of care is associated with better outcomes (Saultz and Lochner, 2005), while others claim that continuity is an outcome to be valued in its own right (Christakis, 2003). This raises the questions, What is continuity of care?, How can continuity of care be measured? and What is its value?

2.1 Two meanings of continuity of care

Continuity of care is emphasised in the primary care literature, where it is identified as a key value (Rogers and Curtis, 1980). The American Academy of Family Physicians defines continuity of care as

> *the process by which the patient and the physician are cooperatively involved in ongoing health care management toward the goal of high quality, cost-effective medical care.*
>
> (American Academy of Family Physicians, 2005)

According to this definition, continuity of care characterises the relationship of the individual patient with their physician over time. Continuity is viewed as extending beyond interpersonal aspects of care to encompass questions of quality and cost-effectiveness. This is important because continuity of care will not be useful if the care provided is unsatisfactory.

A different view of continuity has been proposed by those responsible for the care of patients with prolonged illnesses with complex care needs which must be met by professionals with a range skills in a number of settings. This form of continuity of care was defined by Shortell (1976) as

> *'the extent to which services are received as part of a coordinated and uninterrupted succession of events consistent with the medical care needs of patients.*
>
> (Shortell, 1976; 377)

This definition again concerns the delivery of care over time but it focuses on the degree coordination and consistency between different care settings and between different individual members of staff.

In contrast to other models of quality in health care, which generally consider assessments of care at a single point in time, the concept of continuity of care adds a longitudinal, temporal element (Haggerty *et al.*, 2003). Quality in health care is recognised to be a multi-dimensional concept and continuity of care is especially concerned with the dimension which the Institute of Medicine refers to as patient-centredness (Haggerty *et al.*, 2003; Institute of Medicine, Committee on Quality of Health Care in America, 2005). According to the Institute of Medicine definition, patient-centredness means

> *providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.*
>
> (Institute of Medicine, Committee on Quality of Health Care in America, 2005; 6)

In Maxwell's formulation of quality of care (Maxwell, 1984), patient-centredness concerns social or interpersonal acceptability and relevance to need. Donabedian (2003) does not mention continuity of care but identifies the doctor–patient relationship as one of the more important influences on the acceptability of care. Continuity of care may also include questions of access, effectiveness and efficiency as suggested by the American Academy of Family Physicians' definition (American Academy of Family Physicians, 2005). Equity also represents an important moral value in terms of ensuring satisfactory continuity of care for all groups of patients. In the broadest sense, continuity of care concerns the assessment of quality of care in a longitudinal, temporal domain. However, the meaning of continuity of care is more specific and two core ideals are revealed by the preceding definitions: continuity as a 'continuous caring relationship' between patient and physician (Institute of Medicine, Committee on Quality of Health Care in America, 2005) and continuity of care as the delivery of a 'seamless service' (Haggerty *et al.*, 2003).

2.2 Continuity of care as a continuous caring relationship

When a health-care professional is responsible for attending to most of the care needs of individual patients whom the professional may know well, continuity of care generally refers to the concept of a continuous caring relationship between doctor and patient. This concept of continuity of care is an integral feature of the Institute of Medicine definition of primary care as

> *the provision of integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practicing in the context of family and community.*
>
> (Institute of Medicine, 1994; 31)

In the UK, where there is universal eligibility to care, general practices provide care to registered populations which may remain stable over

many years, and interpersonal continuity of care is facilitated. In other health systems, stability of individual professional is harder to achieve; continuity of care may depend on health-insurance coverage or adequate access to health care. The significance of continuity of care may therefore vary in different health systems and empirical data should be compared cautiously between systems.

At the simplest level, the interpersonal aspect of continuity of care may be measured in terms of the extent to which a patient's consultations are concentrated in the hands of one or a small number of providers (Bice and Boxerman, 1977). However, the quality of the relationship between patient and professional is also regarded as important in the delivery of 'personal care' (Tarrant *et al.*, 2003). This requires that care is tailored to individuals' needs, with 'human communication' and a concern for the 'whole person' so that the illness is managed in the context of the patient's life (Tarrant *et al.*, 2003).

Continuity of interpersonal care may not always be desirable, and in any case is becoming difficult to sustain. General practitioners (GPs) are increasingly organised into multi-partner practices with only 7% of English GPs now working in solo practice, out-of-hours care is being devolved to specialist emergency-care provider organisations and general practices employ staff with a range of skills, with nurses taking responsibility for much routine care, especially in chronic illness. There is increasing diversity of primary-care provision, from walk-in clinics and community pharmacies to telephone helplines (Grant *et al.*, 2002). These are symptomatic of a growing trend towards more differentiated, specialised and flexible provision of primary care. The concept of continuity of care as a seamless service is therefore becoming more relevant, even in primary care settings.

2.3 Continuity of care as a seamless service

The ideal of continuity of care as a seamless service was described by Bachrach (1981) in the following terms:

> *Continuity of care may be understood as a process involving the orderly, uninterrupted movement of patients among the diverse elements of the service delivery system.*
>
> (Bachrach, 1981; 1449)

In hospital services, specialisation of roles is a key value which is most highly developed in tertiary care settings. Hospital-based systems of care are generally organised so as to facilitate the efficient delivery of specialist care, with interpersonal continuity taking a secondary place, if it is considered at all. In this context, continuity of care concerns the degree of consistency and coordination between different members of specialist teams, between different specialties and across the interface with primary care. These forms of continuity are often dependent on adequate record keeping, on sharing of records and on the sending of written letters and summaries. Thus in hospital-based services and

vertically integrated systems of care, continuity of care mostly refers to the concept of a seamless service.

2.4 Multidimensional models of continuity

The two main concepts of continuity of care represent two conflicting value systems in the delivery of medical care. This was recognised in a commentary by Starfield (1980), in which she used two different terms to distinguish between the two concepts of continuity of care. 'Longitundinality', she wrote, 'is the building and maintaining of a long-term patient-practitioner relationship'. In Starfield's formulation, longitudinality represents a 'continuous caring relationship'. 'Continuity', she went on, 'should characterise those aspects of secondary and tertiary care that involve the management of an episode of illness or chronic disease' (Starfield, 1980; 118); in other words, continuity represents the concept of a 'seamless service'. The apparent tension between these two different concepts of continuity has been resolved through the development of multidimensional models of continuity of care (Table 1).

Table 1 Multi-dimensional models of continuity of care

	Haggerty *et al.* (2003)	**Freeman *et al.* (2000, 2003)**	**Bachrach (1981)**	**Hennen (1975)**
1 General concepts				
a care over time		Experienced	Longitudinal	Chronological
b convenience and consistent with individuals' changing needs		Flexible	Flexibility; accessibility	
c information and communication	Informational continuity	Information	Communication	
2 Continuous caring relationship	Relational continuity	Longitudinal/ relational	Relationship Individual	Interpersonal
3 Seamless service	Management continuity	Team; cross-boundary	Comprehensiveness	Interdisciplinary Geographical

In 1975 Hennen described four dimensions of continuity of care in general practice. The *chronological* dimension encompassed long-term observation of the individual patient and their illness over time; *geographical* continuity referred to continuity between different sites in the community and in the hospital at which care is provided;

interdisciplinary continuity referred to continuity between providers from different clinical disciplines; whereas the *interpersonal* dimension of continuity included the provider–patient relationship and also the relationships between different professionals. In this model, the chronological dimension represents an over-arching aspect of continuity describing the delivery of care over time (Table 1). Geographical and interdisciplinary continuity relate to the concept of continuity as a seamless service, while interpersonal continuity refers predominantly to the concept of a continuous caring relationship. However, in Hennen's framework, the meaning of *interpersonal* continuity is ambiguous because it includes both continuity of the patient–provider relationship and the coordination between members of clinical teams.

Hennen's four dimensions (Hennen, 1975) were elaborated by in a review by Bachrach (1981). Bachrach wrote from the perspective of a psychiatrist; indeed, she argued that continuity of care in psychiatry was distinct from that in other specialties because of the complexity of needs of patients with long-term mental illnesses. However, the dimensions she suggested have been widely applied. Bachrach introduced the term *longitudinal continuity* in place of chronological continuity, and used this to describe the way that individual episodes of care, or contacts with health services, are organised together into a course of treatment. The *individual* dimension concerned care 'planned with and for the patient and his family'. This corresponds to the notion of 'personal care' described by Tarrant *et al.* (2003), in which care is tailored to individual needs. *Comprehensiveness* referred to the extent to which services meet all of the patient's needs, usually through contributions from different disciplines. *Flexibility* describes the response of the service to the patient's changing needs over time. *Relationship* refers to the extent that a patient's contacts with the health-care systems and its providers are characterised by 'familiarity and closeness'. *Accessibility* requires that the patient will be able to reach health care when it is needed. In other words, continuity requires that the patient does not experience physical, financial, personal or organisational barriers to contacting services. *Communication* included communication with the patient and between professionals.

Bachrach's model identifies *longitudinal* continuity as an overarching concept and also recognises that *communication* is required to support this. *Flexibility* and *accessibility* are also identified as overarching concepts and these require services to provide convenient, accessible care which meet patients' needs over time. The dimensions of *relationship* and *individual* continuity correspond to the notion of a continuous caring relationship. The dimension of *comprehensiveness* corresponds to the notion of a seamless service but this concept of continuity may also include other elements; for example, *accessibility* might be used to refer to the ease with which patients are able to negotiate boundaries between organisations or between primary and

secondary care. Hennen's and Bachrach's models are important because they recognise that continuity is a multi-dimensional concept but they both suffer from the limitation that they employ terms which suffer from duplication and ambiguity.

The review by Freeman *et al.* (2000) for the NHS Service Delivery and Organisation (SDO) Programme was one of the first studies to adopt a systematic approach to reviewing previous work on continuity of care. The model proposed in this report (Freeman *et al.*, 2000) built on earlier work, but refined the terms used by previous writers in order to reduce the ambiguity and duplication which existed (Box 1). A key element was the over-arching concept of *experienced continuity* –' the experience of a coordinated and smooth progression of care from the patient's point of view' (Freeman *et al.*, 2003). The other elements of continuity of care were viewed as supporting the achievement of experienced continuity. In defining experienced continuity as the 'coordinated and smooth progression of care', Freeman appears to emphasise the ideal of the 'seamless service', yet in primary care more significance is generally attached to concepts of longitudinal and relational continuity. The remaining dimensions map readily between Bachrach's and Freeman's model (Table 1). However, there is a difference of emphasis in the definition of longitudinal continuity; while Bachrach refers to the integration of care longitudinally over time, Freeman refers to 'care from as few professionals as possible' and this is consistent with the predominant notion of continuity in primary care.

Box 1 The model of Freeman and colleagues (2000)

Experienced continuity: the experience of a coordinated and smooth progression of care from the patient's point of view.

To achieve this the service needs:

continuity of information: information transfer following the patient;

cross-boundary and team continuity: effective communication between professionals and services, and with patients;

flexible continuity: adjusting to needs of individuals over time;

longitudinal continuity: care from as few professionals as possible.

In their recent review for the Canadian Health Services Research Foundation, Haggerty *et al.* (2003) synthesised these ideas and suggested that continuity is essentially concerned with the care of individual patients in a longitudinal, chronological dimension. They suggested that there are three key types of continuity: *relational continuity*, 'an ongoing therapeutic relationship between a patient and one or more providers'; *management continuity,* 'a consistent and coherent approach to the management of a health condition that is responsive to a patient's changing needs' and *informational continuity*, 'the use of information on past events and personal circumstances to make current care appropriate for each individual'. Haggerty *et al.*

(2003) observed that the importance attached to each type of continuity varies in different contexts. In general practice, most importance is attached to relational continuity; in mental health and chronic disease management, importance is attached to management continuity; while in the nursing literature, communication, coordination and information transfer are regarded as important.

The synthesis suggested by Haggerty *et al.* (2003) is consistent with the two core concepts of continuity. Relational continuity refers to the concept of a 'continuous caring relationship' whereas management continuity refers to the notion of a 'seamless service'. However, three overarching elements of continuity also emerge from this analysis: the importance of the coherent delivery of care over time is consistent with the notion of *longitudinal* or *chronological* continuity; the importance of delivering care to patients as individuals and adapting services to their needs is consistent with *flexible* continuity; the importance of communication and information to support clinical decision-making and the delivery of personal care over time is recognised in the concept of *informational* continuity.

Consideration of the multi-dimensional models shows that the various dimensions of continuity appear to converge and overlap. For example, a patient's experience of repeating his history to different health professionals may reflect problems with longitudinal continuity, team continuity or informational continuity. Furthermore, different perceptions of continuity of care are obtained from the perspectives of patient and providers.

2.5 Experienced continuity of care and patient satisfaction

Freeman and colleagues' concept of experienced continuity (Freeman *et al.*, 2003) marks a shift in thinking away from continuity of care as an objectively measured process of care, towards the notion of continuity of care as a measure of patients' satisfaction with care received. From this perspective, as Christakis (2003) has observed, continuity of care can be regarded as an outcome worth achieving in its own right. However, the Freeman model goes further by providing a conceptual model for understanding and measuring these specific aspects of patient satisfaction.

The notion of Freeman *et al.* (2003) of *experienced continuity* can be regarded as a theoretical construct which underlies patients' satisfaction with both the interpersonal aspects of their care and the coordination of their care. Items relevant to Freeman's dimensions of continuity can usually be identified in general-purpose patient-satisfaction surveys (Picker Institute, 2005a). The model of Freeman and colleagues provides a conceptual framework for the analysis of empirical data.

2.5.1 Continuity in the delivery of care

Redesign of service-delivery systems, with the aim of facilitating patient 'journeys' to provide faster, better-coordinated and more flexible delivery of care, has become a widespread feature of health systems. Redesign has been promoted in the UK NHS through the work of the NHS Modernisation Agency; it is also a core element in the chronic care model for chronic disease management (Wagner *et al.*, 2001). Redesign involves developing multidisciplinary teams, improving teamwork, integrating specialist and generalist skills across organisational boundaries, and harnessing new information technology for the coordination of care. These elements can be viewed as aiming to improve continuity of in the delivery of care. The processes of continuity in the delivery of care will often extend beyond of the scope of patients' direct experience; assessment requires objective measurement as well as evaluation of the views of professionals and managers. Continuity in the delivery of care will be valued if it leads to increased patient satisfaction or better health outcomes.

2.6 Measurement of continuity of care

2.6.1 Measures of provider continuity

Several quantitative measures of the extent of longitudinal continuity with an individual care provider (provider continuity) have been proposed based on data for consultations drawn from clinical records. Some studies have used simple measures such as whether a patient consults with only one health professional or with several (Overland *et al.*, 2001); how long subjects have been registered with their GP (Overland *et al.*, 2001); whether they have been registered for at least 2 years (Hanninen *et al.*, 2001) or whether they have received check-ups at least twice a year (Hanninen *et al.*, 2001). These indices suffer from the limitations that they reduce continuity of care to a binary trait and may be confounded by patient age, in the case of length of registration with GP, or by severity of illness, in the case of number of consultations per year.

Shortell (1976) suggested that the concentration of a patients' consultations in the hands of a small number of health professionals should be used as a measure of continuity. Bice and Boxerman (1977) proposed an appropriate numerical index. If a patient makes n visits to health-care providers, n_j is the number of visits to provider j and there are s providers, then the continuity-of-care index is given by

$$\left(\sum_{j=1}^{s} (n_j^2) - n\right) / (n(n-1)) \qquad (1)$$

Values for the index vary between 0 and 1 and approach 0.5 if the consultations are divided evenly between two providers. The index increases as the total number of visits increases and as the patient's

consultations are concentrated with one or a small number of providers, consistent with the notion of longitudinal continuity. The index decreases as the number of different providers increases but it permits comparison between individuals with different numbers of providers. Bice and Boxerman made a distinction between referred and unreferred providers, arguing that consultations with referred providers were consistent with continuity of care. However, this distinction is not essential. The continuity-of-care index, and related indices, have been used in many empirical studies (Parchman *et al.*, 2002; Gill *et al.*, 2003; Dolovich *et al.*, 2004), which were reviewed by Saultz (2003).

Measures of provider continuity based on clinical consultation data suffer from the limitation that they only address a limited aspect of one of the two main concepts of continuity of care. These measures address Freeman and colleagues' notion of longitudinal continuity – care from as few professionals as possible – but they fail to incorporate patients' assessment of continuity. For this reason, such measures have relatively limited application in studies of continuity of care, mainly in primary care settings. In order to address this issue, questionnaire items and measures have been developed.

2.6.2 Measures of continuity in the experience of care

Questionnaire items

Some general household surveys have included specific items concerning subjects' experiences of continuity in health care. The third US National Health and Nutrition Examination Survey (NHANES III) questionnaire included the following items: Is there a particular clinic, health centre, doctors' office or other place that you usually go to if you are sick, need advice for your health or for routine care?, and, if affirmative, Is there one particular doctor or health professional that you usually see? (Koopman *et al.*, 2003).

Questionnaire measures of patient satisfaction and patient-assessed quality of care commonly include items concerning continuity of care. The General Practice Assessment Questionnaire (GPAQ; National Primary Care Research and Development Centre, 2005) includes 27 items concerning patients' experience of access, continuity and interpersonal care in the context of general practice consultations. The GPAQ continuity-of-care items are: How often do you see your usual doctor? and How do you rate this? Other GPAQ items concerning access may be viewed as relating to flexible continuity, whereas items concerning interpersonal quality of care may be interpreted as relating to relational continuity of care (Table 2).

The questionnaires used in NHS surveys of general practices, outpatient departments and hospital inpatients, conducted by the Picker Institute, include items concerning interpersonal aspects of care

and continuity of care. Some of these items are very similar in content to the GPAQ items (Table 2), including, for example, items concerning the doctor's willingness to listen to the patient, explain diagnoses and tests, the doctor's knowledge of the patient's medical history and the patients' confidence in the doctor. Other items in the Picker Institute's questionnaire include: Was there one doctor in overall charge of your care? and Sometimes in a hospital a member of staff will say one thing and another will say something quite different. Did this happen to you? The Rand Patient Satisfaction Questionnaire (PSQ III; Rand Health, 2005) also includes related items (Table 2). In the US National Healthcare Quality Report (Agency for Healthcare Research and Quality, 2005), items about health providers 'listening carefully', 'explaining clearly', 'showing respect for what [patients] have to say' and 'spending enough time with [patients]' are included as indicators of patient-centredness. However, none of these measures builds on a conceptual model of continuity of care, nor do they provide a measure of continuity of care that is distinct from overall patient satisfaction. The inclusion of continuity of care items in the assessment of patient satisfaction is consistent with a suggestion that experienced continuity of care may be regarded as an aspect of patient satisfaction (Christakis, 2003).

Questionnaire measures

Questionnaire measures of continuity of care are now being reported and some examples are described below.

Chao (1988) described a generic measure of continuity of care. This includes 23 statements concerning patients' perceptions of access to doctors and the care provided by doctors. These items are most relevant in a US context.

Kowalyk *et al.* (2004) described a measure of continuity of care for cardiac patients. This included the subscales of 'heart condition explained', 'communication among providers', 'preparation for discharge', 'prehospital care', 'post-hospital review of treatment', 'conflicting information', 'information on medications' and 'knowledge of physical and dietary needs'.

Durbin *et al.* (2004) developed a measure for users of mental health services using Bachrach's model as a conceptual starting point. The resulting 30-item scale was identified as having three subscales based on factor analysis: 'system access', 'interpersonal aspects' and 'care team function'. These three subscales are similar in concept to the three dimensions of the GPAQ measure even though the item specification is very different.

Table 2 Questionnaire items relevant to continuity of care from routine patient-satisfaction surveys

Interpretation	GPAQ (National Primary Care Research and Development Centre, 2005)	NHS General Practice Questionnaire (Picker Institute, 2005a)	NHS Outpatient Questionnaire (Picker Institute, 2005b)	Rand Patient Satisfaction Questionnaire (PSQ III; Rand Health, 2005)
Longitudinal continuity	In general, how often do you see your usual doctor?			
Relational continuity	How do you rate …how much the doctor involved you in decisions about your care?	Were you involved as much as you wanted to be in decisions about your care and treatment?	Were you involved as much as you wanted to be in decisions about your care and treatment?	
	…how well the doctor explained your problems or any treatment that you needed?	Did the doctor explain the reasons for any treatment or action in a way you could understand?	Did the doctor explain the reasons for any treatment or action in a way you could understand?	Sometimes doctors use medical terms without explaining what they mean.
	…how well the doctor listened to what you had to say?	Did the doctor listen to what you had to say?	Did the doctor listen to what you had to say?	Doctors listen carefully to what I have to say.
	…the doctor's patience with your questions and worries?		If you had important questions to ask the doctor, did you get answers you could understand?	
	…the doctor's caring and concern for you?			The doctors who treat me have a genuine interest in me as a person.
		Did you have confidence and trust in the doctor?	Did you have confidence and trust in the doctor examining and treating you?	
			Did the doctor seem aware of your medical history?	

Table 2 ***continued***

Interpretation	GPAQ (National Primary Care Research and Development Centre, 2005)	NHS General Practice Questionnaire (Picker Institute, 2005a)	NHS Outpatient Questionnaire (Picker Institute, 2005b)	Rand Patient Satisfaction Questionnaire (PSQ III; Rand Health, 2005)
Flexible continuity	If you need to see a doctor urgently, can you normally get seen on the same day?	How do you feel about the length of time you had to wait for an appointment with a doctor?	Were you given a choice of appointment times?	It is easy for me to get medical care in an emergency/I find it hard to get an appointment for medical care right away.
Team and cross-boundary continuity			Sometimes in a hospital or clinic, a member of staff will say one thing and another will say something quite different. Did this happen to you?	
			Did hospital staff tell you whom to contact if you were worried about your condition or treatment after you left hospital?	

Nair *et al.* (2005) carried out focus groups with patients with diabetes who were attending a group health centre in Canada. They reasoned that a researcher-focused definition of continuity of care might 'miss important aspects that patients define as continuity of care'. They therefore asked patients to discuss continuity of care but the researchers 'bracketed their assumptions' and 'few parameters were placed on participants' discussion of continuity of care'. From the transcripts of the focus groups five factors were identified that enhanced or detracted from continuity of care. There were access to services, interactions with physicians, interactions with other health-care providers, personal self-responsibility and communication. While this study was not based in a conceptual model of continuity of care, it is interesting to note that the concepts of flexible continuity (access), relational continuity (interactions with physicians and other health-care workers) and informational continuity (communication) were identified in the data. However, the inclusion of self-care or personal self-responsibility was not justified with reference to a conceptual model of continuity of care, notwithstanding its importance for chronic disease management.

Dolovitch *et al.* (2004) subsequently described a questionnaire measure of continuity of care for type 2 diabetes (Diabetes Continuity of Care Scale) based on the qualitative data of Nair *et al.* (2005). The scale included 47 items divided among the five domains identified by Nair *et al.* (2005). In a small sample, the scale showed satisfactory internal consistency and moderate associations with clinical outcomes such as glycated haemoglobin and blood pressure. The scale may be viewed as having some potential. However, it suffers from the limitation that it was developed in the setting of a single health-care provider organisation and was not been field-tested with a sufficient number of patients.

2.7 Relevance for this study

This section has described how the concept of continuity of care has evolved. It went on to outline several multidimensional conceptual models of continuity of care. In general these models are not well grounded in empirical data and a key purpose of the SDO projects in continuity of care is to test and refine the concept of continuity of care by collecting appropriate data from patients and professionals. It follows that existing methods of measurement are poorly developed, and more appropriate measurement models are also an objective of this research.

Section 3 The context: diabetes, management of chronic disease and continuity of care

3.1 Importance of chronic illness

Chronic illnesses such as diabetes mellitus impose a significant burden on health services. The UK Department of Health estimated that 17.5 million people in Great Britain are living with one or more chronic diseases (National Statistics, 2005). The prevalence of chronic illnesses increases sharply with age (Figure 1). These numbers of people affected are expected to rise as life expectancy, and the proportion of the population entering older age groups, increases.

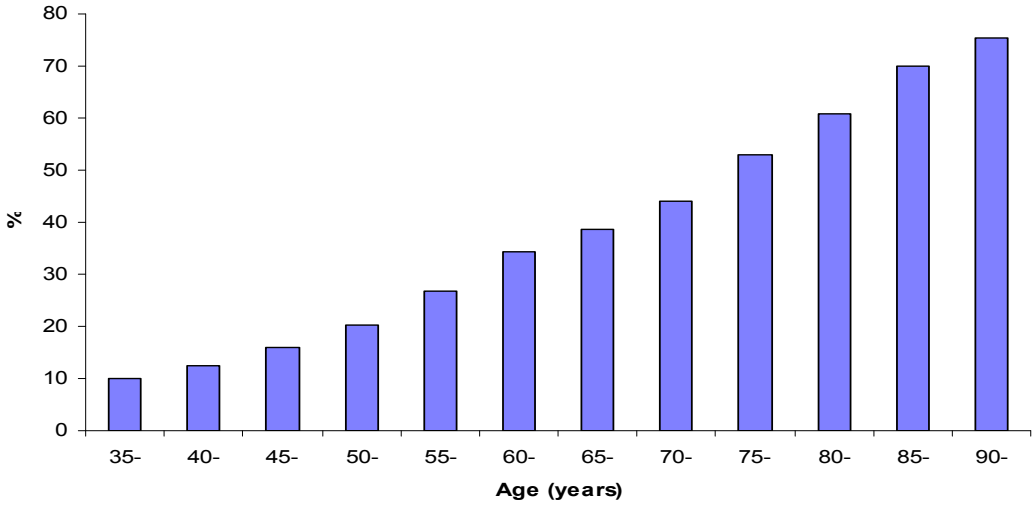


Figure 1 Long-term illness or disability which restricts daily activities by age, April 2001 in England and Wales

Source: National Statistics (2005).

Chronic diseases have important implications for carers and health and social care services. In the 2001 census nearly 2.8 million people aged 50 and over in England and Wales provided unpaid care for dependent friends or relatives. Caring imposed a significant burden, with 24% of carers over the age of 50 spending 50 hours or more a week caring, increasing to 50% at ages of 85 and over (National Statistics, 2005). Chronic diseases account for approximately 80% of general practice consultations, 60% of hospital bed days and some 78% of all direct health-care costs (Department of Health, 2005a). However, standards of care are often unsatisfactory and preventive medical care rarely achieves optimal outcomes. A report from the US Institute of Medicine referred to the gap between what is currently achieved, and what is achievable, as a 'quality chasm' (Institute of Medicine, Committee on Quality of Health Care in America, 2005). Bunker *et al.* (1994) estimated

that 2 years could be added to life expectancy across the population if available medical interventions were implemented more completely. Other studies suggest that utilisation of hospital inpatient services may be reduced through more effective preventive care of chronic diseases. As well as representing a major inefficiency, the failure to fully implement effective interventions for chronic diseases is a cause of inequity because difficulties with access and quality in services for chronic diseases generally disadvantage lower socioeconomic groups (Shi and Starfield, 2001; Gulliford, 2002).

3.2 Diabetes mellitus

Diabetes mellitus is a chronic condition which exemplifies many of the problems of chronic disease management. The more frequent form of the condition, type 2 diabetes, is characterised by hyperglycaemia resulting from a relative deficiency of insulin production and action (Stumvoll *et al*., 2005). It is commonly associated with obesity, high blood pressure and abnormal blood lipid profiles. The condition, which increases in frequency with age, has a long clinical course and the frequency of complications increases over time. These may result from acute metabolic disturbances; from atheroma affecting the large blood vessels causing myocardial infarction, stroke or peripheral vascular disease; or from disease of the microcirculation, eyes and peripheral nerves causing renal failure, visual impairment or foot disease (Stumvoll *et al*., 2005).

On a global basis, the prevalence of type 2 diabetes mellitus is increasing as a result of adverse trends in the major lifestyle risk factors, obesity and physical inactivity. The absolute numbers affected by diabetes are also increasing as a result of the increasing age profile of populations. The International Diabetes Federation has estimated that there were 194 million people with diabetes worldwide in 2003 and this figure may double by 2025 (International Diabetes Federation, 2003). There are few reliable population-based estimates of the prevalence of diabetes in the UK. Data for self-reported diabetes from the Health Survey for England show a striking increase in the prevalence of known diabetes between 1994 and 2003 (Figure 2; Sproston and Primatesta, 2004) but this may be partly explained by increased case ascertainment. In the 2003 survey, 3% of all men and 0.7% of women aged 35 and over had undiagnosed diabetes based on a fasting plasma glucose of 7 mmol/l or higher (Sproston and Primatesta, 2004).

Data from the Health Survey for England also provide an insight into the utilisation of health care by people with known diabetes: the estimated number of GP consultations per year was eight for men with diabetes and 12 for women; 60% of men and 67% of women with diabetes were taking four or more prescribed medicines; approximately 60% of diabetic subjects attended hospital as an outpatient in the last year and 3 or 4% were admitted to hospital as an inpatient (Sproston and Primatesta, 2004).

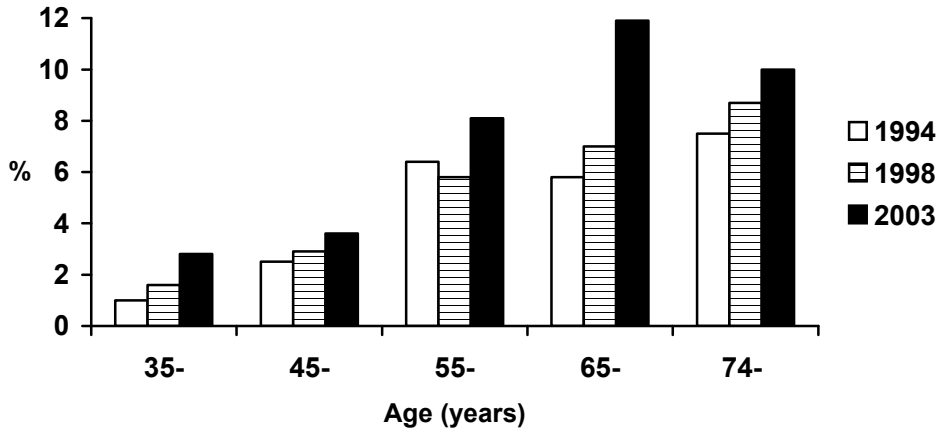


Figure 2 Trend in prevalence of self-reported diabetes diagnosed by a doctor in men from 1994 to 2003

Source: Health Survey for England (Sproston and Primatesta, 2004)

3.3 Clinical effectiveness in type 2 diabetes mellitus

There have been important recent advances in the potential for medical care to modify the course of diabetes. Perhaps most important is evidence from randomised controlled trials to show that the onset of diabetes may be prevented or delayed through lifestyle change to improve diet and physical exercise habits (Diabetes Prevention Program Research Group, 2002). There is also accumulating evidence from large, multicentre, randomised controlled trials that complications of diabetes may be prevented or delayed by means of drug treatment to intensify control of blood glucose, blood pressure or serum cholesterol levels (Table 3).

These secondary prevention trials show that long-term intervention in type 2 diabetes, with the aim of normalising metabolic abnormalities and blood pressure, can reduce clinical morbidity and mortality associated with the condition. These interventions are considered to have satisfactory cost-effectiveness when compared with other health-service interventions (UKPDS Group, 1998d; Gray *et al.*, 2000). They may also reduce the overall costs of complications of diabetes and increase the length of time free from complications (Gray *et al.*, 2000). Other evidence shows that regular self-care and monitoring for early signs of complications may reduce the occurrence and facilitate early treatment of complications such as foot disease (National Institute for Clinical Excellence, 2005).

Table 3 Results of major secondary prevention trials in type 2 diabetes mellitus

Trial	Intervention	Outcome	Relative risk reduction (95% CI)	Number needed to treat[a]
UK Prospective Diabetes Study (UKPDS Group, 1998a)	Intensified glucose control (insulin or sulphonylurea drugs)	Any diabetes-related endpoint	12% (1–21%)	196 patient years
		Microvascular endpoints	25% (7–40%)	357 patient years
UK Prospective Diabetes Study (UKPDS Group, 1998b)	Metformin	Any diabetes-related endpoint	32% (13–47%)	74 patient years
UK Prospective Diabetes Study (UKPDS Group, 1998c)	Intensified blood-pressure control	Any diabetes-related endpoint	24% (8–38%)	61 patient years
MRC/BHF Heart Protection Study (2003)	Simvastatin	Major coronary events	27% (21–33%)	31 patients for 5-year study duration

CI, confidence interval.

[a]*The number of patient years of therapy required on average to prevent one adverse outcome event.*

Diabetes care should be regarded as a complex intervention composed of several individual clinical interventions (Mulrow and Pugh, 1995). The organisational context, and the extent to which health professionals are able to educate and empower patients, are important in determining the extent of implementation of advice on lifestyle, self-care, self-monitoring and pharmacological therapy (Sheldon, 2001). Achieving potential health gains requires careful long-term follow-up, with monitoring of blood glucose, blood pressure and serum cholesterol levels, and appropriate education, counselling and drug treatment.

3.4 Organisation and delivery of care and continuity

There are several models for the organisation of diabetes care. The oldest is the hospital diabetes clinic, with patients attending for review several times a year. The hospital clinic provides access to specialist skills in diabetes but is traditionally overcrowded, offers short consultation times and limited interpersonal continuity of care because of the rapid turnover of staff in hospitals. Systematic review evidence has shown that prompted care in general practice, with registration, recall and review of the practice's diabetic patients (Greenhalgh, 1994),

may offer clinical outcomes that are at least as good as those achieved in the hospital clinic (Griffin, 1998). This has prompted a gradual shift towards primary care as the main location for routine care of patients with type 2 diabetes. Continuity of individual health professional has traditionally been an important feature of general practice care, but this has tended to diminish over time as group practices have replaced 'single-handed' practices and nurses and other allied professions have been employed as members of multidisciplinary primary care teams, often with special responsibility for the care of patients with diabetes and other chronic conditions.

Many audit studies have shown that horizontally organised systems in either primary care or hospital clinics offer very variable standards of care and, as a generalisation, optimal treatment outcomes are not achieved (Audit Commission, 2000). This echoes the finding of the US Institute of Medicine report which referred to a 'quality chasm' in the management of chronic diseases such as type 2 diabetes (Institute of Medicine, Committee on Quality of Health Care in America, 2005). There have been two main policy responses to these problems. The first has been the development and implementation of agreed standards of care for diabetes and other chronic conditions. In England, this is reflected in the publication of a National Service Framework for type 2 diabetes mellitus (Department of Health, 2001) and the negotiation of a new contract for GPs which identifies type 2 diabetes as a one of a number of key areas for the achievement of quality standards (Roland, 2004). The GP contract offers practices financial rewards for the achievement of quality standards. Second, there has been a growing interest in 'system redesign' and the development of vertically integrated systems for chronic disease management which help to reduce discontinuities at the primary/secondary interface by facilitating the sharing of specialist skills with care providers in primary care settings.

3.5 Management of chronic disease

The term chronic-disease management encompasses a range of models for organising care and these include several common elements (Box 2). There is a growing evidence base to support these models (Ouwens *et al.*, 2005). Renders *et al.* (2001) reported a systematic review of randomised controlled trials of interventions to improve the quality of diabetes care. Professional interventions included education of health-care professionals through organised meetings or office visits, development of clinical guidelines through local consensus procedures, and audits of clinical care with feedback of results. Organisational interventions generally included changing staff roles with extended roles for nurses or pharmacists, or changes to medical-record systems to prompt patient follow-up and support appropriate clinical decision-making. The reviewers concluded that most of these interventions had the potential to improve clinical process of care measures while the addition of patient education, or extension of nurses' roles, could lead to

better outcomes, including measures of blood-glucose control, blood pressure or serum cholesterol concentration.

Box 2 Key features of chronic disease management

Promotion of self-monitoring and self-care by patients

Providing care in the least-intensive setting and minimising unnecessary visits and admissions

Development of multidisciplinary teams

Integration of specialist and generalist skills across organisational boundaries

Use of information systems to facilitate integration and coordination of care

Adapted from Department of Health (2005a).

This type of evidence (Renders *et al.*, 2001) has been used to support attempts to improve the quality of chronic-illness management, especially in primary care settings, by redesigning care-delivery systems so as to provide more effective care to meet patients' needs. Wagner and colleagues (2001) described a Chronic Care Model which identified several key aspects on which such design efforts should focus: community resources such as exercise facilities, patient self-care support, clinical information systems and clinical decision support, and health-care organisation and delivery-system redesign. Wagner *et al.* (2001) argue that improving the quality of chronic-disease management generally requires 'comprehensive system change' because present systems of health-care organisation are generally oriented towards responding to acute episodes of illness rather than the provision of effective preventive clinical care over the long course of a chronic illness.

3.6 The policy context

The Chronic Care Model and related approaches to chronic-disease management have been fairly widely adopted in US health-care organisations (Rundall *et al.*, 2002) and have also been recommended for adaptation in England (Department of Health, 2005a). Impetus for change in England followed from the introduction of medical audit in the 1989 White Paper *Working for Patients*, which revealed widespread variations in the quality of care (Audit Commission, 2000). Changing managerial arrangements in primary care, with the organisation of general practices into primary care groups (later primary care trusts) following the White Paper *The New NHS* (Department of Health, 1997) led in 1998 to increasing clinical accountability in primary care. This trend was increased by the introduction of national standards through the National Institute for Clinical Excellence and National Service Frameworks (Department of Health, 2001) and the later implementation of a new GP contract in 2004 (Roland, 2004). In 2000 the NHS Plan (Department of Health, 2000) encouraged NHS organisations to experiment in systems redesign (or 'modernisation' as it became known) supported by the NHS Modernisation Agency, later the NHS Institute for

Innovation and Improvement. The result has been a rapid evolution of different models of care for diabetes and other chronic conditions (Audit Commission, 2000). These changes look set to accelerate following the publication of guidance on the 'patient-led' NHS in 2005 with its emphasis on choice, flexibility and diversity (Department of Health, 2005b).

3.7 Relevance for this study

The way that health services are organised for the management of chronic diseases is of great importance because of the substantial burden of disease and the increasing potential for effective intervention. Recent literature reviews have sought to identify organisational solutions which have been shown to be effective across a range of chronic illnesses. The problems of delivering effective care for diabetes mellitus are similar to those experienced by patients with heart failure, stroke, chronic respiratory diseases and musculoskeletal conditions and arthritis. Present policies to improve the organisation and delivery of services for patients with diabetes may have significant implications for continuity of care. In general, current developments would be seen to promote the seamless service as an ideal for diabetes care, with management continuity being achieved through the integration of staff with specialist skills into models led by primary care teams.

Section 4 Current evidence: continuity in diabetes care

4.1 Objective and methods

This section summarises previous research that focused on the measurement of continuity of care in patients with diabetes and evaluated the relationship between continuity of care and health outcomes or patient satisfaction in type 2 diabetes mellitus.

We implemented searches using text terms and subject headings for 'diabetes mellitus' and 'continuity of care'. References were identified using Medline from 1966 to 2005 (148 citations) as well as PubMed (178 citations), Science Citation Index (37 citations) and Google Scholar (100 out of 8960 citations reviewed). We excluded papers concerned with the transition from child or adolescent services to adult services, papers concerned with experiences of First Nation populations and studies which evaluated more general questions of quality of care. We screened the remaining abstracts for relevance and retrieved relevant remaining papers. We screened the cited references from these papers. We also evaluated published general literature reviews on continuity of care as provided by Freeman *et al.* (2000) and by Haggerty *et al.* (2003), who provide an extensive bibliography. Previous empirical work concerning the definition and measurement of continuity of care and the nature of its associations with patient satisfaction, clinical outcomes and resource use has been systematically reviewed recently by Saultz and coworkers (Saultz, 2003; Saultz and Albedaiwi, 2004; Saultz and Lochner, 2005).

4.2 Continuity and patient satisfaction

Saultz and Albedaiwi (2004) implemented a systematic review to determine whether interpersonal continuity of care was associated with patient satisfaction. They identified 20 primary research studies including four randomised trials, four cohort studies and 12 cross-sectional studies. The majority of the studies, including 19 out of 22 separate reports, suggested that interpersonal continuity of care was associated with increased patient satisfaction. None of the studies suggested that there were aspects of satisfaction which were negatively associated with continuity of care. However, there was considerable diversity and lack of standardisation in the measurement of both continuity of care and patient satisfaction. Continuity of care was most frequently assessed using consultation-based measures such as the continuity-of-care index and its variants but in some instances patient-based assessments of interpersonal continuity of care were employed. The finding that patient-based measures of continuity may be associated with satisfaction is consistent with the view that experienced continuity of care is an aspect of patient satisfaction. This highlights a need for

greater precision in the definition and measurement of continuity of care.

4.3 Continuity and clinical outcomes

Saultz and Lochner (2005) reported the findings of a systematic review that investigated whether continuity of care was associated with outcomes of health care. Their review identified 41 reports from 40 studies including seven clinical trials, 14 cohort studies, 17 cross-sectional studies and two case-control studies. Continuity of care was measured in 10 different ways including provider continuity indices, the duration of relationship with primary physician and patient questionnaires. In the randomised trials, subjects were randomised to attend clinics which offered continuity of provider or usual care. A range of outcomes was examined including delivery of preventive care, hospital admission rates or clinical management indicators for chronic illness or maternity care. There were 81 outcomes reported and 51 of these showed more favourable values in association with continuity of care. There was also evidence of lower resource utilisation in association with continuity of care, especially because fewer tests were ordered and there were fewer emergency-care visits and hospital inpatient admissions.

A similar but less comprehensively described review was reported by Cabana and Jee (2004) with similar conclusions. While both of these reviews found that continuity of care was associated with better outcomes, it is important to recognise that the outcomes found to be associated with continuity were measures of health-service utilisation such as hospital admissions, emergency-room visits and the uptake of preventive medical interventions, including immunisations and screening tests. Saultz and Lochner (2005) found that there was little evidence that continuity of care was associated with more specific health outcomes in chronic illnesses. They recommended that further studies are required to evaluate whether continuity of care is associated with health outcomes and that these should utilise better measures of interpersonal continuity.

4.4 Continuity and diabetes mellitus

Some studies have specifically investigated whether continuity of care is associated with favourable changes in the delivery of diabetes care.

4.4.1 Diagnosis

Koopman *et al.* (2003) analysed data from NHANES III to evaluate whether patients who reported having a usual provider of medical care were less likely to have undiagnosed diabetes, hypertension or hypercholesterolaemia. Analyses were adjusted for variables associated with continuity of care including sex, age, race, insurance status, education, health status, number of outpatient visits and income. Among

all subjects with diagnosed and undiagnosed diabetes, subjects were less likely to have undiagnosed diabetes if they identified a usual care provider (odds ratio 0.30, 95% CI 0.10–0.95). However, reporting a usual site of care without a usual professional was not associated with reduced undiagnosed diabetes. Subjects who had not visited a physician in the last year were more likely to have undiagnosed diabetes (odds ratio 3.80, 1.46–9.93). In adjusted analyses, having a usual care provider was not an independent predictor of undiagnosed hypertension or hypercholesterolaemia. In the US health system, continuity of health-care provider may be an indicator of access to health care and the observation of Koopman and colleagues fails to fully distinguish questions of access and continuity.

Broom (2003) suggested that discontinuities in care may sometimes be associated with establishing a diagnosis of diabetes. She interviewed Australian adults who were diagnosed with type 2 diabetes. She found that more than half of subjects had their diabetes diagnosed under conditions of discontinuity, such as a hospital admission, change of doctor or a patient initiative. Broom suggested that familiarity may sometimes 'breed neglect' in terms of reduced medical vigilance leading to possible delays in diagnosis.

4.4.2 Process of care measures

Parchman and Burge (2002) analysed cross-sectional data for 397 patients attending six clinics in south Texas. Continuity was measured using the provider continuity index. There was a weak association between the provider continuity index and a composite measure of quality of care. Patients who had seen their usual provider in the last year were more likely to have had a foot examination, blood-pressure measurements or a lipid analysis in the last year. The study shows that when continuity of care is evaluated as a process of care, it may be associated with other process measures.

In a larger study utilising cross-sectional data for 1795 subjects from a national private health plan, Gill *et al.* (2003) found that provider continuity in patients with type 2 diabetes was not associated with frequency of testing for glycosylated haemoglobin, lipids or eye examinations. Gill *et al.* excluded subjects with fewer than two visits in the last 12 months because they observed that continuity of care could not be defined for these subjects. This methodological difference may explain the lack of consistency with the findings of Parchman and Burge (2002).

4.4.3 Self-care behaviours

In a different study, Parchman *et al.* (2002) interviewed 256 adults with type 2 diabetes on two occasions 19 months apart. The stages of change model was used to assess alterations in subjects' self-care behaviours between baseline and follow-up in relation to provider continuity. The authors found that patients who advanced through stages of change for

diet had higher provider continuity scores than those who did not. This pattern of association did not hold for exercise habits. The authors concluded that the observed association might account for an association between provider continuity and lower HbA1c concentrations. In a cross-sectional interview survey of 166 diabetic clinic attenders, Sherina *et al.* (2003) found no association between provider continuity and self-care behaviours, including home monitoring, diet control and sugar avoidance, exercise, drug compliance or smoking.

4.4.4 Intermediate outcomes

A number of studies have investigated a possible association between continuity of care and blood-glucose control (Table 4). Mainous *et al.* (2004) analysed data collected from adult diabetic subjects by the NHANES III. After adjusting for a number of confounding variables (see Table 4 for details), subjects who reported a usual source of care had greater odds of having HbA1c values below the cut-off points of either 6 or 7%. There was no difference in odds between subjects with a usual professional and those with a usual source of care but no usual professional. There was no difference in blood pressure or lipid control according to source of care. The authors suggest that when care is fragmented between different providers then diabetic control may be compromised. However, in the US context, this observation may relate to questions of access to health care because having a usual source of care may be an indicator of satisfactory access even though adjustment was made for insurance coverage. It would appear difficult to generalise about the UK context from this observation, except perhaps in the case of marginalised groups such as homeless people or new refugees.

In Parchman and colleagues' cohort study (Parchman *et al.*, 2002) greater provider continuity was negatively associated with change in HbA1c during the time of study. The authors suggested that this might be accounted for by more favourable dietary self-care behaviour in patients who experienced greater continuity of care. Alazri and Neal (2003) analysed data for the General Practice Assessment Survey (GPAS) for 106 patients from two general practices in Leeds, England. They found that HbA1c values were negatively correlated with each of the GPAS measures, with the highest correlation coefficient (0.328) being with the continuity-of-care scale. Overland *et al.* (2001) analysed data for 479 patients attending a hospital diabetes centre in Sydney, Australia. Continuity of care, in terms of duration of registration with a GP, was not associated with HbA1c. Hanninen *et al.* (2001) reported an interview survey of 381 type 2 diabetic patients from one district in Finland. Continuity of care, in terms of consulting with the same GP for 2 years, was associated with higher glycated haemoglobin. This might have been explained by greater duration of illness in the group with high continuity, although adjusted analyses were not reported. Higher scores for health-related quality of life in association with greater continuity, using the short-form (SF)-20 measure, were an unexpected finding in this study.

While the different effect measures employed in studies reported to date prevent a quantitative synthesis, taken together the results suggest a lack of association between continuity of care and measures of blood glucose control in type 2 diabetes mellitus. This finding will be discussed further in a later section of the report.

4.5 Limitations of previous work

Previous work on continuity in diabetes care is of limited scope and quality for several reasons, as follows.

Definition and measurement of continuity of care: few studies have included an explicit definition of continuity of care. Most studies appear to refer to concepts of longitudinal, relational or interpersonal continuity with measurement in terms of provider continuity indices. As discussed above, these provide very limited measures of continuity of care. There is a need for studies which employ more sophisticated measures of continuity in both the experience and delivery of care.

Confounding variables: previous studies have reported associations between continuity and intermediate outcomes but there has generally been very poor control for confounding variables. The duration of the diabetic illness is strongly associated with increasing glycated haemoglobin levels and the development of long-term complications of diabetes but may also be associated with assessments of continuity of care. In US studies, continuity of care may depend on subjects' eligibility and access to health care. In most settings, socioeconomic status may modify patients' ability to obtain satisfactory continuity of care.

Temporality: the majority of studies reported to date have been cross-sectional in nature. Cross-sectional data do not permit the evaluation of temporality.

Publication bias: the extent of publication bias has not been evaluated and remains difficult to assess because of the diversity of the outcome measures that have been utilised.

4.6 Relevance to our study

This review of previous work shows that there is a need to develop new measures of continuity in the experience and delivery of care for chronic illness and to apply these in well-designed studies to evaluate the relationship between continuity and processes and outcomes of care.

Table 4 Summary of previous studies evaluating associations between continuity of care and blood-glucose control

Study	Design	Subjects and setting	Measures	Adjustment	Finding
Alazri and Neal (2003)	Cross-sectional	106 patients from two general practices in Leeds, England	GPAS questionnaire; HbA1c	Age, sex, ethnic group, duration of diabetes, presence of complications	Continuity of care associated with lower HbA1c; correlation coefficient −0.328, $P<0.01$.
Hanninen *et al.* (2001)	Cross-sectional	381 subjects with type 2 diabetes aged less than 65 years, resident in one district in Finland	Attending the same GP for at least 2 years; HbA1c	None	Difference in HbA1c: 8.9 versus 8.3%, $P=0.041$, continuity was associated with higher HbA1c.
Mainous *et al.* (2004)	Cross-sectional	1400 adults with diabetes in the US NHANES III	HbA1c ≤6 or ≤7%; having a usual source of care; having a usual professional	Age, race, education, insurance coverage, health status, income, duration of diabetes, number of consultations in last 12 months	Subjects with usual site of care had higher odds of HbA1c ≤6 or ≤7% than those with no usual site of care; subjects with usual professional had similar glycaemic control to those with usual site but no usual professional.
O'Connor *et al.* (1998)	Cross-sectional	1828 adults with diabetes enrolled with a US health-maintenance organisation	Having a 'regular health-care provider'; HbA1c	Age, sex, duration of diabetes, educational level	HbA1c similar in 'regular provider' and 'no regular provider' groups.
Overland *et al.* (2001)	Cross-sectional	479 patients attending hospital diabetes centre	Length of time under the care of referring doctor; HbA1c	None	No association between HbA1c and length of time under referring doctor
Parchman *et al.* (2002)	Prospective cohort study	256 patients older than 18 years with diagnosed type 2 diabetes, attending five community health centres in Texas	Provider continuity score; HbA1c	Number of visits, baseline HbA1c, duration of diabetes, duration of follow-up, stages of change for diet	Negative association between continuity and HbA1c; correlation coefficient −0.25, $P<0.001$
Pereira et al. (2003)	Matched-cohort study	3931 patients whose primary care physician (PCP) left the practice and 8009 control subjects whose PCP remained	HbA1c; whether the patients' PCP left the practice	None	No difference in HbA1c over time for patients whose PCP left the practice and those whose PCP did not leave
Sherina et al. (2003)	Cross-sectional	166 diabetic patients in hospital-based family medicine clinic in Malaysia	Usual provider continuity index (UPCI); HbA1c	None	No association between UPCI and HbA1c; correlation coefficient 0.054, P=0.505

Section 5 Aims and objectives

5.1 Aims

This mixed-methods study aimed to evaluate and measure patients', carers' and providers' experiences of continuity of care in type 2 diabetes and to determine whether continuity of care is associated with clinical and patient outcomes.

5.2 Specific objectives

1 To hold in-depth interviews with diabetic patients in order understand their values and experiences with respect to continuity in diabetes care.

2 To develop an experience-based questionnaire measure of continuity of care in type 2 diabetes and to test the reliability and validity of the questionnaire measure in quantitative data.

3 To evaluate changes in diabetic patients' experience of continuity of care over time and to evaluate whether these are associated with clinical and patient outcomes.

4 To evaluate the views and experiences of carers and South Asian patients.

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

Table 5 Demographic and social indicators for the study area

	PCT-A	PCT-B	England and Wales
Jarman UPA score (1991)	48	56	0
Indices of Multiple Deprivation (median, range for 21 wards)	35 (25–48)	38 (18–46)	
Owner-occupied	37.2%	31.4%	68.9%
Overcrowding indicator	22.0%	25.3%	7.0%
White	62.4%	63.0%	91.3%
Black Caribbean	21.1%	8%	
Black African	11.6%	16.1%	
Other Black	2.1%	1.8%	

PCT, primary care trust.

5.3 The local context

The study was set in two inner-London primary care trusts which are coterminous with inner-London boroughs which have young, mobile and ethnically diverse populations and high levels of deprivation (Table 5). Primary care in the area is characterised by a high proportion of small practices with less well-developed staffing and facilities when compared to the national average (Adams *et al.*, 2003).

Whereas the characteristics of the local population make this a relevant area for health research, the setting also poses problems of non-participation and non-response. Population surveys in this area of inner London typically give response rates in the range 30–40%. Practice-list inflation in the area has traditionally been rated at over 20% (Millett *et al.*, 2002) and this may have the effect of exaggerating the problem of non-response when general-practice-based sampling frames are used. Goyder and Botha (2001) found that non-responders to a diabetes postal survey were located in more deprived areas, and were more likely to be attending hospital diabetes clinics. This suggests that there is usually some potential for bias from non-response. In view of the anticipated difficulty of non-response, we decided to conduct a home-interview survey in order to optimise the quality of data obtained from participating subjects.

Fieldwork was carried out in practices located in the northern parts of two adjacent primary care trusts in the time leading up to, and after, the implementation of the new GP contract in April 2004. Both primary care trusts were undertaking a considerable amount of development work with general practices in order to prepare for the implementation of the new contract. At the same time, a shared-care scheme for diabetes was being implemented in one of the primary care trusts in association with the diabetes service of the local teaching hospital (Mohiddin *et al*., 2003).

The shared-care scheme included the appointment of a full-time diabetes specialist nurse who liaised with practices and provided training and support for practice staff, especially practice nurses. In addition, dedicated dietitian and podiatrist sessions were funded to provide training and advice in primary care. All of the specialist staff engaged with practices individually and collectively, in the context of organised training sessions, in order to develop skills in diabetes care and to address special problems and difficult cases. At the same time, efforts were made to discharge uncomplicated patients with type 2 diabetes from follow-up at the hospital diabetes clinic, while easy-access appointment slots in the clinic were established. The information technology strand of the project was designed to provide general practices with read/write access to the hospital diabetes electronic patient record (Diabeta3). In addition, a website was developed to provide access to locally developed guidelines and other

relevant materials. General practices varied in the intensity of their participation in the shared-care scheme. In the other primary care trust, structured sharing of specialist skills was not systematically developed. Thus the setting for the study provided a considerable diversity of care delivery and associated patient experiences of continuity of care.

Section 6 Experienced continuity of care: patients' values and experiences

6.1 Summary

Objective: to understand diabetic patients' values and experiences with respect to continuity in diabetes care.

What we did: we held in-depth semi-structured interviews with 25 type 2 diabetic patients from 14 general practices. Interviews were transcribed and analysed thematically using a framework approach.

What we found: patients valued receiving regular reviews with clinical testing and provision of advice longitudinally over time. They valued a relationship with a named 'usual' professional who knew and understood them, was concerned and interested, and took time to listen and explain. Patients were more likely to trust and confide in a usual professional. Continuity was facilitated if patients could make and change appointments flexibly in response to changing needs or unexpected situations, or speak to their usual professional when they needed advice. Patients discussed questions of consistency and coordination between different members of staff, and between hospital and general practice or community settings. Patients who only received hospital-based care for their diabetes described less favourable experiences of seeing usual providers and less flexibility in adapting to changing needs.

What we conclude: these empirical data from patients' are consistent with four dimensions of experienced continuity of care: longitudinal, relational, flexible and team and cross-boundary continuity. Problems of discontinuities of care are most likely to arise when the patient's health status changes, or if patients transfer between different professionals or providers.

6.2 Objectives

This part of the study aimed to investigate patients' values and experiences with respect to continuity of care in type 2 diabetes in order to provide the basis for a measure of continuity of care grounded in patients' experiences.

6.3 Methods

6.3.1 Subjects

All 50 general practices in the study area were sent letters inviting them to take part in the study and 14 practices agreed to participate. We used practices' lists of registered patients with type 2 diabetes and

selected a sample of 30 patients for interview aiming to draw equal numbers from three ethnic groups: white; Black Caribbean and Black African; and Indian subcontinent descent. Letters and an information sheet were sent to patients inviting them to take part in the study. The initial response rate was low (5/30) and follow-up telephone calls were therefore made to each patient 3 weeks after the initial mail-out. The study was approved the by Research Ethics Committee of Guy's Hospital and subjects gave written informed consent to participation.

6.3.2 Interviews

Interviews were held in patients' homes between January and June 2003. The interviews were semi-structured and lasted between 30 and 120 minutes, with the majority lasting about an hour. All interviews were tape recorded. Interviews began by asking patients general open-ended questions concerning their diabetes diagnosis and the type of care they were currently receiving. Other questions and probes were loosely based on a topic guide that was informed by the literature as well as four exploratory interviews that took the form of fairly open discussions of respondents' diabetes care to identify issues of importance for respondents and appropriate probes.

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

Maintaining rapport was of paramount importance so as to encourage interviewees to elicit their experiences. The most effective techniques involved creating a climate for mutual disclosure and empathy. This meant that on occasions the researcher displayed a willingness to share information about her life, culture, family and her research role. Sometimes it was important to let patients talk about subjects that were outside the context of the study such as family disputes, the loss of family members or childminding problems. Listening to their concerns was also useful because it showed respondents that their views and experiences mattered and were of interest. Sometimes these disclosures were useful because they provided an insight into

their lives, behaviour and reactions to specific events. For example, one patient talked about the death of his mother and his difficulty in coping with his loss. He went on to describe how his doctor had visited him regularly, spent time talking to him and checked on him to see if he was okay. This act of 'kindness' as he describes it was an important part of developing and sustaining his relationship with his doctor. Respondents welcomed the chance to share their experiences, for some patients living alone or those less mobile this meeting appeared particularly valuable; one patient revealed that he wasn't likely to see any one since he had became unwell and couldn't get out and about.

Maintaining an awareness of how the interview was going and how the interviewees were reacting to questions was also an effective way of building rapport. Providing reinforcement and positive feedback made interviewees feel that the process was worthwhile. Occasionally, to protect the interviewees' privacy, tapes were temporarily stopped and some interviews were moved to a more suitable room when unforeseen loud background noises occurred or if other people entered unannounced.

During the interview points were fed back to the respondent to check the researcher's understanding and interpretation. Interviewees were also asked to provide examples and probed for a more detailed explanation of their account. Notes were made after each interview to record the researcher's feelings and thoughts about the interviews and any distinct non-verbal behaviour.

6.3.3 Analysis of transcripts

All interviews were tape recorded and transcribed verbatim. The transcripts were anonymised, entered into QSR N6, a computer software package for the management of qualitative data, and analysed thematically. This initially involved coding segments of transcripts that described patients' views and experiences of their diabetes care. These patient-based items were then reviewed by the three authors and grouped into dimensions of continuity of care that were informed by a review of the literature. The mapping of items involved discussion of some individual items to reach a consensus regarding the allocation of items to specific dimensions and involved consideration of contextual factors from the transcripts.

6.4 Interview findings

Twenty-five people with diabetes were interviewed. All had type 2 diabetes and spoke English (see Table 6). Ten respondents were receiving diabetes care from their general practice only, 11 were receiving 'shared' care from both the hospital and general practice, four patients received diabetes care only from the hospital diabetic clinic.

Table 6 Characteristics of respondents

Variable	Category	Frequency
Gender	Male	17
	Female	8
Ethnicity	White	17
	Black Caribbean/African	4
	Indian subcontinent	1
	Other	3
Age (years)	Mean (range)	67 (41–86)
Living arrangement	Lives alone	14
	With other(s)	11
Housing tenure	Owner-occupied	14
	Rented	11
Duration of diabetes (years)	Mean (range)	7 (1–27)
Type of diabetes care	GP	10
	Hospital	4
	Shared care	11

The main aims of the analysis were to refine the conceptual model and identify themes and experiences that were associated with different aspects of continuity of care. Analysis of the main themes from respondents' accounts indicated that these corresponded fairly closely with Freeman *et al.*'s categories of longitudinal, relational, flexible and team and cross-boundary continuity. However, whereas Freeman and colleagues identified a broad category of 'patient experiences' and sub-divided aspects of professionals' experience of delivering continuity of care into longitudinal, flexible, relational, team and cross-boundary and informational continuity, in our study most of these provider-based dimensions also appeared to be applicable to the patient data. The main exception was the dimension of informational continuity, which refers to efficient systems of information transfer, as patients had little knowledge of these processes. However, patients commented on their experiences of problems of communication and if this referred to communication between professionals and across care boundaries was allocated to team and cross-boundary continuity, whereas if it referred to communication with their usual professional and their ability to build and sustain a relationship it was allocated to relational continuity. In a few cases it was difficult to allocate observations between the continuity categories because dimensions are interrelated and some experiences illustrated several dimensions simultaneously. In these cases our emphasis in allocating to a specific dimension involved considering the broader context in which the item occurred. For example, the number of times a patient saw a usual professional was allocated to longitudinal rather than relational

continuity to take account of the temporal dimension. The types of patient experience classified within the four categories of longitudinal, relational, flexible and team and cross-boundary continuity are described below.

6.4.1 Experienced longitudinal continuity

Patients described the ongoing care they received from the time of diagnosis or during episodes of illness. This included making opportunistic visits to their doctor or attending regular check-ups where a number of clinical tests were carried out. This ongoing care corresponds with the notion of longitudinal continuity.

> *…at the practice – on a regular basis, every couple of months I go there, they check everything, my blood, blood pressure…and every so often, I think it's every year, she checks my feet with a…it's like a little prodder – but she only does that once every year really.*
>
> (PA3; shared care)

In some cases patients described problems of the lack of such ongoing care:

> *I used to go to my doctor every 6 months, he would check everything and they would give me appointment date for my next check-up but he's left now and there is someone else doing it. I haven't received anything, no one has bothered. I have to go up there myself. It's really gone down hill.*
>
> (PA5; GP care)

During the initial months after diagnosis, consultations with a consistent, usual care provider were valued because they helped patients increase their understanding of the condition and its treatment. Experienced longitudinal continuity can thus be viewed as a necessary condition for establishing a relationship with their usual professional (relational continuity).

> *Nurse K. She's the only one I see for diabetes. I used to see my own doctor but she said 'I think we'll put you with nurse K because nurse K deals with diabetes all day'. Everybody who has got diabetes goes to see her. So now she does all the test and checks.*
>
> (PA8; GP care)

Longitudinal continuity was also viewed as necessary for delivering personally tailored advice.

> *Whenever I go there she checks my diary and gives me tips on what I should eat. If I have problems with my machine she helps me.*
>
> (PA4; shared care)

6.4.2 Experienced relational continuity

Another major theme was the importance that most patients attached to seeing the same professionals (generally a doctor or nurse) on a regular basis, as this meant that they got to know (and were known

by) this person, with positive implications for their care. In some cases patients were critical of their lack of a usual professional or the quality of the care they provided:

> *I don't think I'm getting good care now because only recently I've been seeing this nurse, she doesn't do all the things the other nurse used to do…I'm not sure whether she knows what she's doing, she looks too young.*
>
> (PA22; GP care)

Problems of doctors' lack of familiarity with the patient were more frequent in the hospital clinic setting:

> *…sometimes when I go to the doctor I find that I have got to remind them or tell them what has happened. Because I only go once a year and you don't always see they same person, well I'm certain I won't see the same person so they are not likely to know what's happened because they look to me like they don't know.*
>
> (PA11; hospital care)
>
> *It's always someone different every time you come here, you never get to see the same person twice.*
>
> (PA12; hospital care)

Positive aspects of relational continuity identified from patients' accounts included the benefits for the medical aspects of their care:

> *Personally I think it's a good thing to see the same person, they know your problems, if you've had a problem before it will be fresh in their minds…when I've seen different staff they don't know what's going on, you have to constantly remind them.*
>
> (PA2; shared care)
>
> *…it's a benefit to the patient to have the same doctor. After all, the doctor, although there are records in front of the doctor and on the screen, there's nothing better than knowing what medicine has been tried, and that's been tried and that's no good – without having to go back and fathoming it all out.*
>
> (PA7; GP care)

Patients also identified the importance of their usual professional knowing and understanding them as a person:

> *I have a good relationship with my doctor, we understand each other…I've been with him for the last 30 years, he knows me and that's not just my diabetes, that's everything.*
>
> (PA6; GP care)
>
> *…and I mean he wasn't just interested in sort of how my diabetes was doing, he was interested in me as a whole person.…*
>
> (PA5; shared care)
>
> *Maybe it's mistrust on my part. Well apart from Nurse T now, I don't know the doctor that I'm seeing. I don't know how interested he is in diabetes. The one or two occasions that I have seen him, he hasn't got the chance to get to know me, I know that. But I did just sort of get the*

> *feeling that it was a question of getting me in and out as quickly as possible. I didn't feel involved, I'm not sure that he will be as thorough.*
>
> (PA6; shared care)

Patients who knew their care providers well explained that this gave them more confidence and trust:

> *Well, I'm satisfied seeing Doctor A and Nurse A, you do what they tell you because they look out for you, they listen to you and you believe in them. I've got trust in them I feel better for it.…*
>
> (PA4; shared care)
>
> *I knew my doctor for a long time, so when he explained things to me, he gave me confidence that I would be fine so long as I looked after myself, you know. I must admit I was frightened but he talked to me, spent a lot of time talking to me, until I understood and felt better.…*
>
> (PA2; shared care)

This last illustration draws attention to another theme, the care provider listening and giving enough time to talk:

> *Dr C never rushes you. He rushes about, but if you've got something to say, he will listen to you and he will ask you questions. And he'll talk to you and, yes he's alright. As I say, he rushes about himself, but no, he doesn't rush you.*
>
> (PA; shared care)

Patients who knew their professional well were also more able to disclose and discuss personal concerns and feelings and for the doctor therefore to be aware of these broader aspects of the patients' experiences:

> *Things that I maybe would not talk with you I talk with him. Things I would not talk with anybody, even the nurse, I would not discuss with her, I would discuss with him so he knows my actual psychological feeling about diabetes and what implications or what feelings I have about it.*
>
> (PA3; GP care)

Another important aspect of good communication was the ability to explain things to patients.

> *She listens to you and she explains things and she doesn't rush in and out. She's a very good doctor. The nurse is very good. I feel I can sit and talk to her more because I've known her longer. The doctor's good, and as I've said to you, she listens and she explains things to you.*
>
> (PA15; shared care)
>
> *…whenever I go up there and get checked out she doesn't really go through the things with me, all she says is that I'm okay. You know I really wish she'd go through things in more detail and tell me what's going on.*
>
> (PA18; GP care)

Thus relational continuity involved not just the degree to which professionals were familiar with their patients but also the extent to which they knew the patient's medical history and treatment plans,

were prepared to listen, were able to explain medical procedures and tests clearly, inspired confidence and involved patients in decisions about their treatment. Most patients said that seeing a usual professional was an important aspect of good care; however, not all patients were able to identify a usual provider. Seeing a usual provider was important to patients during the early months after diagnosis and for those experiencing complications and difficulties in accepting and managing their diabetes. Usual providers were trusted and perceived to be more knowledgeable compared to other professionals.

6.4.3 Experienced flexible continuity

An important feature of continuity of care identified by patients was the ability to get the appropriate assistance and support when required. Since patients' care needs varied and changed over time it was important to them that staff responded quickly. This can be related to the concept of flexible continuity (Bachrach, 1981; Freeman *et al*, 2000), which requires services and staff to be flexible and adjust to the needs of the individual over time. This may include the patient consulting with a chosen professional:

> *The nurse…always makes time for me. If I phone in the she will always call me back on the same day. I have been able to see her when I've needed to.*
>
> (PA3; shared care)
>
> *You don't have a choice in who you see, if you're lucky then you might see the same nurse twice. If you're not well, you know if something's wrong, then you're more likely to see the same consultant, but even that's not guaranteed.*
>
> (PA10; hospital care)

Flexible continuity was also manifest in making and changing appointments in response to changing needs and circumstances.

> *They're very good here you know, whenever I need to see the doctor I can just phone up and get a appointment when you want, you don't have to wait long and they ask you, you know, what's it about so if you need more time then they will book you a double appointment.*
>
> (PA13; GP care)
>
> *You don't make appointments, they send you a letter with an appointment date…there's been one time when I couldn't make it and I phoned and cancelled. Then I had to wait over 6 months before they gave me another appointment, it was ridiculous. So now I try and do me best not to cancel because it takes them so long to book you in again.*
>
> (P14; hospital care)

Flexible continuity was also evident in the response to unexpected situations and emergencies.

> *Sometimes I have to phone them up if I've got a cold and say, 'What can I take for a cold?' because I take so many tablets. It's like anything else, they will say, 'Hold on, I'll see if they're available' – because they*

can't talk – like if she answers the phone when I'm there, she might just say, 'Yes okay'... But sometimes you know, it might be the receptionist, and she'll say, 'They're very busy at the moment, they will call you'. And they always do.

(PA8; shared care)

When I came from my holiday, my machine was wrong. I went straight to the hospital, and the same hour, they gave me a new blood-test machine without anything. No delays. Because I was going to buy one anyway. But, you know, when I came I didn't know exactly how it works, because mine was much easier. I went to my surgery there and I had appointment like for tomorrow to see a nurse and she explained to me, 'well you do this and it will be alright' – and it worked. I have no difficulty.

(PA16; hospital care)

Patients associated greater satisfaction with being able to make and rearrange appointments quickly, seeing their chosen health-care professional and readily speaking to staff in an emergency. Most patients experienced some degree of flexible discontinuity (long waiting times, problems and delays in getting appointments and seeing staff of their choice) but patients who had a good relationship with their provider(s) were more willing to adapt to these difficulties attributing discontinuities to organisational problems.

6.4.4 Experienced team and cross-boundary continuity

Another aspect of continuity of care identified by patients was their experiences and perceptions of how well their overall care was coordinated. Since patients reported seeing different health-care professionals in different care settings, coordination of services was important to them. This relates to Freeman's notion of team and cross-boundary continuity.

The importance of coordination of care applied to care received from different professionals in the same setting:

They talk to each other, sometimes the doctor will come in while I'm seeing the nurse. Sometimes the nurse will go in and talk to the doctor to check on something, it may be about my results or medication. Something like that.

(PA2; shared care)

This was also evident in the degree of coordination of care between different organisational settings:

As I say, they sorted it out for the district nurses to come every day and that, check-up and that carry on. If I had to go up to get a check-up at the surgery department, they would have a car organised for me to take me up there and bring me back.

(PA19; shared care)

Well, when I went up, when I had the first appointment with him, it was August, then it was cancelled until September, and things weren't

> *getting any better. In the meantime, I was seeing the Chiropody Department and they could see it was getting worse and worse, but like everything, things get put back. So that was getting worse. Then when I went in, in October, it's going to be a 50/50 chance of healing. That's after taking the toe off.*
>
> (PA16; shared care)

Team and cross-boundary communication are underpinned by the flow of clinical information. This featured in some patient's accounts:

> *I feel they know me, they know what's going on with my diabetes because sometimes when I've been to the hospital my doctor tells me that he's received the results, he goes through them with me, what they have said and what should be done.*
>
> (PA4; shared care)
>
> *Just recently I have had to change doctors because the doctor that I have been seeing has retired. When I went to the new practice and registered and went to see the nurse, they told me they didn't have any information on me and my medical records hadn't turned up.*
>
> (PA15; shared care)

However, some patients acknowledged that they were not able to judge whether clinical information was available:

> *They must talk to each other, otherwise how would they organise the services? They all say the same thing, I mean they all have their own area but when they have given me advice it has been the same.*
>
> (PA23; hospital care)

Patients' accounts did not provide a large amount of material regarding this dimension, as they believed the organisation and coordination of their care occurred 'behind the scenes' and had little to do with them.

6.4.5 Risks of lack of continuity

Analysis of respondents' experiences of diabetes care identified problems of the lack of experienced continuity of care as mainly occurring at three transition points in terms of service delivery: transfer from hospital to routine general-practice care following diagnosis; referral to hospital following an episode of illness; and provider retirement, holidays or leave, etc. A further transition and problems of continuity arose when changes in patients' own health state necessitated changes in services provided on a regular basis, with requirements for flexible and team and cross-boundary continuity.

These transitions, and their impacts in terms of the dimensions of team and cross-boundary continuity, longitudinal, flexible and relational continuity, are illustrated by four brief case studies derived from respondents' accounts (Table 7). The outcomes for patients of a lack of experienced continuity involved gaps and delays in service provision, lack of information and problems of communication.

Patients' responses to their perception of a serious lack of experienced continuity of care were sometimes to seek alternative care and advice, non-compliance with advice or treatment, or withdrawal from formal services and attempting to monitor and manage their condition themselves.

Table 7 Case studies: problems of continuity of care

Case 1 Female, aged 66, receiving GP care	**Case 2 Female, aged 60, receiving GP care**
Transition: referral from hospital to routine general practice care following diagnosis *Longitudinal/team and cross-boundary continuity:* poor coordination of care, communication between hospital and primary care and transfer of information *Effect*: Delay in care provision: 'I came out of hospital, and I waited. I must have waited for about a month. No one called me…' *Patient's response*: initiate contact, dissatisfied with staff: '…so I went up to see the GP. I explained everything and told him that they had said I could get my care here…. I told them I had been waiting for over a month for someone to call me. They said "we don't know anything about this" apparently they hadn't received the information. They said "they had no idea why the information had not arrived." I was upset with them, I felt that if I hadn't gone in then no one would have bothered to call and check if I was doing fine.'	*Transition*: patient required to change practice as GP retired and practice closed. *Team and cross-boundary continuity*: delays in transferring patient's information. *Effect*: delays in receiving care: 'I went to the new practice and registered only to be told that they didn't have any information on me and my records hadn't turned up. So they couldn't do anything with me. I had to fill in a form and they said that I could come in for my diabetes when me notes had arrived...they did take my blood pressure but that was all.'
Case 3 Male, aged 73, receiving shared care	**Case 4 Male, aged 74, receiving shared care**
Transition: admitted to hospital for big-toe amputation. *Relational continuity with hospital staff*: conflicts over wound care, unhappy about seeing different professionals and thinks staff are not interested in his diabetes. *Effect*: discontinued treatment and self-manages at home: 'I said I'd had enough, I wasn't coming again. I said I'll do it myself (wound cleaning and dressings) – the consultant was very annoyed with me'.	*Transition:* increasingly unsteady on feet and housebound, recent cataract operation and unable to cut nails. *Flexible/team and cross-boundary continuity*: poor coordination and communication between primary care/community services and response to patients' changing circumstances. *Effect*: gaps in care: 'The district nurses, one came round twice. Then she didn't come no more. Then another one came round twice. She hasn't been seen since…. Also I did agree to go to a community centre, once a week, for about a month. I don't know what they do there. I haven't heard no more.'

6.5 Summary of patient-derived themes

Patients evaluate services based on their perception and experience. In the model of Freeman and colleagues, experienced continuity referred to the coordinated and smooth progression of care from the patients' point of view. Our empirical data suggest that experienced continuity may have a wider significance, with four distinct dimensions identified from patient interview data as being of importance in achieving experienced continuity, as follows.

- *Experienced longitudinal continuity* involves a regular source of care and a decision by the patient to use it when care is needed. This may involve patients visiting a specific setting for regular check-ups, and seeing a regular provider for their overall diabetes care or during an episode of illness.
- *Experienced relational continuity* refers to the experience of establishing and maintaining a satisfactory relationship between patient and professional. This dimension was particularly important to all patients. Good relational continuity depended on patients' evaluation of how well their provider(s) knew their medical history, how confident they felt with their treatment and how involved they were in decisions about their treatment.
- *Experienced flexible continuity* refers to health-care professionals and services adjusting to changes in a person's life over time. Patients from our interviews evaluated this dimensions in terms of how flexible professionals and services were in meeting their changing care requirements; for example, how quickly they could see their chosen health-care professional or their regular provider, how quickly could they get advice from a professional in an emergency and how they rated the waiting time.
- *Experienced team and cross-boundary continuity* involves effective communication between health-care professionals and coordination of services. In this dimension patients tended to evaluate whether health-care professionals involved in their care were aware of their diabetes status, treatment plan and medical history and how they rated the overall service.

Table 8 provides a summary of key themes associated with each of the proposed dimensions of experienced continuity of care. These themes provided a basis for the development of a measure of patient experienced continuity of diabetes care (Section 7).

Table 8 Summary of patient-derived themes for each dimension of experienced continuity of care

Longitudinal	Relational	Flexible	Team and cross-boundary
Regular consultations	Identifies usual doctor/nurse	Making and changing appointments	Appropriate coordination of services
Receives appointment letters	Usual doctor/nurse knows and understands me	Speaking to a usual doctor/nurse when needed	All staff know medical history and treatment
Regular tests and checks	Doctor/nurse listens, enough time to talk	Getting advice in an emergency	Staff communicate with each other
Regularly sees usual doctor/nurse	Can talk about anything, confiding		Staff give consistent advice
	Doctor/nurse concerned and interested		
	Mutual trust and confidence		
	Doctor/nurse explains things		

Section 7 Experienced continuity of care: development of a new measure

7.1 Summary

Objective: to develop an experience-based measure of continuity of care in type 2 diabetes and test the reliability and validity of the measure in quantitative data.

What we did: we used the qualitative data to develop a 19-item measure of experienced continuity of care in type 2 diabetes mellitus (ECC-DM). The measure includes four sub-domains: longitudinal continuity (four items), flexible continuity (four items), relational continuity (six items) and team and cross-boundary continuity (five items). Scores ranged from 0 to 100. The measure was administered by interview in a survey of 209 type 2 diabetic subjects registered with 19 general practices.

What we found: the mean score was 62.1 (SD ±16.0). The average inter-item correlation was 0.343 and Cronbach's alpha was 0.908. Factor analysis revealed four factors which were consistent with the four sub-domains of continuity of care. The questionnaire was additionally tested in self-completion and telephone interview formats with satisfactory results. Test-retest reliability was good. Mean scores varied significantly (P=0.001) from 46 to 78 among patients registered with different general practices. Experienced continuity of care was lower for subjects who only received diabetes care from hospital-based clinics than for subjects who received diabetes care from their general practice (difference 13.7, 8.2–19.2, P<0.001). Patients gave higher continuity-of-care scores at general practices with a named lead doctor for diabetes (difference 8.2, 2.7–13.6, P=0.003).

What we conclude: the experienced continuity-of-care measure gives reliable, valid results and is easily applied. Patients' experiences of continuity depend on the organisation of care: if general practices have a named lead professional for diabetes then their patients generally experience better continuity of care; patients attending hospital diabetes clinics for most of their diabetes care experience lower continuity.

7.2 Introduction

The preceding section described patients' experiences and values with respect to continuity of diabetes care and used these to develop a conceptual framework for measuring experienced continuity of care. In this section, we describe the development and testing of a questionnaire measure of experienced continuity of care in diabetes

mellitus. This measure will be referred to as the ECC-DM. This section comprises three elements. First a development phase, which included development and cognitive testing of the new measure as well as a pilot evaluation of the measure in 40 subjects. Second, a formal cross-sectional survey to test the measure in an achieved sample of 193 diabetic patients registered with 19 family practices. Third, the measure was evaluated for test-retest reliability and self-completion in two separate convenience sub-samples from the main study sample.

7.3 Development of the measure

The qualitative stage of the project provided us with a classification of four dimensions of experienced continuity of care, together with key themes or experiences which were associated with each dimension (Table 7). We used the qualitative data relating to each theme to develop the content of questionnaire items. The wording of questionnaire items was also influenced by the qualitative data, by the wording of similar items in existing questionnaires including the GPAQ (National Primary Care Research and Development Centre, 2005) and the Picker Institute NHS Survey Questionnaires (Picker Institute, 2005a). The response sets for each item were coded using standard Likert-type scales which each had six response options.

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

The relationship between the final questionnaire items and the qualitative data is illustrated in Table 9. Each of the items was supported by qualitative data. A comparison of the ECC-DM items with similar GPAQ and Picker NHS Survey Questionnaire items is shown in Table 10. Items about the professional listening, explaining and involving patients were common to each of the instruments and were also identified in the qualitative data (Table 9). Of the 19 items in our patient questionnaire, 11 were similar to either GPAQ or Picker items, nine were comparable between the GPAQ instrument and our patient measure, and seven were similar between the ECC-DM and the Picker NHS Survey items. This sharing of items is considered to enhance the face validity of the patient questionnaire, especially as the GPAQ instrument is designed to evaluate continuity of care, interpersonal care (relational continuity) and access (flexible continuity). However, there were a substantial number of other GPAQ or Picker items which did not relate to concepts identified in our qualitative data and which are not included in our patient-based continuity-of-care measure.

Table 9 Comparison of patient questionnaire items with qualitative data

ECC-DM	Qualitative data
Longitudinal continuity	
GP/H1. How many times have you spoken with staff at the practice/hospital about your diabetes?	'**I used to go to my doctor every 6 months**, he would check everything and they would give me appointment date for my next check-up but he's left now and there is someone else doing it**. I haven't received anything**, no one has bothered. I have to go up there myself. It's really gone down hill.' (PA5; GP care)
GP/H2. How many times has the practice/hospital sent you an appointment letter for your diabetes?	
GP/H3. How many times have you had a blood test taken for your diabetes at the practice/hospital?	'…at the practice – on a regular basis, **every couple of months I go there, they check everything, my blood, blood pressure**… and every so often, I think it's every year, she checks my feet with a…it's like a little prodder – but she only does that once every year really.' (PA3; shared care)
GP/H7. How many times have you seen your usual doctor or nurse at the practice/hospital?	'**I always see the same person**. Nurse A, she takes the blood test to see if the sugar levels are within the scope they should be. She asks how I'm coping, if I'm feeling okay and then she goes through all the bits.' (PA3; shared care)
Flexible continuity	
GP/H4. If you need advice urgently how long does it take to get to speak to a doctor or nurse at the practice?	'**They're very good here** you know, **whenever I need to see the doctor I can just phone up and get an appointment** when you want, you don't have to wait long and they ask you, you know, what's it about so if you need more time then they will book you a double appointment.' (PA13; GP care)
GP/H5. How would you rate the length of time you've had to wait before you spoke to a doctor or nurse at the practice?	
GP/H6. If you have a problem with your diabetes, how well does your practice respond to it?	If I can't make it or when it's been pouring with rain and I just… We've phoned up before and they've booked me another date. **They've been good that way.**
GP/H8. If you need to speak to your usual doctor or nurse about your diabetes, how easy is it for you to speak to your usual doctor or nurse at the practice?	'The nurse … always makes time for me. **If I phone in the she will always call me back on the same day**. I have been able to see her when I've needed to.' (PA3; shared care)

Table 9 *continued*

ECC-DM	Qualitative data
Relational continuity	
GP/H9. How well does your usual doctor or nurse at the practice explain medical procedures and tests done for your diabetes?	'I knew my doctor for a long time, so when **he explained things to me**, he gave me confidence that I would be fine so long as I looked after myself, you know. I must admit I was frightened but he talked to me, spent a lot of time talking to me, until I understood and felt better…' (PA2; shared care)
GP/H10. My usual doctor or nurse…involves me in decisions about my diabetes.	'The one or two occasions that I have seen him, he hasn't got the chance to get to know me, I know that. But I did just sort of get the feeling that it was a question of getting me in and out as quickly as possible. **I didn't feel involved**, I'm not sure that he will be as thorough.' (PA6; shared care)
GP/H11. …listens to what I have to say.	'**She listens to you** and she explains things and she doesn't rush in and out. She's a very good doctor. The nurse is very good. I feel I can sit and talk to her more cos I've known her longer. The doctor's good, and as I've said to you, she listens and she explains things to you.' (PA15; shared care)
GP/H12. …knows about my medical history.	'I have a good relationship with my doctor, we understand each other… I've been with him for the last 30 years, **he knows me and that's not just my diabetes, that's everything**.' (PA6; GP care)
GP/H13. …makes the best decisions about my diabetes treatment.	'I am pleased that I see the same people…it makes my relationship with them more trustful and you try and take on what they say because **they know best.** They always tell you everything you need to know so I am aware of what is going on.' (PA17; GP care)
GP/H14. …is concerned about me.	'…and I mean he wasn't just interested in sort of how my diabetes was doing, **he was interested in me** as a whole person..' (PA5; shared care)

Table 9 *continued*

ECC-DM	Qualitative data
Team and cross-boundary continuity	
O1. In general, how well is your diabetes care coordinated?	'Oh yes, it's reassuring to me – I had a new consultant this time, a new doctor. I hadn't seen him before. And he said to me, "Who is your doctor?" and I said, "He's just gone down the corridor, it's Dr D". "Oh, [first name]?" And I said, "Yes, he's my doctor". And he said, "Oh that's good". But you see, occasionally, [first name] will come in and when I'm having my eyes photographed, he will come in and just check the photograph, which is very useful because we can then discuss it.' (PA6; shared care)
O2. They all give me the same information and advice.	'**They all say the same thing**, I mean they all have their own area but when they have given me advice it has been the same.' (PA23; hospital care)
O3. They all know my medical history.	'Sometimes when I go to the doctor I find that I have got to remind them or tell them what has happened. Because I only go once a year and you don't always see they same person, well I'm certain I won't see the same person so they are not likely to know what's happened because **they look to me like they don't know'**. (PA11; hospital care)
O4. They all know about my diabetes treatment.	'**They all seem to know about me when I go to them** and in my opinion it has been very good opinion.' (PA17; GP care)
O5. They share an agreed plan of treatment for my diabetes.	'I feel they know me, **they know what's going on with my diabetes** because sometimes when I've been to the hospital my doctor tells me that he's received the results, he goes through them with me, **what they have said and what should be done**.' (PA4; shared care)

Table 10 Comparison of patient questionnaire items with existing instruments

ECC-DM	GPAQ[a]	Picker NHS surveys[b]
Longitudinal continuity		
GP/H1. How many times have you spoken with staff at the practice/hospital about your diabetes?	1. How many times have you seen a doctor from your practice?	
GP/H2. How many times has the practice/hospital sent you an appointment letter for your diabetes?		
GP/H3. How many times have you had a blood test taken for your diabetes at the practice/hospital?		
GP/H7. How many times have you seen your usual doctor or nurse at the practice/hospital?	In general, how often do you see your usual doctor?	
Flexible continuity		
GP/H4. If you need advice urgently how long does it take to get to speak to a doctor or nurse at the practice?	5a. Thinking of the times when you are willing to see any doctor, how quickly do you usually get seen?	
GP/H5. How would you rate the length of time you've had to wait before you spoke to a doctor or nurse at the practice?	5b. How do you rate this?	GP3. How do you feel about the length of time you had to wait for an appointment with a doctor?
GP/H6. If you have a problem with your diabetes, how well does your practice respond to it?		
GP/H8. If you need to speak to your usual doctor or nurse about your diabetes, how easy is it for you to speak to your usual doctor or nurse at the practice?	4. Thinking of the times when you want to see a particular doctor, how quickly do you usually get to see that doctor?	
Relational continuity		
GP/H9. How well does your usual doctor or nurse at the practice explain medical procedures and tests done for your diabetes?	10e. How well the doctor explained your problems or any treatment that you need	GP9/OP14. Did the doctor explain the reasons for any treatment or action in a way you could understand?
GP/H10. My usual doctor or nurse…involves me in decisions about my diabetes.	10d. How much the doctor involved you in decisions about your care?	GP8/OP28. Were you involved as much as you wanted to be in decisions about your care and treatment?

Table 10 ***continued***

ECC-DM	GPAQ[a]	Picker NHS surveys[b]
Relational continuity		
GP/H11. …listens to what I have to say.	10c. How well the doctor listened to what you had to say?	GP6/OP16. Did the doctor listen carefully to what you had to say?
GP/H12. ...knows about my medical history.		OP18. Did the doctor seem aware of your medical history?
GP/H13. ...makes the best decisions about my diabetes treatment.		GP10/OP17. Did you have confidence and trust in the doctor?
GP/H14. ...is concerned about me.	10h. The doctor's caring and concern for you?	
Team and cross-boundary continuity		
O1. In general, how well is your diabetes care coordinated?		
O2. They all give me the same information and advice.		OP27. Sometimes in a hospital or clinic, a member of staff will say one thing and another will say something quite different. Did this happen to you?
O3. They all know my medical history.		
O4. They all know about my diabetes treatment.		
O5. They share an agreed plan of treatment for my diabetes.		

[a]*Numbers refer to item numbers in the GPAQ instrument.*

[b]*Numbers refer to item numbers in either the NHS general practice (GP) questionnaire or hospital outpatient (OP) questionnaire.*

A difficulty arose because patients might receive diabetes care in more than one health-care setting. Patients' present care could be classified as general practice only, hospital only or shared care for their diabetes. The assessment of certain dimensions of continuity might differ for different settings. For this reason, the items for longitudinal, flexible and relational continuity were repeated, first with reference to general practice and then with hospital settings. The items for team and cross-boundary continuity referred to patients' overall experience of care.

There were eight items which asked about care received from the usual doctor or nurse in a given setting. The usual doctor or nurse was further defined as the doctor or nurse who 'knows you and your diabetes best'. This is adapted from the wording used in the GPAQ instrument. The first of these items included a response option for 'I don't have a usual doctor or nurse'. If the patient had no usual doctor or nurse than it was necessary to skip the remaining items concerning the usual provider. In view of the importance of this item, we later added a supplementary question to confirm that there was no usual provider. During interview administration care was taken to ensure that respondents fully understood this question and that an appropriate response was obtained.

It may be noted that each of the six relational continuity items refers to the concept of the 'usual' doctor or nurse. Each item then addresses key elements from the qualitative data including 'listening', 'explaining', 'involving patients in decisions', 'knowing about the patient's history', 'showing concern' and 'making the best decisions'.

The final version of the patient questionnaire is shown in Appendix 1.

7.3.1 Initial testing of the experienced continuity-of-care measure

A pilot study was conducted through interview administration of the patient questionnaire to 40 diabetic subjects who were attending for consultations at local general practices. The qualitative feedback obtained from these interviews were used to make a number of adjustments to the wording and structure of the questionnaire. The quantitative data from the pilot study were used to explore the psychometric properties of the measure. The results of these analyses were broadly similar to results obtained for the larger sample from the baseline survey for the cohort study and the latter were therefore preferred for presentation here.

7.4 Testing the patient-based continuity-of-care measure: methods

7.4.1 Approach to testing

We obtained data for the measure in a cross-sectional survey of diabetic subjects and the data were used to analyse the properties of the measure. The following steps are presented:

1 item responses and missing data;

2 scale and subscale scores, item-score and inter-item correlations and Cronbach's alpha;

3 factorial composition and construct validity;

4 criterion validity;

5 results from self-completion and telephone interviews and assessment of test-retest reliability.

7.4.2 Subjects and procedures

The measure was tested in a cross-sectional survey of subjects with type 2 diabetes who were registered with 19 general practices in two inner-London boroughs. The patients were subjects with diabetes who were registered with the practices and had returned a postal questionnaire as part of a local service evaluation (Mohiddin *et al*., 2003). From these, subjects who were diagnosed with diabetes over the age of 30 years and who did not require insulin within 6 months of diagnosis were selected as having type 2 diabetes. Further details of the sampling procedure are given in Section 8 (Figure 4).

The survey questionnaire included the measure of experienced continuity of care. In addition questions were included concerning the type of care received (general practice only, hospital only or shared care), age, sex, ethnicity, duration of diabetes and general health. The questionnaire was administered by interview in patients' homes. In some cases, if it was convenient for the subject, interviews were held in the hospital diabetes clinic and all such interviews were held in a private room. After the interview, measurements were made of patients' weight, height and blood pressure and arrangements were made for a blood sample to be sent for estimation of glycated haemoglobin (HbA1c). Data were abstracted from clinical records at the patients' general practice concerning the total number of visits, and numbers of visits to either a doctor or nurse, in the 12 months preceding the interview. Patient questionnaire data were also linked to data for an organisational profile of the general practice which was obtained as part of a local evaluation of diabetes services. This included an item concerning whether the practice had a named lead doctor for diabetes.

7.4.3 Analysis

Initially, item responses were tabulated to assess their distribution and the frequency of item non-response. When only one item was missing for a given sub-domain, then the value was imputed by taking the mean of the items with complete data. The maximum number of cases with imputed data was six for item RC2 (see Table 11 for item wording).

The total experienced continuity-of-care (ECC) score and scores for the sub-domains of longitudinal (LC), flexible (FC), relational (RC) and team and cross-boundary (TCB) continuity were calculated. Sub-domain scores were calculated by summing item scores and rescaling to give a score

ranging from 0 to 25. The ECC score was obtained by summing the four sub-domain scores to obtain a score ranging of 0–100. If subjects received care in both general practice and hospital clinic settings, LC, FC and RC sub-domain scores were obtained separately for each setting. In order to obtain the total ECC score, the sub-domain score from the general practice setting was used but this was replaced by the score for the hospital setting if the latter was higher or if no score was recorded for the general practice setting. The item responses used for analysis were obtained in the same way.

Item-score correlations and Cronbach's alpha values were estimated. Factor analysis was used to explore the factorial composition of the measure using the principal factor method in Stata version 9 (Stata Corporation, 2005). Factor loadings were obtained after varimax rotation. The number of factors was selected after inspecting the Eigenvalues and a scree plot, and by using maximum-likelihood estimation to compare the goodness of fit of models with different numbers of factors (Streiner, 1994; Fayers and Machin, 1998). In order to evaluate criterion validity, linear-regression models were fitted to evaluate whether mean experienced continuity scores varied in different groups of patients or different organisational settings. The general practice was fitted as a random effect with maximum-likelihood estimation using the 'xtreg' and 'xtmixed' commands in Stata version 9 (Stata Corporation, 2005). Intraclass correlation coefficients were estimated using maximum-likelihood estimation. We compared continuity of care according to type of diabetes care received and according to whether the practice had a named lead for diabetes care.

7.5 Testing the patient-based continuity-of-care measure: results

7.5.1 Subjects and response rate

At the 19 general practices there were 553 eligible subjects with type 2 diabetes. Interviews were obtained with 209 (38%) subjects and, after excluding cases with missing values, data were analysed for 193 (92%) participants with total experienced continuity-of-care scores. The mean age was 65 years (range 32–90 years), and there were 96 men and 97 women. There were 44 subjects presently receiving diabetes care only from general practice, 35 receiving care only from a hospital clinic and 114 receiving shared care from both general practice and specialist clinics.

7.5.2 Item responses

Table 11 shows the wording for each item and the response profiles obtained for each of the 19 items as well as the item mean score. The distributions were generally unimodal. For items concerning care from a usual doctor or nurse there were 34 cases who responded negatively to all items because they had no usual doctor or nurse. Table 12 shows the patterns of item response separately for general-practice or hospital-care settings. It can be seen that the hospital-referenced items generally yielded low ratings with a high proportion reporting no experience of hospital care from a usual doctor or nurse.

Table 11 Item responses combined across settings for 193 cases with complete data

	Response option						Item mean
	0	**1**	**2**	**3**	**4**	**5**	
Longitudinal continuity							
LC1. How many times have you spoken with staff at the practice/hospital about your diabetes?	0	26	41	27	38	61	3.34
LC2. How many times has the practice/hospital sent you an appointment letter for your diabetes?	97	31	35	12	5	13	1.15
LC3. How many times have you had a blood test taken for your diabetes at the practice/hospital?	4	39	62	32	22	34	2.68
LC4. How many times have you seen your usual doctor or nurse at the practice/hospital?	42	15	42	26	27	41	2.54
Flexible continuity							
FC1. If you need advice urgently how long does it take to get to speak to a doctor or nurse at the practice?	11	2	5	8	16	151	4.43
FC2. How would you rate the length of time you've had to wait before you spoke to a doctor or nurse at the practice?	7	11	26	61	58	30	3.25
FC3. If you have a problem with your diabetes, how well does your practice respond to it?	1	1	9	56	91	35	3.76
FC4. If you need to speak to your usual doctor or nurse about your diabetes, how easy is it for you to speak to your usual doctor or nurse at the practice?	46	1	11	51	61	23	2.77
Relational continuity							
RC1. How well does your usual doctor or nurse at the practice explain medical procedures and tests done for your diabetes?	34	0	8	36	87	28	3.17
RC2. My usual doctor or nurse…involves me in decisions about my diabetes.	34	1	13	66	54	25	2.93
RC3. …listens to what I have to say.	34	0	1	49	79	30	3.19
RC4. …knows about my medical history.	34	1	9	60	60	29	3.03
RC5. …makes the best decisions about my diabetes treatment.	34	1	5	65	63	25	3.02
RC6. …is concerned about me.	34	0	6	63	62	28	3.05

Table 11 ***continued***

	Response option						Item mean
	0	**1**	**2**	**3**	**4**	**5**	
Team and cross-boundary continuity							
TCB1. In general, how well is your diabetes care coordinated?	1	1	11	64	93	23	3.64
TCB2. They all give me the same information and advice.	0	2	12	109	51	19	3.38
TCB3. They all know my medical history.	0	1	28	98	51	15	3.26
TCB4. They all know about my diabetes treatment.	0	1	12	105	57	18	3.41
TCB5. They share an agreed plan of treatment for my diabetes.	0	1	20	109	47	15	3.27

Figures are frequencies.

Table 12 Comparison of item responses for different care settings

Item (row total)	Response option						Item mean
	0	1	2	3	4	5	
Longitudinal continuity (general practice)							
LC1. (GP1) How many times have you spoken with staff at the practice about your diabetes? (160)	2	17	28	27	31	55	3.46
LC2. (GP2) How many times has the practice sent you an appointment letter for your diabetes? (158)	112	17	16	7	1	5	0.63
LC3. (GP3) How many times have you had a blood test taken for your diabetes at the practice? (158)	10	30	46	27	18	27	2.59
LC4. (GP7) How many times have you seen your usual doctor or nurse at the practice? (158)	19	19	30	26	26	38	2.85
Longitudinal continuity (hospital)							
LC1. (H1) How many times have you spoken with staff at the hospital about your diabetes? (156)	10	75	44	8	9	10	1.75
LC2. (H2) How many times has the hospital sent you an appointment letter for your diabetes? (148)	2	79	44	9	5	9	1.75
LC3. (H3) How many times have you had a blood test taken for your diabetes at the hospital? (148)	30	59	42	6	7	4	1.41
LC4. (H7) How many times have you seen your usual doctor or nurse at the hospital? (149)	80	34	26	3	1	5	0.83
Flexible continuity (general practice)							
FC1. (GP4) If you need advice urgently how long does it take to get to speak to a doctor or nurse at the practice? (158)	12	2	7	12	16	109	4.18
FC2. (GP5) How would you rate the length of time you've had to wait before you spoke to a doctor or nurse at the practice? (158)	5	16	26	47	41	23	3.09
FC3. (GP6) If you have a problem with your diabetes, how well does your practice respond to it? (158)	0	2	9	48	69	30	3.73
FC4. (GP8) If you need to speak to your usual doctor or nurse about your diabetes, how easy is it for you to speak to your usual doctor or nurse at the practice? (158)	19	0	17	44	56	22	3.16
Flexible continuity (hospital)							
FC1. (H4) If you need advice urgently how long does it take to get to speak to a doctor or nurse at the hospital? (121)	24	1	0	1	12	83	3.86
FC2. (H5) How would you rate the length of time you've had to wait before you spoke to a doctor or nurse at the hospital? (121)	4	11	22	35	36	13	3.05
FC3. (H6) If you have a problem with your diabetes, how well does your hospital respond to it? (141)	2	0	3	46	70	20	3.72

Table 12 ***continued***

Item (row total)	Response option						Item mean
	0	**1**	**2**	**3**	**4**	**5**	
Flexible continuity (hospital)							
FC4. (H8) If you need to speak to your usual doctor or nurse about your diabetes, how easy is it for you to speak to your usual doctor or nurse at the hospital? (144)	80	6	11	25	18	4	1.35
Relational continuity (general practice)							
RC1. (GP9) How well does your usual doctor or nurse at the practice explain medical procedures and tests done for your diabetes? (158)	19	0	7	37	70	25	3.35
RC2. (GP10) My usual doctor or nurse…involves me in decisions about my diabetes. (158)	19	2	11	60	44	22	3.10
RC3. (GP11) …listens to what I have to say. (158)	19	0	0	45	67	27	3.41
RC4. (GP12) …knows about my medical history. (158)	19	1	5	54	52	27	3.27
RC5. (GP13) …makes the best decisions about my diabetes treatment. (158)	19	1	6	59	52	21	3.18
RC6. (GP14) …is concerned about me. (158)	19	0	7	52	54	26	3.27
Relational continuity (hospital)							
RC1. (H9) How well does your usual doctor or nurse at the hospital explain medical procedures and tests done for your diabetes? (144)	79	0	3	12	36	14	1.78
RC2. (H10) My usual doctor or nurse…involves me in decisions about my diabetes. (142)	79	0	9	27	20	7	1.51
RC3. (H11) …listens to what I have to say. (146)	79	0	2	29	27	9	1.67
RC4. (H12) …knows about my medical history. (145)	79	0	11	31	17	7	1.50
RC5. (H13) …makes the best decisions about my diabetes treatment. (145)	79	0	4	28	27	7	1.62
RC6. (H14) …is concerned about me. (146)	79	0	3	35	23	6	1.60

Figures are frequencies.

7.5.3 Inter-item and item–score correlations

Table 13 shows the item–score correlations, average inter-item correlations and Cronbach's alpha for each of the items and the overall score. The effect of omitting each item in turn is also shown. The overall mean inter-item correlation was 0.343 and Cronbach's alpha was 0.908. All of the items which concerned a usual provider showed a high correlation with the overall score and this was explained because there were 34 cases who were unable to identify a usual doctor or nurse and gave zero scores for each of these eight items.

Table 13 Item statistics for continuity-of-care scale

	Item–score correlation	Average inter-item correlation[a]	Alpha[a]
LC1. Times spoken with staff	0.377	0.361	0.910
LC2. Appointment letters	0.137	0.379	0.917
LC3. Blood tests	0.313	0.366	0.912
LC4. Times seen usual doctor	0.644	0.340	0.903
FC1. How long to get urgent advice	0.410	0.358	0.910
FC2. Rate the length of time	0.572	0.346	0.905
FC3. Have a problem	0.580	0.345	0.905
FC4. Need to speak to usual doctor	0.776	0.330	0.899
RC1. Explains medical procedures	0.833	0.326	0.897
RC2. Involves me in decisions	0.817	0.327	0.897
RC3. Listens to what I have to say	0.841	0.325	0.897
RC4. Knows about my medical history	0.857	0.324	0.896
RC5. Makes the best decisions	0.858	0.324	0.896
RC6. Is concerned about me	0.857	0.324	0.896
TCB1. How well is care coordinated	0.534	0.349	0.906
TCB2. The same information/advice	0.587	0.345	0.905
TCB3. Knows my medical history	0.536	0.349	0.906
TCB4. Knows about my treatment	0.579	0.345	0.905
TCB5. Share an agreed plan	0.564	0.346	0.95
Scale score		**0.343**	**0.908**

[a]*Statistic obtained after omitting specified item, except for scale score.*

Data for 193 cases with complete data.

Table 14 shows the same statistics for the subscales of longitudinal, flexible, relational and team and cross-boundary continuity. Note that alpha depends on the number of items, *n*, in a scale, as illustrated by the Spearman–Brown prophecy formula:

$$\alpha = \frac{n.\bar{r}}{1+(n-1).\bar{r}}$$

where $\bar{r}$ is the average inter-item correlation. Thus alpha will be lower for a short scale than a long scale even if the average inter-item correlations are the same. In this case the average inter-item correlations were sometimes greater for the subscales than for the overall scale. This would be expected if the subscales were more homogenous than the overall scale. The resulting values for alpha were considered to be satisfactory for scales with few items (Streiner and Norman, 1989).

Table 14 Item statistics for continuity-of-care subscales

	Item–score correlation	**Average inter-item correlation[a]**	**Alpha[a]**
Longitudinal continuity (LC)			
LC1. Times have you spoken with staff	0.850	0.178	0.393
LC2. Appointment letters	0.417	0.581	0.806
LC3. Blood tests	0.836	0.191	0.414
LC4. Times seen your usual doctor	0.694	0.323	0.589
LC scale		**0.318**	**0.651**
Flexible continuity (FC)			
FC1. How long to get urgent advice	0.714	0.416	0.681
FC2. Rate the length of time	0.826	0.305	0.568
FC3. Have a problem	0.778	0.353	0.620
FC4. Need to speak to usual doctor	0.633	0.495	0.747
FC scale		**0.392**	**0.721**
Relational continuity (RC)			
RC1. Explains medical procedures	0.949	0.926	0.984
RC2. Involves me in decisions	0.945	0.928	0.985
RC3. Listens to what I have to say	0.978	0.909	0.980
RC4. Knows about my medical history	0.965	0.916	0.982

Table 14 ***continued***

	Item–score correlation	Average inter-item correlation[a]	Alpha[a]
Relational continuity (RC)			
RC5. Makes the best decisions	0.974	0.911	0.981
RC6. Is concerned about me	0.976	0.910	0.981
RC scale		**0.917**	**0.985**
Team and cross-boundary continuity (TCB)			
TCB1. How well is care coordinated	0.674	0.619	0.866
TCB2. The same information and advice	0.816	0.525	0.815
TCB3. Know my medical history	0.813	0.526	0.816
TCB4. Know about my treatment	0.851	0.501	0.801
TCB5. Share an agreed plan of treatment	0.818	0.523	0.815
TCB scale		**0.539**	**0.854**

[a]*Statistic obtained after omitting specified item, except for scale score.*

Data for 193 cases with complete data.

7.5.4 Factorial composition and construct validity

Factor analysis was performed in order to explore the factorial composition of the measure and to determine whether this was consistent with the expected dimensions or constructs of continuity of care. Table 15 shows rotated factor loadings from a factor analysis with four factors. A four-factor solution was chosen on the basis of inspecting the Eigenvalues and the scree plot, and by comparing the fit of models obtained through maximum-likelihood estimation. Items associated with relational continuity loaded strongly on the first factor. Items LC4 and FC4, which include the concept of a usual doctor or nurse, also loaded strongly on this factor. The second factor was associated with items representing team and cross-boundary continuity, the third with longitudinal continuity and the fourth with flexible continuity (shown by the shading in the table).

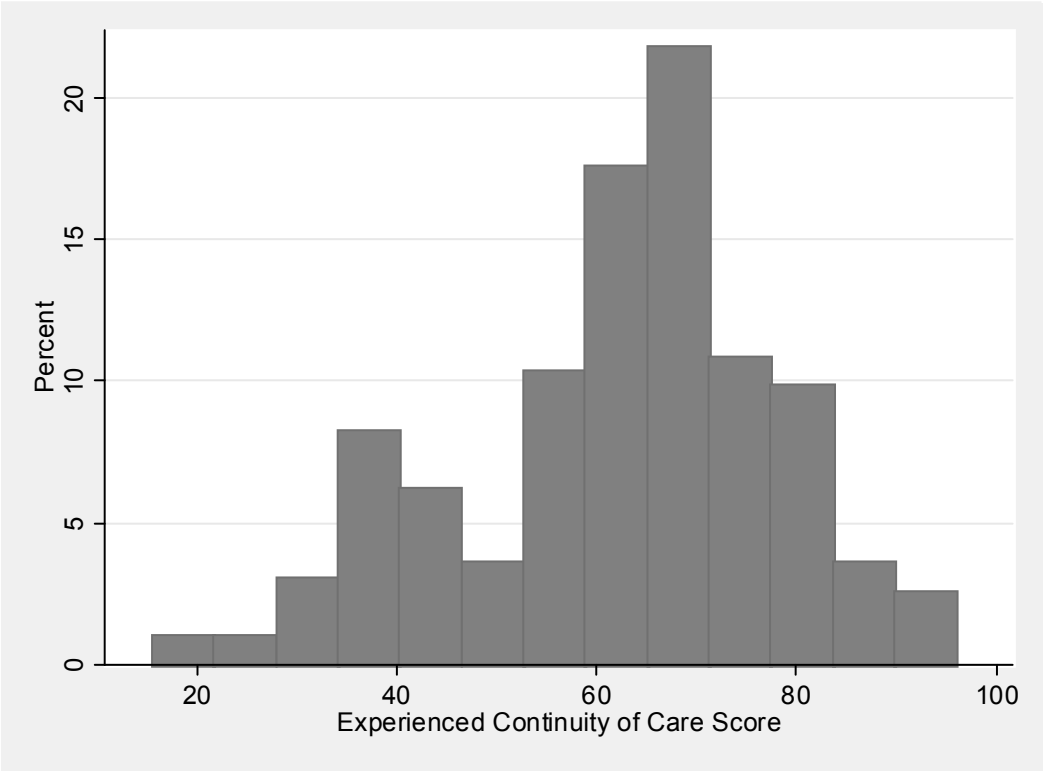
Table 15 Rotated factor loadings from factor analysis with four factors

	Factor 1	Factor 2	Factor 3	Factor 4	Uniqueness
LC1. Times spoken with staff	0.178	−0.023	0.835	0.050	0.268
LC2. Appointment letters	−0.067	0.038	0.131	0.202	0.936
LC3. Blood tests	0.095	−0.009	0.746	0.038	0.432
LC4. Times seen usual doctor	0.647	0.012	0.549	−0.051	0.277
FC1. How long to get urgent advice	0.147	0.073	0.097	0.629	0.569
FC2. Rate the length of time	0.234	0.287	0.026	0.712	0.357
FC3. Have a problem	0.321	0.286	−0.016	0.522	0.542
FC4. Need to speak to usual doctor	0.815	0.184	0.043	0.082	0.293
RC1. Explains medical procedures	0.927	0.076	0.073	0.153	0.106
RC2. Involves me in decisions	0.912	0.128	0.064	0.067	0.144
RC3. Listens to what I have to say	0.960	0.106	0.073	0.071	0.056
RC4. Knows my medical history	0.940	0.167	0.084	0.078	0.075
RC5. Makes the best decisions	0.944	0.150	0.058	0.109	0.071
RC6. Is concerned about me	0.958	0.157	0.077	0.060	0.049
TCB1. How well is care coordinated	0.200	0.443	0.090	0.366	0.622
TCB2. Same information and advice	0.266	0.680	−0.058	0.205	0.423
TCB3. Knows my medical history	0.217	0.775	−0.032	0.044	0.349
TCB4. Knows about my treatment	0.216	0.813	0.019	0.083	0.285
TCB5. Agreed plan of treatment	0.199	0.676	0.006	0.233	0.450

Uniqueness represents the proportion of the item's variance that is not shared with the factor structure. The finding of high values for uniqueness suggest that these items provide a less satisfactory 'fit' to the measurement model. Low values for uniqueness should be obtained with a satisfactory solution and these were only markedly elevated for the item about appointment letters and the overall coordination of care. The item about appointment letters gave a substantially lower mean score than any of the other items (Table 11).

Figure 3 shows the frequency distribution of total experienced continuity-of-care scores. The mean (±SD) ECC-DM score was 62.1 (±16.0). A high SD for the scale score is a desirable property resulting from higher inter-item correlations (Nunally, 1978).

Figure 3 Histogram showing distribution of experienced continuity-of-care scores



7.5.5 Test-retest reliability and telephone administration

Interviews were repeated by means of telephone administration after an interval for 30 subjects. Scale scores were compared for the two administrations and the results are shown in Table 16. There was close agreement between results obtained on successive administrations of the questionnaire.

Table 16 Results obtained from repeat interview by telephone with 30 subjects

Scale (number analysed)	Interview	Repeat interview by telephone	Mean difference (95% CI)
Total experienced continuity (26)	67.4 (11.8)	67.1 (12.8)	−0.4 (−4.2 to 3.4)
Longitudinal continuity (30)	12.9 (4.7)	11.7 (4.10)	−1.3 (−2.8 to 0.3)
Flexible continuity (28)	20.0 (3.6)	20.9 (3.9)	0.9 (−0.9 to −2.7)
Team and cross-boundary continuity (28)	17.1 (2.8)	17.0 (2.3)	−0.1 (−1.2 to 0.9)

Figures are mean (±SD) scale scores except where shown.

7.5.6 Self-completion

A self-completion version of the ECC-DM was developed (see Appendix 1). In order to compare scale scores and item responses from self-completion and interview formats, we aimed to obtain data for the self-completion

questionnaire from a convenience sample of about 60 subjects who had already been interviewed during the follow-up survey. Subjects from the convenience sample were either given a self-completion version of the questionnaire at the end of the interview and asked to complete this in the next few days and return it by post, or alternatively questionnaires were mailed to subjects with a reply-paid envelope. Questionnaires were returned by a total of 56 subjects but the response rate in self-completion format was not formally evaluated. There were 19 questionnaires returned from subjects who were given them after the interview, these were returned within several days; there were 37 questionnaires returned from the postal survey, some more than 1 month after the original interview. Item responses and scale scores were compared for interview administration and self-completion.

The self-completion questionnaire included three items concerning subjects' impressions of the design of the instrument. There were 45 (80%) who reported that the questionnaire was 'very easy' or 'easy' to understand; 51 (91%) reported that the questionnaire was 'very easy' or 'easy' to read; 48 (86%) were 'very satisfied' or 'satisfied' with the appearance of the questionnaire.

After imputing item non-response where only one item was missing in each subscale, the total experienced continuity score could be calculated for 48/56 (86%) of subjects, which was considered satisfactory in this small sample. The mean (±SD) scores for interview administration and self-completion are shown in Table 17. There was a slight positive bias, of about 4 units, from self-completion as compared to interview administration. This resulted from slightly more favourable rating of relational continuity and team and cross-boundary continuity in the self-administered questionnaire format. These differences were slight but nevertheless worth considering if studies use a variety of modes of administration.

Table 17 Comparison of scale scores from interview administration and self-completion

Scale	Interview	Self-completion	Difference (95% CI)
Total experienced continuity	67.0 (12.5)	71.0 (12.9)	4.0 (1.2 to 6.9)
Longitudinal	12.5 (5.9)	12.6 (5.3)	0.1 (−1.3 to 1.5)
Flexible	19.5 (4.7)	19.0 (4.2)	−0.5 (−1.8 to 0.7)
Relational	17.9 (5.0)	20.3 (4.4)	2.4 (1.3 to 3.5)
Team and cross-boundary	17.1 (2.6)	19.1 (3.6)	2.1 (1.0 to 3.2)

7.5.7 Criterion validity

The criterion validity of the measure was tested in several ways, based on the expectation that patients' experiences of continuity of care would depend in part on their own characteristics and more particularly on the care received. Thus continuity-of-care scores would be expected to vary between general

practices, between primary care and hospital clinic settings, according to the detailed organisational arrangements for delivering health care, and according to patients' attendance patterns.

Criterion 1: experiences of continuity of care will vary at different general practices

Table 18 shows the variation in mean continuity scores among 19 different general practices. The mean number of subjects per practice was 10. The mean total experienced continuity score varied from 46 to 78 at different practices. This variation in mean score between practices was quantitatively important in terms of the overall distribution of scale scores. The intraclass correlation coefficient was 0.14 (95% CI 0.04–0.32, *P*=0.001). This provides strong evidence that subjects from the same practice tend to rate their experience of continuity of care more similarly than subjects registered with different practices. The same was true for the subscale scores for longitudinal, flexible and relational continuity but not for team and cross-boundary continuity, which might depend on experience of care in different settings.

Table 18 Variation in mean continuity-of-care scores between 19 different general practices

Figures are general practice specific mean scale scores.

	Lowest-scoring practice	25%	Median	75%	Highest-scoring practice	*P* value[a]
Total continuity-of-care score	46	55	62	66	78	0.001
Longitudinal continuity	6	9	12	14	17	0.005
Flexible continuity	13	16	18	19	21	0.005
Relational continuity	6	12	14	17	21	0.023
Team and cross-boundary continuity	15	16	17	17	19	0.211

[a]*Test for variation in scores between practices*

Criterion 2: experiences of continuity of care will vary between care settings

Table 19 shows the general practice-referenced and hospital-referenced sub-domain scores of longitudinal, flexible and relational continuity. Low ratings were obtained for the hospital-referenced scales of longitudinal or relational continuity. Fewer valid responses were obtained for the hospital-referenced flexible continuity sub-domain score because patients had less experience of obtaining urgent advice from the hospital clinic.

Table 19 Comparison of experienced continuity subscales reported for general-practice and hospital settings

Scale	Setting	Number of scores	Mean (±SD)[a]
Longitudinal continuity	General-practice score	158	12.0 (5.3)
	Hospital score	148	7.3 (4.8)
Flexible continuity	General-practice score	158	17.7 (4.7)
	Hospital score	120	15.2 (5.1)
Relational continuity	General-practice score	158	16.3 (6.8)
	Hospital score	142	7.9 (9.2)

[a]*Subscale scores ranged from 0 to 25.*

Table 20 gives overall assessments of experienced continuity-of-care and sub-domain scores according to patients' self-reported type of care. When compared with subjects who received some diabetes care from their general practice, those subjects who reported receiving diabetes care only from the hospital clinic gave lower scores for experienced continuity of care as well as longitudinal, flexible and relational continuity. These differences were not explained by adjusting for whether the practice had a named lead GP for diabetes. These results are consistent with qualitative data.

Criterion 3: experiences of continuity of care will vary according to organisation of care

Subjects from practices with a named lead doctor for diabetes gave higher continuity-of-care scores than subjects registered with practices with no specified named lead for diabetes (Table 20). Adjusting for the type of diabetes care received by registered patients and whether the practice had a named GP lead for diabetes explained much of the observed variation in continuity-of-care scores between practices. The intraclass correlation coefficient for total ECC score by general practice adjusted for the variables in Table 18 was 0.04 (0.00–0.25, P=0.169).

Criterion 4: experiences of continuity of care will vary according to attendance pattern

Table 21 shows mean experienced continuity-of-care scores according to number of consultations in the last 12 months based on data obtained from general-practice clinical records. The total experienced continuity-of-care score and scores for the longitudinal continuity sub-domain were associated with number of consultations in the last 12 months. Scores for flexible continuity were not associated with number of consultations, whereas scores for relational and team and cross-boundary continuity were weakly and inconsistently associated with numbers of consultations.

Criterion 5: experiences of continuity of care will be less strongly associated with individual patient characteristics

Experienced continuity-of-care scores were not associated with age, sex or duration of diabetes (Table 22). Patients whose first language was not English

experienced lower continuity of care, with lower scores for the sub-domains of flexible and relational continuity (Table 22).

Table 20 Distribution of continuity-of-care scores by type of care setting and whether practice has named diabetes lead

	Frequency (column %)	Total continuity score	Longitudinal continuity	Flexible continuity	Relational continuity	Team and cross-boundary continuity
Type of care						
GP only	44	65.1 (15.6)	12.5 (5.3)	18.4 (4.5)	17.0 (7.0)	17.2 (3.4)
Hospital clinic only	35	50.2 (18.1)	9.1 (5.4)	15.4 (5.9)	9.4 (9.5)	16.3 (3.1)
Shared care	114	64.7 (13.8)	12.8 (5.0)	18.3 (4.1)	16.5 (6.4)	17.1 (3.1)
Adjusted difference[a] (95% CI) (hospital clinic vs. general practice or shared care)		−13.7 (−19.2 to −8.2)	−3.2 (−5.1 to −1.2)	−2.8 (−4.5 to −1.2)	−7.1 (−9.7 to −4.5)	−0.7 (−1.8 to 0.5)
P value		<0.001	0.001	0.001	<0.001	0.239
Practice has named lead doctor for diabetes (number of practices)						
No named GP lead (7)	59	56.8 (15.4)	10.9 (4.7)	16.4 (5.3)	13.5 (8.1)	16.1 (2.5)
Named GP lead (9)	96	65.6 (16.0)	12.6 (5.3)	18.9 (4.3)	16.5 (7.4)	17.6 (3.3)
Not known (3)	38	61.6 (14.8)	12.6 (5.8)	17.2 (4.2)	15.1 (7.4)	16.7 (3.5)
Adjusted difference[b] (95% CI)		8.2 (2.7 to 13.6)	1.7 (−0.3 to 3.6)	2.3 (0.6 to 4.0)	2.7 (0.2 to 5.2)	1.5 (0.5 to 2.5)
P value		0.003	0.088	0.007	0.036	0.003

[a]*Adjusted for whether practice has named lead doctor for diabetes.*

[b]*Adjusted for type of care.*

Table 21 Associations between continuity-of-care scores and numbers of consultations in the preceding 12 months

Total number of general practice consultations	Frequency	Total continuity	Longitudinal continuity	Flexible continuity	Relational continuity	Team and cross-boundary continuity
0–1	37	52.9 (17.4)	9.2 (5.0)	16.1 (5.2)	11.5 (9.0)	16.0 (3.3)
2–3	52	61.9 (14.3)	10.6 (4.9)	18.2 (4.4)	15.9 (7.3)	17.2 (3.2)
4–5	47	65.4 (12.7)	13.8 (4.8)	18.1 (3.9)	16.6 (6.5)	16.9 (2.7)
6+	43	68.0 (16.6)	15.0 (4.6)	18.7 (4.6)	16.8 (7.6)	17.6 (3.5)
Not known	14	58.5 (16.3)	10.4 (5.1)	16.4 (6.4)	14.7 (7.4)	16.9 (2.7)
P value[a]		<0.001	<0.001	0.105	0.011	0.053

[a]*Test for trend in score with increasing number of consultations.*

Figures are means except where indicated.

Table 22 Distribution of continuity-of-care scores by type of care setting and ethnicity

	Frequency (column %)	Total continuity score	Longitudinal continuity	Flexible continuity	Relational continuity	Team and cross-boundary continuity
First language						
English	146	63.6 (15.6)	12.2 (5.1)	18.4 (4.6)	15.9 (7.4)	17.1 (3.2)
Other	47	57.5 (16.6)[a]	11.8 (5.9)	15.7 (4.6)[b]	13.5 (8.4)[c]	16.6 (3.1)
Gender						
Male	96	63.6 (15.6)	12.2 (5.4)	18.2 (4.5)	15.8 (7.7)	17.4 (3.2)
Female	97	60.7 (16.3)	11.9 (5.2)	17.4 (4.9)	14.8 (7.7)	16.5 (3.1)
Duration of diabetes (years)						
1–5	63	65.4 (14.7)	13.2 (5.5)	18.2 (4.4)	17.0 (6.3)	16.9 (3.1)
6–10	61	61.9 (16.0)	11.6 (4.7)	18.1 (4.5)	15.5 (7.5)	16.7 (3.3)
11–15	33	63.6 (15.8)	11.1 (5.7)	18.6 (7.6)	16.0 (7.6)	17.9 (3.0)
16+	32	54.9 (17,4)	11.8 (5.4)	15.4 (5.7)	11.2 (9.2)	16.5 (3.3)
Not known	4	60.3 (12.3)	11.6 (5.7)	17.8 (2.6)	14.0 (10.1)	17.0 (3.5)
Age group (years)						
<45	12	65.1 (12.1)	12.1 (4.4)	19.6 (2.5)	16.7 (6.3)	16.8 (3.6)
45–54	24	61.4 (10.8)	11.9 (4.5)	17.3 (3.1)	16.0 (5.4)	16.2 (3.1)
55–64	48	60.9 (17.6)	12.4 (5.7)	17.1 (5.4)	14.9 (7.8)	16.5 (3.1)
65–74	73	63.9 (15.6)	12.5 (5.6)	18.1 (4.9)	16.0 (7.5)	17.3 (3.2)
≥74	36	59.8 (18.6)	11.0 (4.8)	17.6 (4.8)	13.7 (9.5)	17.4 (3.2)

[a]P=0.009; [b]P<0.001; [c]P=0.042.

Figures are mean (±SD) except where indicated.

7.6 Discussion

This section has described the development and testing of a 19-item measure of experienced continuity of care in type 2 diabetes mellitus. The measure is grounded in qualitative data from diabetic patients. It provides an overall measure of experienced continuity of care as well as sub-domains of longitudinal, flexible, relational and team and cross-boundary continuity. Evidence for the reliability of the overall scale is provided by the item–score correlations and satisfactory value for Cronbach's alpha. The alpha coefficient can be interpreted as the expected correlation of the measure with a hypothetical alternative questionnaire composed of a different sample of the same number of items (Nunally, 1978). The square root of alpha, in this case 0.953, gives the estimated correlation of measured scale scores with error-free 'true' scores (Nunally, 1978). Further evidence of the reliability of the measure is provided by the observation that subjects registered with the same general practices gave more similar scores for experienced continuity of care than subjects from different practices. Evidence of test-retest reliability or repeatability was provided by comparing responses obtained from repeat administration in self-completion and telephone interview formats. Evidence for the construct validity of the continuity-of-care measure is provided by the results of the factor analysis which confirmed the proposed structure of the measure. The criterion validity of the measure is supported by the finding that measured experienced continuity of care was substantially higher for subjects who received some diabetes care from their general practice, especially if there was a named lead doctor for diabetes. This is consistent with the qualitative data.

Whereas the experienced continuity-of-care measure generally had satisfactory psychometric properties, some issues require clarification in future studies. The second longitudinal continuity item appeared to have different properties than the other ECC items with low values for mean score, inter-item correlation and factor loading and high uniqueness. This was explained by the finding that 70% of patients receiving care from their general practice did not receive appointment letters. It was decided to retain this item because systematic review evidence suggests that call–recall systems in primary care can improve longitudinal continuity and outcomes of care (Griffin, 1998; Renders *et al.*, 2001). Eight of the items referred to the concept of a usual doctor or nurse. This was further defined as the doctor or nurse who knows you and your diabetes best. When a patient could not identify a usual doctor or nurse then all of these items scored zero, leading to high correlation between these items. Although this lack of independence is an undesirable property of the measure from a statistical point of view, the importance attached to the concept of a usual doctor or nurse, both in the literature on continuity of care (O'Connor *et al*., 1998; Kearley *et al.*, 2001) and in our qualitative data, make this essential. When the dependent items were omitted, then alpha was estimated to be a satisfactory 0.793 from a scale with 12 independent items. The team and cross-boundary continuity items

appeared to have satisfactory psychometric properties but assessment of team and cross-boundary continuity did not vary between practices, between types of care, or according to frequency of general practice visits. This may suggest that team and cross-boundary continuity does not vary according to these variables, but equally it is possible that the questions relating to team and cross-boundary continuity lack discrimination because patients are not well able to judge these aspects of their care.

A limitation of this study is the low response rate achieved in the interview survey. This is a general finding in inner-city areas. The sample included subjects with a wide range of continuity scores and the low response rate is unlikely to have affected the internal validity of our findings. We acknowledge that larger studies will be required in order to establish the external validity of these findings with more confidence.

7.7 Summary

We have described a 19-item measure of experienced continuity of care which may be used in research and routine monitoring of diabetes services. We have provided evidence for the reliability, construct validity and criterion validity of the measure. The measure is brief, quick to complete, acceptable to patients and applicable for use in both hospital and care settings, and therefore suitable for use in the routine monitoring of quality of care. The measure may be used in ambulatory care in both specialist and general-practice settings in order to provide information concerning factors that enhance or impede continuity of care and the relationship between continuity, processes of care and health outcomes.

Subjects with diabetes mellitus often have other comorbid conditions. Diabetes is viewed as part of a metabolic syndrome in which obesity, hypertension and hyperlipidaemia may also coexist. As complications develop later in the course of the illness, patients may develop angina or congestive cardiac failure or disability from stroke or visual loss. As multiple chronic problems may often be present, it will be useful to develop a more generic measure of continuity of care in chronic illness. This may be achieved by adapting the ECC-DM measure into a generic form.

Section 8 Experienced continuity of care and health outcomes: cohort study

8.1 Summary

Objective: to evaluate changes in clinical and patient outcomes over time and to evaluate whether these are associated with continuity in the experience of care.

What we did: we conducted a cohort study of type 2 diabetic patients attending 19 general practices in two inner-London Boroughs. Subjects were interviewed at home; the study questionnaire included the experienced continuity-of-care measure, the SF-12 questionnaire, a measure of global satisfaction with care, and confounding variables. Measurements were made of height, weight, blood pressure and glycated haemoglobin (HbA1c). Patients were followed-up with repeat interviews and measurements after 10 months. Analyses were adjusted for baseline values, age, sex, ethnicity, duration of diabetes, diabetes treatment, education, housing tenure and whether living alone.

What we found: interviews were obtained at baseline with 209/553 (38%) of eligible subjects. Experienced continuity scores were obtained for 193 (85%) of participants at baseline and 156 (75%) at follow-up. There were no differences in continuity scores or health measures between those followed-up and those lost to follow-up. Higher experienced continuity of care was associated with higher global satisfaction ratings. Experienced continuity of care was positively associated with number of consultations in the last 12 months, but negatively associated with the number of different individual professionals seen. Experienced continuity of care was not associated with HbA1c (coefficient for 10-unit increase in ECC score, −0.09%, −0.29 to 0.12%, P=0.402). ECC scores were not associated with systolic or diastolic blood pressure, body weight, body mass index or SF-12 physical or mental functioning scores.

What we conclude: experienced continuity of care encompasses patients' perceptions of the interpersonal aspects of their care and the degree of coordination of care. Dimensions of experienced continuity are therefore conceptually related to more traditional assessments of patient satisfaction. Measurements of experienced continuity of care are associated with patients' global ratings of their overall satisfaction with care received.

Experienced continuity of care is not associated with health outcomes including changes in glycated haemoglobin (HbA1c), blood pressure or body weight during approximately 10 months of follow-up; nor is experienced continuity of care associated with physical and mental functioning scores from the SF-12 questionnaire.

8.2 Introduction

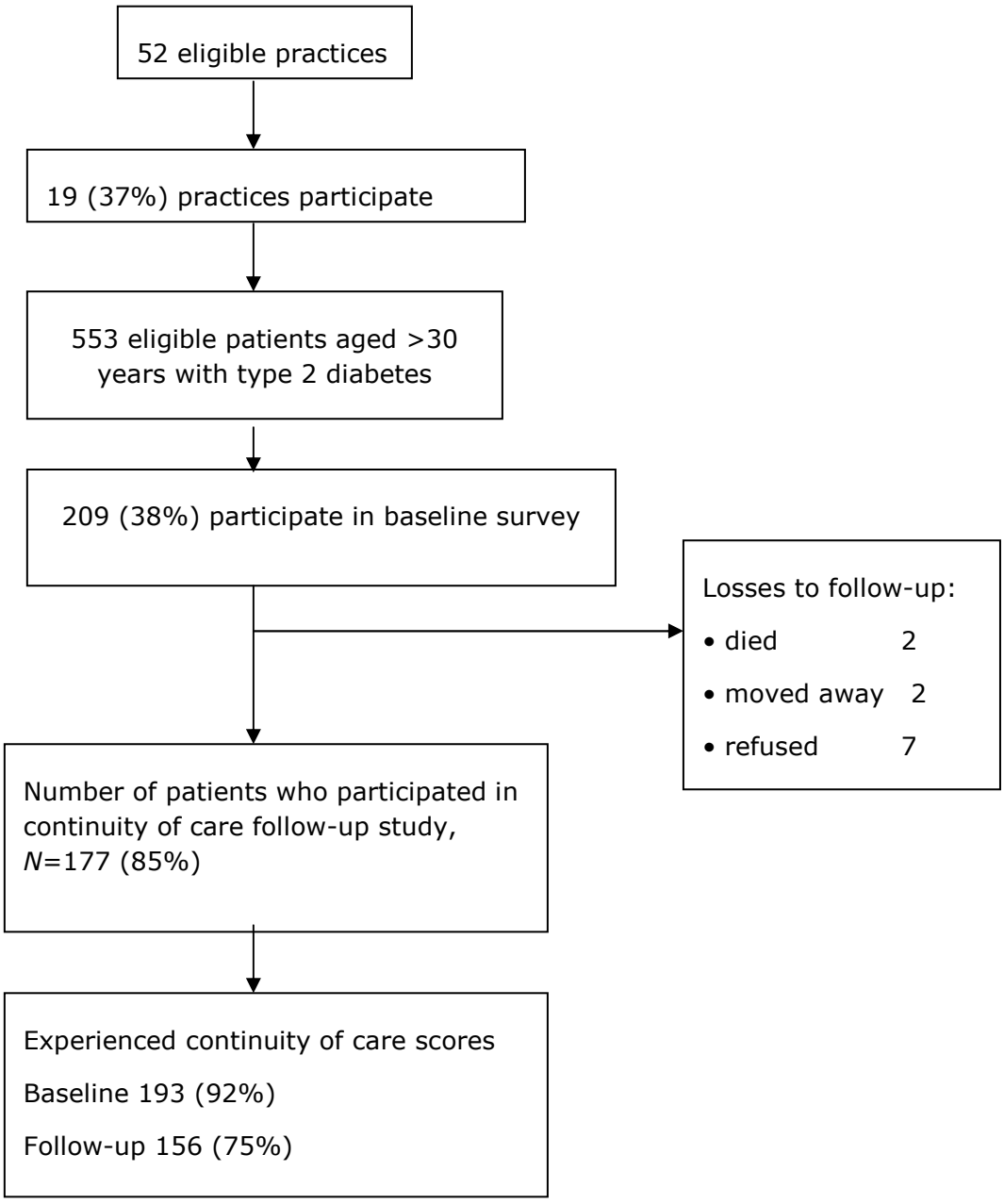
A cohort study was conducted in order to evaluate whether continuity of care is associated with health outcomes in type 2 diabetes mellitus. Patients' experienced continuity of care was measured using the new ECC-DM measure, while continuity in the delivery of care was measured using the number of consultations and the number of different individual professionals seen in the last 12 months. Health outcomes included glycated haemoglobin (HbA1c), blood pressure, weight, body mass index and physical and mental functioning. A global measure of patients' satisfaction with their care was obtained.

8.3 Methods

8.3.1 Subjects

We invited all 52 general practices within the boundaries of two adjacent inner-London primary care groups to participate in the study and 19 agreed to participate. These included 16 practices that had recently participated in a locally organised evaluation of diabetes care. For the diabetes-care evaluation, each practice provided a list of all registered diabetic patients and all were included if the total was less than 100, or a random sample of 100 if there were more than this number. There were three practices which gave updated lists of patients with type 2 diabetes for the present continuity of care study. This gave a sample of 1438 diabetic patients. For the present continuity-of-care study, we selected the 435 (30%) of patients who had returned the postal evaluation questionnaire and who had type 2 diabetes based on age at diagnosis greater than 30 years and not treated with insulin within 6 months of diagnosis. These subjects were chosen because they had already consented to participate in the earlier study. For three additional practices which did not take part in the local diabetes evaluation, we obtained new lists of 118 registered patients with type 2 diabetes diagnosed by the clinical staff. This gave a total of 553 patients from 19 general practices who were eligible for the present study (Figure 4).

Figure 4 Selection and follow-up of subjects for cohort study



8.3.2 Procedures

Interview

Subjects were invited to participate by letter; non-responders were followed-up by telephone and repeat letters. Participating subjects were visited at home and gave written informed consent to participation. The study questionnaire (Appendix 1) was administered by interview. The questionnaires used at baseline and follow-up included the experienced continuity-of-care measure; age, sex, ethnicity and language; socioeconomic variables; lifestyle variables; diabetes treatment; type of care arrangement; adherence with medicines; and health status (Table 23). In the follow-up questionnaire the SF-12 measure was included in place of self-rated

health, and an item was included concerning overall satisfaction with treatment.

Table 23 Questionnaire items at baseline and follow-up

	Baseline questionnaire	Follow-up questionnaire
Experienced continuity of care	Y	Y
Date of birth	Y	Y
Sex	Y	Y
Duration of diabetes	Y	Y
Current treatment for diabetes	Y	Y
Type of care arrangement	Y	Y
Ethnicity	Y	Y
Language	Y	Y
Access to interpreter	Y	Y
Highest qualifications	Y	Y
Living arrangement	Y	Y
Employment status	Y	Y
Car ownership	Y	Y
Housing tenure	Y	Y
Alcohol and smoking	Y	Y
Self-reported conditions	Y	Y
Long-standing illness	Y	Y
Physical activity	Y	Y
Adherence with medicines	Y	Y
Self-rated health	Y	–
SF-12	–	Y
Self-reported treatment of conditions	–	Y
Satisfaction with treatment	–	Y

Measurements

After the interview, measurements were made of height, weight and blood pressure. Standard measurement procedures were used, adapted from the protocol of the Health Survey for England (Erens and Primatesta, 1999). Height and weight were measured in subjects wearing light indoor clothes but without shoes. Height was measured using a Soehnle electronic height-measuring unit; weight was measured using electronic weighing scales (Seca 884). Weight was recorded once; height was taken twice, but repeated if values differed by more than 1 cm, and the mean value was used. Blood pressure was measured using an Omron 705IT blood-pressure-measuring device, using a large cuff if the patient was obese. The Omron device has been shown to give valid results (dabl Educational Trust, 2005). Blood pressure was taken with the subject seated after completing the

interview. Three blood-pressure readings were taken and the mean of the second two used. Any difficulties encountered in the measurements were recorded. Fieldworkers were trained in measurement procedures and a pilot study was conducted on non-study subjects. The pilot-study results (Table 24) showed that there was good precision for all measurements and excellent inter-observer reliability for measurements of weight and blood pressure. For height, there was a slight bias for one fieldworker as compared to the other of 0.68 cm, which was considered to be quantitatively unimportant. Finally, a blood sample was taken for HbA1c estimation. The blood sample was either taken in the patient's home, or the patient was provided with a request form and asked to have the test taken at either their general practice or the hospital clinic. All HbA1c estimations were performed in the Chemical Pathology laboratories at Guy's and St Thomas' Hospitals.

Table 24 Results of pilot study of measurement procedures on 20 subjects before baseline survey showing agreement between two fieldworkers

	Fieldworker 1	Fieldworker 2	Mean difference (95% CI)
Height (cm)	170.1 (9.0)	170.8 (9.5)	−0.68 (−1.29 to −0.06)
Weight (kg)	72.1 (13.9)	72.0 (13.8)	0.16 (−0.03 to 0.35)
Systolic blood pressure (mmHg)	121.8 (9.5)	122.3 (11.2)	0.53 (−4.37 to 3.32)
Diastolic blood pressure (mmHg)	74.7 (9.0)	74.4 (6.9)	0.28 (−3.30 to 3.85)

Data in the fieldworker columns are means±SD.

Clinical-data abstraction

Data were extracted from each patient's general-practice record. Information was obtained concerning patterns of consultation in the 12 months before the interview date. The items of data collected at baseline and follow-up are summarised in Table 25. At follow-up we specifically collected data concerning the number of different individual professionals seen for consultations during the study period. All clinical-data extraction was performed by SN.

Table 25 Clinical-data abstraction at baseline and follow-up

	Baseline	Follow-up
Date	Y	Y
Sex	Y	Y
Date of birth	Y	Y
Date of first visit for diabetes	Y	Y
Age at diagnosis	Y	Y
Insulin treatment	Y	Y
Duration of diabetes	Y	Y
Weight	Y	Y
Height	Y	Y
Blood pressure	Y	Y
Glycated haemoglobin	Y	Y
Total consultations	Y	Y
Number of professionals seen	–	Y
GP consultations	Y	Y
Number of different GPs seen	–	Y
Nurse consultations	Y	Y
Number of different nurses seen	–	Y
Other consultations	Y	Y
Number of other professionals seen	–	Y
Hospital outpatient visits	Y	Y
Inpatient visits	Y	Y

8.3.3 Analysis

The primary objective of the analysis was to determine whether continuity of care was associated with outcome measures, including HbA1c (the primary outcome), blood pressure, weight and body mass index or subjective health status. An analysis-of-covariance framework was employed to evaluate whether HbA1c at follow-up was associated with experienced continuity of care after adjusting for HbA1c at baseline. Experienced continuity was fitted as the mean of the values at baseline and follow-up, but the results were not sensitive to

whether either baseline or follow-up value or both were fitted. Additional adjustment was made for age, sex, ethnicity, duration of diabetes, diabetes treatment, housing tenure, educational qualifications and whether living alone. Models were fitted, with the patient's general practice as a random effect, using maximum-likelihood estimation. Additional models were fitted with the number of consultations in the last 12 months, the number of different professionals seen or the global rating of patient satisfaction as predictors. The continuity-of-care index was also calculated but as this index was not linearly associated with the total number of consultations in the last 12 months, it was considered more appropriate to fit the number of consultations, and number of professionals seen, as two independent predictors.

8.3 Results

There were 553 eligible subjects and 209 (38%) were interviewed at baseline. Of these 177 (85%) were re-interviewed at the follow-up visit, which was at a mean of 43 weeks (range 24–76 weeks) later. The characteristics of the subjects included in the study are shown in Table 26. The mean age was 65 years (range 32–90 years) and 97 were women. Consistent with the inner-city location of the study, 52% of subjects were from ethnic minorities with African and African Caribbean groups being the most frequent; 24% did not have English as their first language; 65% were in rented accommodation; only 7% had university qualifications; and 35% were living alone (Table 26).

Table 26 Characteristics of 193 subjects included in study

Variable	Category	Frequency (%)
Age (years)	<45	12 (6)
	45–54	24 (12)
	55–64	48 (25)
	65–75	73 (38)
	≥75	36 (19)
Sex	Women	97 (50)
Duration of diabetes (years)	≤5	63 (33)
	6–10	61 (32)
	11–15	33 (17)
	≥16	32 (17)
	Not known	4 (2)
Diabetes treatment	Diet	17 (9)
	Tablets	131 (68)
	Insulin	45 (23)
Type of care at baseline	General practice	44 (23)
	Hospital	35 (18)
	Shared care	114 (59)
Ethnicity	'White'	92 (48)
	'Black Caribbean/African'	60 (31)
	'Indian subcontinent'	18 (9)
	'Other'	23 (12)
Language	English not first language	47 (24)
Housing tenure	Owner-occupied	67 (35)
	Local-authority rented	93 (48)
	Housing association/private rented	33 (17)
Education	No qualifications/O level	143 (74)
	A level or technical	36 (19)
	University	14 (7)
Living alone		68 (35)
Current smoker		28 (15)
Self-reported morbidity	High blood pressure	134 (69)
	Angina	48 (25)
	Heart attack	27 (14)
	Stroke	19 (10)
Self-rated health	Fair or poor	116 (60)

There were 193 subjects whose responses provided a total experienced continuity score at baseline and 156 who gave scores both at baseline and follow-up. The overall distribution of experienced continuity scale scores were similar at baseline and follow-up (Table 27), as were values for health outcome measures (Table 27). As expected, the highest correlations between baseline and follow-up were observed for weight, height and body mass index. Correlation coefficients of about 0.5 were observed for blood pressure and glycated haemoglobin, and the correlation for the total experienced continuity score was only slightly lower at nearly 0.4. This was judged to be satisfactory. Correlations for subscale scores were generally slightly lower but these were based on responses to small numbers of items.

Table 27 Assessment of experienced continuity of care at baseline and follow-up

	Baseline (*n*=193)	**Follow-up (*n*=156)**	**Correlation (*n*=156)**
Experienced continuity of care			
Total experienced continuity of care	62.1 (16.0)	64.8 (12.8)	0.398
Longitudinal continuity	12.1 (5.3)	12.5 (5.6)	0.388
Flexible continuity	17.8 (4.7)	18.9 (4.4)	0.412
Relational continuity	15.3 (7.7)	16.9 (5.5)	0.276
Team and cross-boundary continuity	17.0 (3.2)	16.6 (2.7)	0.234
Health outcome measures			
HbA1c (%)	7.62 (1.71)	7.70 (1.62)	0.524
Systolic blood pressure (mmHg)	149.0 (21.8)	146.7 (20.8)	0.526
Diastolic blood pressure (mmHg)	79.3 (10.7)	76.7 (10.9)	0.538
Weight (kg)	83.4 (16.2)	83.6 (16.8)	0.962
Height (m)	165.3 (9.71)	165.8 (9.75)	0.944
Body mass index (kg/m^2)	30.6 (5.7)	30.5 (5.6)	0.944
SF-12			
Physical component	–	39.2 (13.0)	–
Mental component	–	49.0 (10.4)	–

Data in the middle columns are means±SD.

Table 28 shows baseline values for outcome measures, self-rated health, total experienced continuity-of-care score and numbers of consultations in the preceding 12 months for those who were successfully followed-up with repeat interviews and those who were not. There were no systematic differences between those who were re-interviewed and those who were not for any of the measures. A slightly higher proportion of subjects lost to follow-up rated their

health as 'poor', and the consultation rate was slightly lower, but these differences were not statistically significant.

Table 28 Comparison of patients lost to follow-up with those interviewed at follow-up

	Baseline values		***P* value**
	Followed-up (n=156)	***Lost to follow-up (n=37)***	
HbA1c (%)	7.62 (1.73)	7.61 (1.69)	0.999
Systolic blood pressure (mmHg)	148.9 (22.2)	149.2 (20.2)	0.932
Diastolic blood pressure (mmHg)	79.3 (10.9)	79.0 (9.9)	0.840
Weight (kg)	84.2 (16.5)	80.3 (14.9)	0.193
Height (m)	165.7 (9.6)	163.8 (10.1)	0.277
Body mass index (kg/m^2)	30.7 (5.7)	30.1 (6.1)	0.568
Self-rated health			
Excellent/very good	16 (10)	4 (11)	0.367
Good	48 (31)	9 (24)	
Fair	69 (44)	14 (38)	
Poor	23 (15)	10 (27)	
Total experienced continuity of care	62.0 (15.3)	62.6 (18.8)	0.732
Number of consultations in preceding 12 months	4.2 (3.1)	3.5 (2.5)	0.187

The main results from the cohort study are shown in Table 29. The difference in outcome for each 10-unit increase in experienced continuity of care was estimated after adjusting for the baseline value of the outcome. It was clear that total experienced continuity of care was not associated with HbA1c, systolic blood pressure, diastolic blood pressure, weight, body mass index or SF-12 physical or mental component scores. Modelling experienced continuity of care as a categorical variable with four quartiles did not lead to any difference in interpretation. Adjusting for a wide range of confounders had negligible influence on the estimates. Adjusting the analysis for the mental component score for physical component score had little effect. Table 30 shows the association of experienced continuity of care with consultation-based measures. Experienced continuity of care increased with the number of consultations in the last 12 months, but decreased as the number of different individual professionals seen increased. Neither consultation measure was associated with the HbA1c value.

Table 29 Change in outcome measure associated with a 10-unit change in experienced continuity of care

	Cases analysed	Model 1[a]		Model 2[b]	
		Coefficient[c] (95% CI)	***P value***	***Coefficient[c] (95% CI)***	***P value***
HbA1c (%)	151	−0.07 (−0.26 to 0.13)	0.504	−0.09 (−0.29 to 0.12)	0.402
Systolic blood pressure (mmHg)	155	−1.72 (−4.1 to 0.63)	0.150	−0.41 (−2.88 to 2.06)	0.746
Diastolic blood pressure (mmHg)	155	0.09 (−1.13 to 1.31)	0.886	0.24 (−1.03 to 1.51)	0.713
Weight (kg)	155	0.31 (−0.31 to 0.93)	0.329	0.23 (−0.40 to 0.86)	0.473
Body mass index (kg/m^2)	150	0.03 (−0.23 to 0.28)	0.850	−0.08 (−0.34 to 0.18)	0.562
SF-12[d]					
Physical component score (range 0–100)	153	1.03 (−0.54 to 2.61)	0.201	0.73 (−0.88 to 2.35)	0.375
Mental component score (range 0–100)	153	0.73 (−0.61 to 2.07)	0.286	0.33 (−1.11 to 1.77)	0.655

[a]*Model 1: adjusted for baseline value of outcome only.*

[b]*Model 2: adjusted for baseline value of outcome, age, sex, ethnicity, duration of diabetes, type of treatment, qualifications, housing tenure and living alone.*

[c]*Coefficients represent the unit change in outcome per 10-unit change in total experienced continuity-of-care score; see text for details.*

[d]*Models were adjusted for self-rated health at baseline.*

Table 30 Association of outcomes with consultation-based measures

	Observations	Median (range)	Experienced continuity score		HbA1c	
			Coefficient (95% CI)[a]	***P value***	***Coefficient (95% CI)[b]***	***P value***
Number of consultations in last 12 months	135	5 (0–16)	2.21 (1.29 to 3.13)	<0.001	0.05 (−0.06 to 0.15)	0.398
Number of different professionals seen in last 12 months	135	2 (0–7)	−1.92 (−3.74 to −0.08)	0.041	0.05 (−0.16 to 0.27)	0.611

[a]*Coefficient represents change in experienced continuity per additional consultation, or per additional professional seen, adjusted for the other variable.*

[b]*Coefficient represents change in HbA1c per additional consultation, or per additional professional seen, adjusted for the other variable and for baseline HbA1c.*

Table 31 shows the association of experienced continuity of care with patients' global ratings of satisfaction with care. The rating was made on a Likert scale, ranging from one to six in value, but as there were only seven values rated lower than four, the lowest four categories were combined. Total experienced continuity of care was strongly associated with patients' global rating of satisfaction with their treatment. The subscales of flexible, relational and team and cross-boundary continuity were similarly associated. Longitudinal continuity, which depended on the number of consultations, was not associated with patient satisfaction. Relational continuity was only associated with satisfaction after additional adjustment for the type of care received. The proportion of subjects receiving 'hospital-only' care was not distributed uniformly across satisfaction categories.

Table 31 Association of continuity-of-care scores with global satisfaction ratings

Experienced continuity of care	Satisfaction rating			*P* value[a]
	Lowest (n=43)	***Middle (n=48)***	***Highest (n=65)***	
Total	60.9 (11.7)	62.8 (13.3)	68.9 (12.1)	0.001
Longitudinal	12.1 (5.4)	12.3 (6.0)	12.8 (5.5)	0.533
Flexible	16.9 (5.4)	18.5 (3.8)	20.6 (3.5)	<0.001
Relational	16.5 (4.6)	15.5 (6.6)	18.2 (5.1)	0.060[b]
Team and cross-boundary	15.4 (2.2)	16.5 (2.5)	17.4 (2.8)	<0.001

[a]*Test for trend across satisfaction ratings.*

[b]*After adjusting for type of care setting (hospital, GP or shared), P=0.028.*

Figures are means (±SD) except where indicated.

8.4 Discussion

In this health-care setting, patients' ratings of experienced continuity of care are strongly associated with their overall ratings of satisfaction with care received. Experienced continuity of care also increases as the consultation frequency increases and the number of different professionals seen declines. However, over a period of approximately 10 months, experienced continuity of care is not associated with intermediate outcomes of diabetic care including glycated haemoglobin, blood pressure and body weight or with health-related quality of life measured using the SF-12 questionnaire.

8.4.1 Interpretation

The view that establishing and maintaining experienced continuity of care should result in better management decisions, improved personal care and increased patient adherence with treatment recommendations may be considered a naïve view. This can be illustrated by a number of hypothetical examples (Table 32). First, experienced continuity of care may be expected to increase during the course of diabetic illness as patient and professional become better acquainted and establish a 'close' and 'familiar' relationship

but, at the same time, the natural history of the diabetic illness is for blood-glucose control to deteriorate. In the UK Prospective Diabetes Study, blood-glucose concentrations increased over time in both the intensive-control and usual-care groups (UKPDS Group, 1998a). According to this scenario, increasing continuity of care may be associated with worsening blood-glucose control (Table 32). Second, if a patient's blood-glucose concentration reaches levels which the patient's professional considers unacceptable, the patient may be referred to the hospital clinic for initiation of insulin therapy. Here, experienced continuity of care may be expected to deteriorate, yet blood-glucose control may improve. Third, if a 77-year-old patient has been managed for years by an older GP who considers that tight blood-glucose control is not essential in older patients. When the GP retires and is replaced by a young doctor who is more enthusiastic about tight blood-glucose control then experienced continuity of care may again deteriorate while blood-glucose control improves. This example is consistent with Broom's suggestion that familiarity may sometimes breed neglect (Broom, 2003).

Table 32 Hypothetical scenarios giving differing associations between continuity of care and glycated haemoglobin values

Scenario	Events	Experienced continuity	HbA1c
'Naïve'	Patient and provider establish a relationship over time leading to improving treatment outcomes	↑	↓
'Natural history of disease'	Patient and professional establish a relationship over time; condition progresses over time with worsening blood-glucose control	↑	↑
'Transitions associated with lower continuity'	Unsatisfactory blood-glucose control; patient referred to hospital clinic for initiation of insulin	↓	↓
	Older GP retires, younger replacement adopts more-intensive management approach	↓	↓
	Patient develops infected foot ulcer associated with worsening blood-glucose control, requires admission to hospital and follow-up in hospital clinic	↓	↑

Consideration of plausible chains of causation suggest that blood-glucose control and experienced continuity of care may sometimes be positively or negatively associated, either in different patients or at different times in the same patient.

A further reason why continuity of care may not be associated with health outcomes is that there may be no consistent association between continuity and other aspects of quality of care. The technical quality of care is part of the pathway which is presumed to link continuity of care to health outcomes, but there may not be any direct link between patients'

experiences of continuity of care and the quality of care as judged according to the medical model.

Another important consideration is the relatively limited effectiveness of interventions in type 2 diabetes. Even in the context of clinical trials of efficacy, the secondary prevention interventions illustrated in Table 3 are generally associated with 'numbers needed to treat' to prevent one adverse event of 100 patient years or more. Somewhat lower effectiveness may be expected in routine clinical practice. When interventions are of limited effectiveness, possible associations with patient-centred measures may not be readily demonstrated.

The finding of no consistent overall association between experienced continuity of care and blood-glucose control is, in our view, a credible and fully understandable finding. Continuity of care is valued as an indication of greater patient-centredness of care; the expectation that continuity of care should necessarily be associated with greater effectiveness or efficiency may be regarded as a category error.

8.4.2 Patient safety

Our data do not address questions of patient safety. It is plausible that continuity of provider may be associated with fewer adverse events such as prescribing errors, or avoidable metabolic emergencies including hypoglycaemic episodes, or late presentations with advanced diabetic complications. Larger studies would be required to determine whether such associations exist. If there is an association between continuity of care and patient safety, then this would be important.

8.4.3 Strengths and limitations of study

The data collected for the study were obtained from face-to-face interviews and from specially organised measurements. We showed that the measure of experienced continuity-of-care measure had satisfactory psychometric properties as well as good short-term repeatability. The measurement procedures were standardised and their reliability was demonstrated. A limitation of the study is the response rate of approximately 38% in the baseline survey. This may compromise the generalisability of the study. In addition, if subjects who took part in the survey differed from those who declined to take part then the validity of the main results may be questioned. However, among those who participated at baseline, there was no difference in continuity of care or health measures between those who were successfully followed-up and those who were lost to follow-up. This is an important observation which provides evidence against a systematic non-response bias. It appears unlikely that those who participated at baseline differed systematically from non-responders, whereas at follow-up there was no difference between responders and non-responders. Analysis of data according to follow-up status therefore provides strong evidence against a substantial effect from non-response bias. Whereas the achieved sample size was relatively modest, the estimates were precise and it was clear that there was no evidence against the null hypothesis for any of the outcomes.

We made adjustment for a range of confounders including socioeconomic status and duration of illness as well as the baseline value of the outcome as a covariate. In general, adjustment for confounders had negligible effect on the magnitude of the estimates and this argues against the possible influence of unmeasured confounders.

8.4.4 Comparison with previous studies

Two systematic reviews (Cabana and Jee, 2004; Saultz and Lochner, 2005) have suggested that continuity of care is associated with better 'outcomes', but in these reports continuity of care was associated with patterns of health-service utilisation, including hospital admissions and uptake of preventive medical services. Empirical studies investigating whether continuity of care is associated with glycated haemoglobin have given inconsistent results, with some showing no association and others showing either positive or negative associations (O'Connor *et al*., 1998; Hanninen *et al.*, 2001; Overland *et al.*, 2001; Parchman *et al.*, 2002; Alazri and Neal, 2003; Sherina *et al.*, 2003; see Table 4). Thus the present results are consistent with those of previous studies.

8.5 Conclusion

This study provides precise estimates of the association between experienced continuity of care and health outcomes in type 2 diabetes mellitus. We provide evidence that the negative findings are unlikely to be explained by non-response bias. We have also adjusted for a range of relevant confounders. Based on these analyses, it appears safe to conclude that experienced continuity of care is not, in this health-care setting, an important influence on values for glycated haemoglobin, blood pressure, body weight or health-related quality of life in subjects with type 2 diabetes.

Section 9 Vulnerable groups and continuity of diabetes care: experiences of carers and South Asian patients

9.1 Summary

Objective: to conduct further qualitative work including the evaluation of the views and experiences of carers and South Asian patients.

What we did: in-depth interviews were held with seven carers of diabetic patients and 12 South Asian patients in order to understand their experiences with respect to continuity of care.

What we found: carers generally commented negatively on the quality of their relationships with health professionals. Carers perceived that professionals' reluctance to involve carers could result in a failure to fully appreciate patients' and carers' needs. This could be a particular problem with respect to mental health needs. South Asian patients generally expressed similar experiences and values with respect to continuity as other patients did. Differences in language contributed to less favourable experiences of continuity of care, whereas services were sometimes not sufficiently flexible with respect to cultural differences, as for example in the provision of appropriate dietary advice.

What we conclude: differences in language, culture, disability or mental illness may contribute to difficulties in establishing and maintaining continuity of care.

9.2 Background

South Asian patients and carers of diabetic patients were identified as groups who could experience particular difficulties with respect to continuity of care. In-depth interviews were therefore carried out in order to understand the experiences of these groups of service users.

9.3 Carers of diabetic patients

The importance of carers in the management of patients with chronic illnesses was highlighted in Section 3.1 of this report. Unpaid care to dependent friends and relatives is provided by 16% of people over 50 years, with nearly one-quarter of carers providing care for 50 or more hours a week. Such informal care may be very important for patients with diabetes of long standing who may have multiple complications of the condition.

9.3.1 Aims and objectives

Qualitative methods were used to evaluate carers' experiences of continuity of care in type 2 diabetes. The specific objectives of this part of the project

was to hold in-depth interviews with carers of diabetic patients understand their values and experiences with respect to continuity in diabetes care.

9.3.2 Subjects and interviews

Potential participants were identified by the two fieldworkers (SN and SW; see Contributors) while carrying out interviews with diabetic patients for the cohort study. SN contacted each potential participant by phone and explained the nature of the research study. An information sheet was also provided and consent sought. When consent was obtained, the researcher contacted the participant and arranged a convenient time, location and language for the interview. All of the interviews took place in the homes of the participants. All the interviews were conducted in English. Four of the interviews were conducted in the presence of the care recipient. Interviews covered respondents experiences of caring, their relationship with staff across care settings, the flexibility of services provided, the changing needs of the care recipient and the availability of information and support.

All interviews were audio-taped and fully transcribed. Interviews took between 45 and 90 minutes to complete. Analysis of the interviews involved using a thematic approach.

The seven carers interviewed comprised five white respondents and two people of South Asian origin. Their ages ranged from 25 to 76 years. Six were female, caring on a full-time basis for over 5 years (see Table 33). Care recipients' ages ranged from 66 to 78 years. They included four partners and two parents, and one was a friend. Six care recipients were currently receiving diabetes care from the general practice, with district nurse home visits and occasional visits to the practice. Diabetes often has accompanying (or underlying) problems, and all care recipients were living with at least two of the conditions listed in Table 33.

Table 33 Characteristics of carers and care recipients

Carers		**Care recipients**	
Carer gender		***Care recipient gender***	
Male	1	Male	5
Female	6	Female	2
Carer ethnicity		***Care recipient ethnicity***	
White	5	White	3
Indian	1	Indian	2
Bangladeshi	1	Bangladeshi	1
		Black	1
Carer conditions[a]		***Care recipient's treatment***	
Arthritis	5	Tablets and diet	4
Asthma	1	Insulin	3
Heart trouble	1	***Type of care***	
Mobility difficulties	1	GP only	6
Sensory impairment	1	Hospital only	0
'Stress'/depression	3	Shared care	1
Hypertension	3	***Care recipient's conditions[a]***	
Diabetes	1	Arthritis	4
Carer staus		Asthma	2
Main carer	5	Heart trouble	4
Secondary carer	2	Mobility difficulties	4
Types of caring responsibility		Sensory impairment	4
Domestic (cooking, cleaning)	5	Stroke	2
Personal (washing, bathing	2	Bell palsy	1
Emotional and social support	7	Mental health problems	4
Administering medication	4	Hypertension	7
Help with moving around	5	Crohn's disease	1
Keeping an eye them	7	***Care recipient's relationship to the carer***	
Translation	2	Husband	4
Monitoring diabetes	7	Mother	1
[a]Subjects may have more than one condition.		Father	1
		Friend	1

9.3.3 Findings

Caring activities and caring roles

Carers undertook a variety of tasks in and around the home, including domestic, personal, social and emotional caring responsibilities. The carers were also involved in the care of the recipient's diabetes. These responsibilities ranged from basic tasks such as making appointments, arranging transport and accompanying them to their diabetes-related consultations, to more complex tasks such as monitoring blood-sugar levels, adjusting insulin dosages and administering medications.

The experiences of carers were influenced by a variety of factors, such as the nature of the care recipient's problems and the state of mind of the person they are caring for. To illustrate these points four carers gave their accounts of the some tasks they undertook.

> *I make sure that he's got enough insulin and that, because he's on like two different insulins.... I always make sure that if we're going to go out for the day, then he's got his insulin with him and also something to eat.... S copes himself, but I see that the right amount is on his needle.... Any appointments that he has, I always go with him, yes.... I usually sit in the waiting room while S goes and has drops and that put in his eyes. And then he comes out and then he goes back again. Then he comes out and like and then we make the appointment for the next time.... Also I always make sure that whatever prescriptions and that he wants, you know.... I take his blood.*
>
> (CA6: wife)

> *I get up, get myself ready, get rid of this tribe (CA4's family), then I'll go up there and I could be up there anything between 2 and 3 hours. Washing, ironing, whatever needs doing on the day.... The only thing that Mum really insists on doing is the cooking. She likes to cook.... The microwave helps because that way, there's no pans and boiling water around.... But we have to be careful, if she's having a bad day then I try to encourage her not to do it in the first place or if I'm cooking I'll always offer it. She'll nod off and... I'll potter up there at tea time to see if she wants anything. And she knows we're always at the end of the phone.... I usually give her flat the once over. If there any painting and decorating that needs doing I'll do that as well. Mum getting progressively worse, she's go various things wrong with her, there's the arthritis, asthma, diabetes just to name a few. I find it very difficult with Mum, because she won't help herself. There are still plenty of things she could do but won't....*
>
> (CA4: daughter)

> *When he came out of hospital after they amputated his leg...I had to run his bath and get him in and out of bed and around the house. But now he helps himself a lot more now he's got his leg and that. So he puts his leg on when he's had his breakfast, he keeps his leg on all day so now he can get around the house. He can go out without me for a walk, to the shops. I just help him out if he asks.*
>
> (CA1: wife)

> *Since Mum died I tend to go everywhere with him, I think he's lonely, he's very sad. I noticed his confidence has gone down. I go with him. I translate what other people are saying. Like when he needs to go for his eyes or to the hospital, I go with him.*

(CA7: son)

Carers' responsibilities were also influenced by their understanding about their relative's illness and ways of managing it.

Once a week, he has a bath, because he's got very thin skin on his feet. The chiropodist told me. So he sits on top of the board and we have a big splash. He gets a wash down every day, he's not dirty. Also, well in the beginning when he came home, he did a wee every three-quarters of an hour. So I said to him, I said, 'We have to strengthen the pelvic floor or something' – you know, and so I make him put his knees apart. And it did a lot of good.

Interviewer: How do you know what to do?

Well I watched them do it – the physio. And I just do the same at home. And I put this, because one foot is not very, he can't manage, so, I put his foot up and down like this. And round and round and round and up and down. He can put his knees up to his mouth.

(CA2: wife)

Access to social and external formal support and the family structure also influenced carers' experiences. This woman's account highlights some of the difficulties she faced when monitoring her friend's diabetes progress.

I go with A sometimes and then other times she may go with her other friend who lives near her. It depends on the situation really…it's difficult to know what's really going on, like I say I don't really see her regularly. I don't know if she is taking her medication. I think it is unlikely because she can't read her prescription…when I have gone with her and I seen her prescription then I tell her but I don't know if she is really taking them or not.'

(CA3: friend)

The common factor linking these activities is that they are not necessarily occasional tasks but are undertaken as part of the carers' day-to-day life.

The role of the carer and the situation of the care recipient were found to have special relevance for continuity of care for several reasons. First, the role of the carer introduces an added dimension to the customary relationship between the patient and professional although, as will be seen, this was not always recognised. Second, care recipients generally had many needs for care but some of these might not be readily apparent to professionals. Third, because many care recipients were housebound, this presented special difficulties in terms of continuity across organisational boundaries.

Relational continuity: lack of communication with professionals

Poor communication between the carer and health professionals was a significant feature in most respondents' accounts and it is perhaps the one single issue that they were most concerned about. Professionals were rarely seen to consult carers about the needs of the person they were caring for, while expecting them to be responsible for the care of the patient. Many of the difficulties arising out of caring for a relative or friend were heightened by the absence of support services, which continued to see carers as an invisible group. This is illustrated by the following respondent, who when

asked 'Do you feel involved in discussions when you attend consultations?', said

> *I go with him to the doctor, any appointments he has got. I translate for him, but no one asks me how he's doing, whether there have been any difficulties, if I am coping or not. No one has asked if I am okay. It's as if I'm not there. I know it they're looking after my Dad but so am I. My Dad is really depressed. I am worried about him. I want to say something but they just ignore me. If they asked me in front of him then I would say 'I think he is feeling low' he might not like it but I won't lie. And he couldn't say anything to me because the doctor would ask me in front of him. So it's not as if I was going behind his back.*
>
> *Interviewer: Have you mentioned this to the doctor?*
>
> *I've tried once but he wasn't really interested, the next time I went with him it was the same, I was ignored.*
>
> (CA7)

Care recipients' refusal to allow respondents to discuss problems was another factor affecting communication, as this carer explains.

> *He's sort of lost interest. I mean he can't spend time doing anything. He can't be bothered with anything. When the nurse comes round I want to mention it but I don't because he would not be pleased. I think if Stan was here, he wouldn't like me to say anything about him, you know.*
>
> (CA1: wife)

Flexible continuity: professionals' lack of awareness of care recipients' needs

Poor communication contributed to professionals' unawareness of care recipients needs. None of the respondents interviewed had received a carer's assessment and three stated that this research project had been the first time anyone had asked to hear their opinions. Professionals sometimes made contact with carers regarding their experiences when respondents identified problems with the care recipient, as illustrated by this carer's account:

> *They've only been to see him once. She left me the phone number. I think two nurses came in. Just to say, 'How do you do, are you doing all right? 'Bye, 'bye.' I know why they came in, I asked for those pants. Because when we go out, I have to put them on. He can't go longer than 3 hours because he will be soaked. So we have to go somewhere where we can change him. There are not many places. There're very few places. No, you have to think ahead a bit.*
>
> (CA2)

Unmet mental health needs were particularly important. Four care recipients were reported to have mental health problems.

> *He has a terrible temper. He can get really nasty. Two different people. Actually he's a manic depressive. So if he gets nasty, he can get nasty. Sometimes he doesn't answer. If he doesn't feel like it, if he's in a bad mood, he just won't talk. Oh, in the evening he gets very morose and sometimes if you give him medicine, he will say, 'I don't want that, I don't need that' – and the dinner goes all over the place. And I go and pick it up and he grabs my hair.... I get a little bit worried sometimes in the evening when I know his*

sugar is low and he won't eat. But usually I put – in the beginning I used to worry, I used to tell him off and we'd have an argument.

Interviewer: How do you cope with his mood and his temper? Do you get any help from outside?

No, no help. He's always been morose. He's had several sort of breakdowns and things like that. So I've got to know him now, I know how to ward it off. I have to tell a joke or something. And sort of change the subject. Yes. And then most of the time, if I catch it early enough or I take him for a walk. I ignore him if he's naughty. But you can't go near him because he bashes you. Yes, he does. I have to be very careful.

(CA2: wife)

Lack of appropriate support, advice and information about how best to cope with problems created anxiety.

I can understand that he's depressed because he can't just get up and walk out or go out. He won't get one of those mobiles. I tried to encourage him, you know to go out, see his friends. He loves going to museums. But he is not interested. He's not interested in anything anymore. I've tried everything, but nothing seems to be working. Now every time I mention anything like that he gets angry so I've stopped that. The worse thing is he won't talk about it. I am worried that it may affect the other things, like his blood pressure, his asthma and the diabetes…if he keeps on the way he does. At the moment he is good he takes him medication but what happens if he decides he doesn't want to do that either…? It puts a lot more strain on me. Physical and mental. Because I mean, they change. He's sort of changed. And physically like he doesn't do anything. So I'm doing everything now. You know. That's really the only ways things have changed. Physically and mentally. It does put a strain, more strain on you'

(CA1: wife)

Cross-boundary continuity: coordination of services

Most of the care recipients were housebound and this presented an additional organisational boundary across which care required coordination.

They're only across the road. But since my Mum's been at home, they don't always come, I think the doctor thinks it takes too much time, she can't be bothered, that's what I think. But they know how ill she was, the only reason I've ever managed to get that doctor home to her was because I kept on at her, because they needed to come over and actually look at the problem.

(CA4: wife)

Where care recipients had numerous other health issues carers reported that service provision was lacking and where present, it was uneven and almost always unsupportive. This carer's account illustrates that although care professionals adapted her home to the needs of her husband they failed to recognise her need for domestic support.

Well I found it hard at first. You know, because he had to have a lot of help. And I had to run his bath and get him in, help him in and out, and he was in to bed, you know, and things like that all the time. Not really, we weren't offered any day help as such. I mean the Social people came down to put rails up in the bathroom, so that as he got out of the wheelchair, he can hang on the sides. You know, to go to the loo. Get some grip and support. And they

put a rail up where the bath is, and they come and put a shower in. But really, no actual sort of domestic help.

(CA1: wife)

Another carer raised concerns regarding the lack of coordination between different professionals and the lack of continuing care when her mother returned home from hospital.

They actually sent a letter. I actually spoke to the general staff on the phone, who then passed all the paperwork back to the doctor's surgery. So, as far as they're concerned, she's nothing to do with them any more.

Interviewer: So you're not getting a good response?

Well there's nothing unless I actually ring them up and say, 'Excuse me, no one has been over to check on my mum for God knows how long, isn't it about time?' It just seems to me as if once you leave hospital, 'Well that's one more patient we haven't got to worry about.' And they just, you know, it's just forgotten about. It's not, 'Put that on the pile to check on her, to see what's going on in a fortnight' – or whatever. It just gets left.... I would imagine that the district nurse was the last person to see Mum, gosh, 3 months ago I suppose. Which is a long time.... It was just after Christmas. So, as far as she's concerned, alright the MRSA has gone, her wound is okay, she hasn't got any more problems, she's on this and on that, various things. You know, it's all for high blood pressure, one's for antacid because she had a full colostomy and her sugar stuff. But she's frail, she can't get about, she got arthritis, Crohn's disease, the diabetes and other stuff going on, you think someone would come in and check on her.

(CA4: wife)

9.3.4 Comment

This brief investigation of the carer role in relation to continuity of diabetes care suggests that there are several issues which require further evaluation. The presence and potential contribution of carers at consultations raises a question concerning whether the concept of relational continuity should be extended to the relationship between health-care professionals and carers. Carers were aware that constructive relationships may not exist at present. One consequence was that professionals were often not sufficiently aware of patients' care needs and this may be particularly true of their mental health needs. As many care recipients are housebound, there are special difficulties in delivering well-coordinated care over time. The interface between the home and primary and community services acts as a barrier to the delivery of services and there are therefore special issues of cross-boundary continuity. This was acknowledged in one of the interviews held with health professionals.

The patients we found most difficulty with are housebound and patients with mental health problems. The vast majority of others by and large are recalled, if they don't attend again they are recalled in 2 months again automatically. We indexed for a recall after 2 months but we have 8–10 housebound patients, which have to be done by the nurse and doctor in a housebound visit. The others that don't attend the clinic are usually there are four patients with mental health problems and when their mental health problems are active and I can name three, the patients haven't attended for the last appointments, and the debate is to whether we ought to consider them

housebound anyway and go and see them as housebound patients, but that has not been resolved.

(PR2: GP)

9.4 South Asian patients

South Asians, taken as a single group, represent the largest ethnic minority group in the UK. This group generally has a prevalence of diabetes which is up to twice as high as in the 'white' population of the same age. Macrovascular complications of diabetes, especially coronary heart disease, are very frequent, particularly in men. Differences of language and culture may raise questions concerning appropriate methods for implementing lifestyle change and self-management strategies, which are key elements in diabetes care. A number of interviews were therefore carried out with South Asian patients with diabetes in South London. As indicated above, South London is not an area with a high concentration of people of South Asian descent and this part of the study should be regarded as exploratory and requiring confirmation in other South Asian communities.

9.4.1 Aims and objectives

The specific objectives of this part of the project was to hold in-depth interviews with South Asian diabetic patients in order understand their values and experiences with respect to continuity in diabetes care.

9.4.2 Subjects and methods

Participants were initially recruited from the cohort study; however, due to a poor response rate (5/18), a further sample of potential participants was recruited from a diabetic outpatient clinic based in one inner-London hospital. The Diabetes Specialist Nurse provided a list of South Asian patients who had used diabetes outpatient services. All patients were sent a letter in English informing them about the study, they were contacted a week later and asked to take part in the study.

Interviews were based on a topic guide that was generated through interviews conducted for a separated group of diabetic patients taking part in the main qualitative study. Eleven of the interviews were undertaken at home and one interview took place in a quiet room situated in the outpatient clinic. Interviews lasted around 30 to 90 minutes; all were tape recorded. Five interviews were assisted by an interpreter. In four interviews a son or daughter assisted in this way and for one interview an interpreter was provided from the hospital service.

The 12 respondents comprised six Indian, three Pakistani, and three Bangladeshi diabetic patients. They were aged 55–79 years. All were recorded as having type 2 diabetes. Ten were receiving shared care and two received hospital care (Table 34). Interviews were carried out as described in Section 6.

Table 34 Characteristics of South Asian patients

Gender	
Male	7
Female	5
Ethnicity	
Indian	5
Pakistani	3
Bangladeshi	3
Treatment	
Tablets and diet	8
Insulin	4
Type of care	
GP only	0
Hospital only	3
Shared care	10
Conditions[a]	
Arthritis	8
Asthma	6
Heart trouble	5
Limited mobility	2
Sensory impairment	2
Stroke	3
Hypertension	9
Length of diagnosis	
Under 10 years	4
10 years and over	8
Language	
English-speaking	8
Non-English-speaking	4

[a]*Subjects may have more than one condition.*

9.4.3 Findings

In general, findings from the interviews with South Asian patients were consistent with those obtained from interviews with other patients (see Section 6). Two distinct areas of concern included problems of language and dietary advice.

Communication between patients and health professionals: barrier to relational continuity

Patients considered that effective communication was important because without it professionals were unable to understand their views, anxieties and experiences and these were often overlooked or dismissed. One respondent describes some of difficulties she faced:

> *I want to make appointment I can't. I don't understand. My daughter do it most time. But if she is working, sometimes she is go far, then she can't. Sometime I get letter I don't know what they said. I forget sometimes to show daughter I don't want to keep troubling her. When I go to doctor alone, same problem, I don't understand, I try but they don't understand.*
>
> (SA12)

Hospitals organised interpreting services more often than general practices, although on occasions patients were unable to access the services because they were busy or unavailable. One patient recalled an occasion when professionals had booked an interpreter for the the wrong language.

> *One time I went to hospital, my daughter phoned up before appointment and told them I will come on my own, they said okay. They will get someone to translate for me. I went, waited for long time, she was late. When they started I realised that she does not speak Urdu but Gujarati. I don't understand it. She doesn't understand Urdu. It was not good.'*
>
> (SA3)

Assumptions were often made that somebody in the family, a neighbour or a relative would attend consultations and translate and therefore there was no need to use the interpreting service.

> *They keep telling me to bring someone, I can't sometimes. No one is at home. My son is working; my daughter doesn't live with me. She is busy with her family; I don't want to ask her.*
>
> (SA2)

When interpreters were not available patients felt that important information was lost because of communication difficulties.

> *There have been some occasions when I was there alone. All of the messages were not clearly understood. Partially understood it was. I just get the medication and then I just take one or two and they I understand. But the messages were bit clearly understood.*
>
> (SA6)

One patient had been told by staff to go home when she arrived at the practice without an English-speaking family member.

> *When I go alone, they tell me, go home, go home.*
>
> (SA12)

She went on to express her frustration with professionals because they continued to ignore her language needs when planning her care.

Dietary advice: lack of flexible continuity

One of the more important information needs identified by respondents was in terms of dietary advice, with patients often being confused and uncertain about the advice provided. All patients had received dietary advice, in either the form of written material or of consultations with a dietitian and with other professionals; however, they viewed the information given as too basic and not taking sufficient account of foods from other cultures.

> *All the information that they have, that like based on what English people food, not like what we Asian people have, you know. Because in English food you know what all the food you can have and you have wholemeal bread, not white bread, you're not allowed to have – you know what sort of fruit to have and not to have, You sort of know the basis but with like Asian food you don't know where you stand. Yes they give you leaflet say about like ghee obviously a stuff like that, but it didn't have that much. Yes it's just like some basic food that were high in fat and things like that.*
>
> (SA4)

This patient explained that information he received was unhelpful because he could not apply it to his own eating patterns at home.

> *I don't think they understand, food we Indians eat because what they got is completely different. Indian, they've got lot of different types of food. There's chapatti, we are eating is very thin chapattis but if you look in the northern part of India, it's very thick. So they didn't mention the size, width of chapatti. It is hard to make a judgement.*
>
> (SA4)

Often when information was lacking patients sought alternative sources such as friends, the temple and the Internet to educate themselves.

9.4.4 Comment

This sub-study showed that language may act as a barrier to achieving relational continuity; the data also identified cultural issues as being relevant to the concept of flexible continuity. This is consistent with the quantitative data presented in Table 22 which showed that subjects whose first language was not English gave lower experienced continuity-of-care scores with lower scores for relational and flexible continuity.

It is important to be aware of the diversity of 'South Asian' populations in England. The present sample is unlikely to be typical of populations from areas where South Asian populations represent a high proportion of the population. Nevertheless, taken together with the findings from the carer interviews, the data from South Asian patients serves to make the point that some groups of patients may have particular difficulties in establishing and maintaining continuity of care. These questions therefore merit further study in larger samples. The needs of more vulnerable groups should be addressed by service providers in order to promote equity in terms of adequate continuity of care for all groups.

Section 10 Continuity in the delivery of care: views of professionals

10.1 Summary

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

What we did: we held interviews with 25 medical, nursing and allied health professionals recruited from primary care and hospital-based diabetes services in order to understand their perceptions of continuity in the delivery of care. The data were used to develop a 28-item measure of continuity in the delivery of care. This was tested in a postal survey of staff in two primary care trusts and three hospitals.

What we found: professionals, like patients, endorsed the importance of regular review consultations with the development of systems to avoid loss to follow-up. Staff generally preferred to see the same patients at successive visits in order to develop a better understanding with the patient and deliver personally tailored care. Coordination between staff in the same setting and between different organisational settings were discussed as important issues. Flexibility in responding to individual needs was considered to be an attribute of the system rather than a distinct dimension of continuity. The 28-item measure included five dimensions of longitudinal, relational, team, cross-boundary and informational continuity. The measure had good psychometric properties including excellent test-retest reliability. Continuity in the delivery of care was rated lower by hospital-based staff than by primary care professionals.

What we conclude: professionals' perceptions and values of continuity in the delivery of care generally endorse those described by patients. However, professionals generally showed greater awareness of organisational questions and the difficulties of delivering a 'seamless service'.

10.2 Objectives

This part of the study aimed

1 to investigate and understand professionals' experiences and perceptions of continuity of care for type 2 diabetes in order to provide items for a measure of continuity in the delivery of care, and

2 to develop, and test the psychometric properties of, a questionnaire measure of the professional experiences of continuity in the delivery of care.

A mixed-method design was employed. Qualitative interviews with health professionals were undertaken to address the first objective. This was

followed by a postal survey to achieve the second objective and test the questionnaire.

10.3 Qualitative study: methods

The qualitative study involved in-depth semi-structured interviews with health professionals involved in the care of diabetic patients.

10.3.1 Subjects

We aimed to include a range of different professionals involved in the delivery of diabetes care in primary care and hospital settings. We initially recruited staff from two hospitals and nine general practices who responded to the invitation to participate but, in order to give adequate numbers of subjects, a third hospital from outside the study area was included later. Invitation letters were sent to 71 professionals, including GPs, practice nurses, consultant physicians, diabetes specialist nurses, dietitians and podiatrists, inviting them to take part in an interview. Non-respondents were contacted with a second letter, followed by a telephone call 2 weeks later.

10.3.2 Interviews

Semi-structured interviews were conducted to elicit health professionals' perspectives regarding continuity of care. Interviews were held in a side room or office and were tape-recorded with the respondents' permission. Respondents were initially asked to describe their role and responsibilities and the organisational systems they used to deliver care to diabetic patients. These questions helped put respondents at ease and to some extent it allowed them to determine the direction of the interview. The interview was based loosely around a topic guide that was informed by Freeman's model and other literature and by preliminary exploratory interviews. Respondents also brought up other topics and directions of thought that were discussed and all responses were probed as necessary to clarify or elaborate.

10.3.3 Qualitative data analysis

All interviews were transcribed verbatim, anonymised and entered into QSR N6, a computer software package for the management of qualitative data. Coding involved a two-stage process. Firstly, codes were assigned to statements regarding aspects of care that providers regarded as contributing to patients' experienced continuity of care. Second, these statements were grouped into dimensions of continuity of care. This categorisation was informed by Freeman's dimensions of continuity of care, although the professionals' responses suggested ways in which this classification required modifying to take account of their views and experiences. Key themes associated with each dimension of continuity were identified and used to develop questionnaire items. We did not attempt to evaluate whether professionals with different types of training expressed different views because of the small numbers of professionals in each group.

10.4 Qualitative study: results

10.4.1 Sample characteristics

Health professionals were interviewed between January and June 2003. Twenty-five professionals were interviewed (response 42%), comprising consultant physicians (3), diabetes specialist nurses (4), podiatrists (2), a hospital-based dietitian (1), GPs (5), practice nurses (9) and a primary care-based dietitian (1). This sample therefore includes all professionals responsible for diabetes care apart from district nurses. The themes identified from respondents' accounts as contributing to patients' experienced continuity of care were mapped onto Freeman's dimensions of continuity.

10.4.2 Longitudinal continuity

An essential aspect of continuity of care identified by all professionals' was the long-term management of diabetic patients. This involved reviewing patients regularly with appropriate tests and delivering appropriate treatment and support from the point of diagnosis and during episodes of illness.

> *...it's really the only way to control their diabetes and check for complications, if we see the patients regularly, check their bloods, blood pressure, eyes, feet, etc. we're able to spot changes, we're able to respond quickly if a patient has any problems or if their health starts to deteriorate.*
>
> (PR6: practice nurse)

A feature that facilitated longitudinal continuity was the use of a recall systems and mailed appointment reminders for monitoring patients' ongoing treatment and identify patient defaulters.

> *We run a computerised recall system. Each month we print out a list of patients who are due appointments...send out one letter which is for a blood test and an appointment with the nurse. We found that since we have adopted this system it has helped us considerably in terms of following patients' diabetes care. There is less chance of patients being lost to follow-up, which probably did happen with the old paper system. I am not saying that it solves the problem of patients defaulting but it certainly has improved it.*
>
> (PR2: GP)

Regular reviews gave professionals the chance to introduce educational programmes and reinforce management advice.

> *In our area its very difficult for the patients to take on board all the lifestyle changes and educational information that we give them. And very often you've done some educational work and it's been forgotten or not understood and it has to be reviewed annually. The information has to be structurally re-introduced...seeing the patients regularly allow us to do that.*
>
> (PR2: GP)

10.4.3 Relational continuity

Care from identified professionals was considered advantageous.

> *The diabetes nurse and the diabetes doctor are the same, we therefore... ...because we only have 200 patients with diabetes and they only see us for the majority of cases, then the continuity of care is the most important thing in terms of consistency.*
>
> (PR2: GP)

Howeber, this could present difficulties:

> *I mean obviously if you think they don't like you or something then I think there may be problems with personalities or something, then we would probably sort it out.*
>
> (PR1: practice nurse)

Care from a usual professional allowed care to be adapted to individual patients' circumstances.

> *Well, the advantages are that they have more personal knowledge of the circumstances of the patients and their families, the patients doesn't have to tell the story each time, we know what treatment they have tried in the past and what hasn't worked, not just from the computers.*
>
> (PR2: GP)
>
> *I think I have an advantage here because I'm the only dietitian they see. So even if I don't achieve anything on the first visit, by seeing me a few times I am able to get to know them, find out what's going on in their lives, what factors are affecting their lifestyle, their eating habits, all of which are important. You're able to build a good rapport and...I've got the flexibility in offering them as many follow-ups as they want. I'm not restricting their follow-up appointments, and if they need to see me every month, I'll try to book them in every month.*
>
> (PR24: practice dietitian)

Professionals generally considered that building good relationships with their patients helped them manage their patients' diabetes more effectively. Achieving relational continuity required good communication skills and a flexible approach to case management.

> *You need to try and understand what's going on, you need to be able to listen to patients, make them feel comfortable.... Getting patients who work to the clinic is tricky, so what I do is try and get them to come in on any day, if that's not possible then I try and squeeze them in before the clinic starts. It's the only way sometimes if you want them to come in.*
>
> (PR7: practice nurse)

It was also considered important to actively involve patients in any treatment decisions.

> *Patients need to do their bit. They need to be made aware of the complications. You need to show them how easy it is to check their blood sugars, explain things in a way that is simple. Get them to make small changes to their lifestyle.... You need to let them make decisions about their care, not just tell them what to do.*
>
> (PR23: hospital specialist diabetes nurse)

Including family and carers during consultations might contribute to relational continuity. It was also an effective way of checking patients' care treatments were understood and followed.

> *When patients can't speak English they tend to bring a family member, and quite often that family member is part of the care. They may be helping with the diet or the cooking or checking that they're taking their tablets. So when they come in you can check that they're doing what you have told them.*
>
> (PR1: practice nurse)

Relational continuity also enhanced professionals' sense of responsibility towards their patients.

> *I feel responsible for the patients I see, I'm not saying that others don't, but when you see them on a regular basis you get to know them…you feel responsible for them particularly if they're having difficulties…there was one person who wouldn't go to the hospital for his treatment, he later died, but I mean I was the last person to see him. We rang him and we said you don't have to go into hospital, come here. We didn't leave him, we kept calling him in, we gave him a choice and his family were very grateful…sometimes its quite upsetting.*
>
> (PR1: practice nurse)

However, delivery of care by a single professional was often not feasible due to limited staff numbers and rapid staff turnover in both primary and secondary care.

10.4.4 Informational continuity

Continuity of information was viewed as requiring accurate medical records documenting patients' episodes of illness as well as follow-up care and management plans. It also required professionals to use information systems, which provide feedback from accident and emergency departments and hospital inpatient care.

Computerised systems were viewed as providing staff with a systematic approach to recording patients' information.

> *[The general practice computer software] is great, the template guides you through everything you need to do, it's so straightforward. There is less chance of you missing something.*
>
> (PR5: GP)

Professionals sharing electronic systems of recording and transferring information reported improvements in the speed and access of information.

> *Huge advantages. I mean if I didn't have [the diabetes electronic patient record (EPR)], I wouldn't' be able to record any information. I don't have the notes. And also the fact that it's at your fingertips. I mean [the EPR] is almost like what keeps the whole unit together as far as transferring information about patients – if we didn't have it, we wouldn't be able to do the job.*
>
> (PR13: hospital diabetes specialist nurse)

This included a higher availability of data from hospital outpatient clinics and patients' records containing significantly more data on clinical measurements.

> *Since we have the same information system we've found the results come to us much faster, the standardised letters are good in that they give us all the essential information and there is less chance of data missing because we all work with the same system. We just recently started to scan all the letters on so now we can see the result and the letter from the hospital on screen.*
>
> (PR5: GP)

Using computerised systems could also save time and enable more time to be given to focusing on patients' needs. However, some professionals did not adhere to protocols with standardised methods of recording and transferring information and this resulted in unnecessary delays in patients' care while information was located or patients having to describe what was happening.

10.4.5 Team and cross-boundary continuity

Professionals' accounts focused on their experiences of coordinating services and interacting with other health-care professionals. Since diabetes care increasingly involved teams of staff with different expertise and training, it is essential that professionals work together across care disciplines and organisational boundaries.

> *Continuity, it's about reviewing patients, working together to deliver good continuous care. You can't just work alone, not if you want to give them the best care possible. So you need the doctor, the practice nurse, the dietician, podiatrists, consultants and the [diabetes specialist nurses]. They all need to work together and communicate with each other.*
>
> (PR3: GP)

Professionals running joint diabetic clinics were able to coordinate and monitor patients' care more effectively, to see more patients and deal with patients' complications more effectively.

> *We've just set up a separate clinic for diabetic patients. The practice where I worked before had one and it was great. It allows you to focus on the diabetes, we are able to manage patients more effectively because you know that this morning you are seeing diabetic patients only so you can prepare everything and mentally you're more focused. I think also that we're are able to see more patients that way, I deal with the routine things, like testing their blood pressure, weight, Hb1AC, cholesterol, feet, etc. and that way it frees up the doctor's time to deal with more complicated patients. I think it's a good thing and I am pleased that we now have a clinic here.*
>
> (PR5: practice nurse)

Some primary care staff were satisfied with access to specialist services.

> *I'm very satisfied, if we find that somebody has got an ulcer on the foot they will be see the next day or the next day by the sub-specialists. If we find that someone has been lost to follow-up for macular oedema, we arrange an appointment within weeks. If we are concerned about it on the day we have an eye casualty department, which is a 24-hour walk in emergent surgery for eye and that can be diabetic eye as well as all the other causes of acute eye problems. We had one patient who went into renal failure and with a telephone call he was seen the following day at a joint renal diabetic clinic at [the hospital]. So the service is first class.*
>
> (PR2: GP)

A common problem faced by primary care staff, however, was the inability to speak to the hospital staff when required. This had implications for the provision of appropriate care, including the need to deal with some emergencies without appropriate specialist staff support.

> *Getting hold of somebody is a problem. So if I've got someone sitting in front of me, they're on maximum medication and I know they probably are a candidate for insulin, for example, and I want them seen fairly quickly. Or they might have been seen at the hospital and they've not had an appointment sent through to them and they're back to me saying, 'Oh my blood sugars are still running at 25'. You know, I would like to be able to ring someone and say, 'Well you know what's going on, when are they going to get an appointment?' Generally in a situation like that I try and do what I can with the patient. I end up leaving a message and then, my patient goes away and then I'll have to say, 'Well I'll contact you when I've been in touch.'*
>
> (PR11: practice nurse)

Hospital staff raised concerns about whether patients' treatment would continue once they returned to the community. In some cases professionals kept patients under their supervision to ensure that continuity of care would be provided.

> *My worry is that not all patients get good follow-up care, some do, but the ones that don't... That's a real concern. If I feel a patient won't get adequate follow-up care, i.e. if I know a doctor isn't very good at this, then I won't discharge that patient back to the community.*
>
> (PR22: hospital consultant)

Differences in prescribing and other practices between professionals could also lead to conflicts in patient management.

> *The diabetic patients often depend on the GP for the prescription of antibiotics, some GPs are fantastic at it and they will prescribe what we request. Other GPs sometimes won't.... I think it's historical, as well; a lot of us came from training in Hospital D where we saw how to manage infections using quite a broad spectrum of antibiotics and it worked. And then when we've sometimes been in primary care and suggested a particular antibiotic...sometimes GPs haven't been willing to prescribe what we have suggested.*
>
> (PR15: hospital podiatrist)
>
> *But it's mostly because of lack of awareness from the other health-care professional about the latest evidence. Let's just say injection sites, that it's okay to inject in your arms with a very long needle. No it's not because you're going intra-muscular.*
>
> (PR19: hospital diabetes specialist nurse)

10.5 Qualitative study: discussion

Respondents' comments could generally be mapped readily to Freeman's dimensions of continuity of care but, as with patients' responses, problems arose in allocating professionals' statements uniquely to categories because Freeman's dimensions are inter-related. For example, information systems facilitate communication between health-care professionals in different settings (cross-boundary continuity) and the monitoring and follow-up of

patients (longitudinal continuity), as well as improving the transfer of information (informational continuity). To avoid repetition we adapted Freeman's dimensions of continuity and used themes from the data to identify boundaries for each dimension and to distinguish between the different dimensions.

10.5.1 Dimensions of continuity in the delivery of care

Continuity in the delivery of care refers to the characteristics of the organisation and delivery of care required to achieve experienced continuity for patients. Five dimensions were identified from interviews with a broad range of health professionals involved in diabetes care.

Delivery of longitudinal continuity primarily refers to organisational arrangements to facilitate follow-up care over time consistent with need. Professionals described this dimension in terms of establishing regular processes (e.g. diabetes review consultations, regular monitoring for complications) and systems for reviewing and following-up patients (e.g. recall systems or using repeat prescriptions as a method of identifying patients who need to be seen). Provision of care from as few professionals as possible was viewed as being of secondary importance in the establishment of longitudinal continuity but a precondition for establishing relational continuity.

Relational continuity refers to continuity of the relationships between professionals and patients, and also those who assist the patients through different aspects of the health-care system (secretaries, receptionists and other practice and hospital staff). This involved building long-term patient–provider relationships and adopting a flexible approach in order to understand patients' behaviour, their medical history and family circumstances, and respond to their needs appropriately.

Team continuity and *cross-boundary continuity* refer to effective communication and coordination of services between professionals within and between organisational settings. Professionals discussed these aspects at length. They felt it was important to establish, use and share systems to bridge the primary and secondary interface and manage and integrate services provided to diabetic patients and their families. These might include information systems, new ways of sharing specialist skills with primary services and joint training sessions to encourage greater communication, improve awareness about the roles and responsibilities of its team members and keep individuals up to date with changes in care practices.

Informational continuity involves appropriate recording and information transfer following the service user. Continuity of information is the continuity given to patients' care by information systems. Unlike previous definitions this dimension specifically aims to evaluate whether professionals have access to information systems and whether medical records accurately document patient's health status, episodes of illness, follow-up and management plans.

Particular problems were identified in the definition of flexible continuity. The health system does not deliver a standard product, instead care is routinely adapted to patients' needs. Flexibility was therefore evident in most aspects of patient care. For example, when professionals spoke about the requirements for continuity of care they highlighted the need to have a flexible approach to understand different patients (relational continuity, the need for review consultations to be flexible and specifically tailored to the needs of individual patients (longitudinal continuity) and the need to take a flexible approach when working with different heath care professionals (team and cross-boundary continuity). Flexibility was therefore an essential attribute of the system that was manifested in each of the dimensions of continuity of care. It can also be argued that only patients will be in a position to judge whether services were adequately adapted to their needs. The dimension of flexible continuity was therefore omitted and relevant themes were allocated to the other dimensions of continuity in the delivery of care: relational continuity, longitudinal continuity, team, cross-boundary and informational continuity (Table 35).

Table 35 Summary of health-professional-derived themes for each dimension of continuity in the delivery of care

Dimension of delivery of continuity of care			
Relational	***Longitudinal***	***Informational***	***Team and cross-boundary***
Flexible approach	Regular visits	Access information	Shared treatment plan
Patient involvement	Send appointment letters	Information is understood	Shared guidelines
Explains things	Seeing the same patients	Information is accessible	Consistent message
Enough time	Regular blood testing	Share records	Speak with staff
Listens			Evaluation of overall care
Knows medical history			

The sample of professionals was diverse with respect to type of training and present roles and the data were consistent across the sample. However, the sample was not sufficiently large to evaluate whether perceptions of continuity differed systematically between different groups of professionals or between organisational settings. Professionals were recruited from general practices and hospital clinics and this resulted in lack of representation of district nurses, a group that may contribute to diabetes care in some areas. This omission reflected the local organisational arrangements, with district nurses being employed through a community NHS Trust until recently.

Table 36 Items for professionals' continuity-of-care questionnaire

Longitudinal continuity
1. For diabetic patients under routine follow-up, how many Practice visits do they generally make over 12 months?
2. How many times a year does the Practice send appointment letters reminding them to attend?
3. How many times a year do patients under routine follow-up care have a HbA1c measurement at the Practice?
4. On average, what proportion of diabetic patients fail to attend their appointments?
Relational continuity
5. It is difficult for diabetic patients to see me personally for their consultation if they want to.
6. If a diabetic patient wants to speak to me urgently about their diabetes, it is easy for them to speak to me.
7. I generally know little about the medical history of the patients I see for routine follow-up at the Practice.
8. I rarely have time to address all the concerns raised by patients during their consultation.
9. I generally try to involve patients in decisions about their diabetes treatment.
Informational continuity
10. I always have access to patients' diabetes notes during their consultation.
11. I always have access to patients' full medical records during their consultation.
12. All the information I need is easily accessible during the consultation.
13. The information is generally difficult to read and understand.
14. All staff share the same clinical records.
Team continuity
15. All staff provide consistent advice to patients.
16. All staff share an agreed treatment plan for each patient.
17. All staff share agreed guidelines for the management of diabetes.
18. Overall, diabetes care is poorly coordinated at the Practice.
19. It is difficult to speak to colleagues about a patient at the Practice.
Cross-boundary continuity
20. It is difficult to obtain information about a diabetic patient from the Hospital.
21. When I see a patient, Hospital letters/summaries are readily available.
22. The advice given by the Hospital is clearly stated.
23. The patient's current medication is clearly stated.
24. All the information I need is provided in the letter/summary.
25. The Practice and Hospital provide inconsistent advice to patients.
26. The Practice and Hospital share an agreed treatment plan for each patient..
27. The Practice and Hospital share agreed diabetes treatment guidelines.
28. Overall, diabetes care is poorly coordinated between Practice and Hospital.

10.6 Quantitative study: methods

A questionnaire was developed from the qualitative data through a process of discussion and consensus, as described for the patient questionnaire. The items developed for the questionnaire measure are shown in Table 36. Data were collected by means of a postal-questionnaire survey of health professionals.

10.6.1 Questionnaire survey

The questionnaire measure was tested in a postal survey of health professionals.

We obtained lists of all GPs and practice nurses working within the two primary care trusts which covered the study area. We also compiled lists of diabetes care staff from the adjacent NHS hospital trust which comprised two hospitals. In order to increase the representation of hospital staff, we also included staff from a third hospital which was outside the study area. We mailed the continuity-of-care questionnaire to each subject in the format appropriate for their setting (hospital or primary care). A reminder letter was sent to non-respondents. Finally a further mailing was sent to subjects who did not respond following the reminder. Owing to an administrative error, the initial mailing to subjects in general practice settings included three items (numbered 1, 20 and 22) which were worded in the format suitable for hospital-based respondents. This mailing was repeated with the correctly worded items. However, we were able to use data from subjects who responded to the initial mailing to evaluate the repeatability of subjects' responses.

10.6.2 Analysis

Initially, items were recoded if necessary so that higher responses were associated with better continuity of care. Item responses were tabulated to assess their distribution and the frequency of item non-response. When only one item was missing for a given sub-domain, then the value was imputed by taking the mean of the items with complete data. The maximum number of cases with imputed data was 10 for item 4 concerning the proportion of subjects who failed to attend for follow-up.

The total continuity in the delivery of care score and scores for the sub-domains of longitudinal continuity (LC), relational continuity (RC), informational continuity (IC), team continuity (TC) and cross-boundary continuity (CBC) were calculated. Sub-domain scores were calculated by summing item scores and rescaling to give a score ranging from zero to 25. The total score was obtained by summing the five sub-domain scores and rescaling to obtain a score ranging from zero to 100.

Item–score correlations and Cronbach's alpha were estimated. Factor analysis was used to explore the factorial composition of the measure using the principal-factor method in Stata version 9 (Stata Corporation, 2005). Factor loadings were obtained after varimax rotation. The number of factors was selected after inspecting the Eigenvalues and a scree plot, and by using

maximum-likelihood estimation to compare the goodness of fit of models with different numbers of factors (Streiner, 1994; Fayers and Machin, 1998). Linear regression models were fitted to evaluate whether mean experienced continuity scores varied in different groups of patients or different organisational settings. The general practice was fitted as a random effect with maximum-likelihood estimation using the xtmixed and xtreg- commands in Stata version 9 (Stata Corporation, 2005). Intraclass correlation coefficients were estimated using maximum-likelihood estimation. We compared professionals' experiences of continuity of care for hospital and primary care settings and between different categories of staff.

10.7 Quantitative study: results

The questionnaire measure of continuity in the delivery of care was evaluated in a postal survey of health professionals. There were 391 subjects eligible for the survey including 340 GPs and practice nurses from 53 general practices and 51 hospital-based professionals from three hospital trusts. Responses were received from 149 (43%) respondents from 47 general practices and 28 (55%) respondents from three hospitals. Respondents from general practice included 92 doctors and 57 nurses, whereas respondents from hospital included 15 doctors, seven nurses and six other health professionals.

10.7.1 Item responses and associations between items

Tables 37 and 38 provide details of the item responses obtained from the 177 respondents. The overall level of item non-response was approximately 9%. The distribution of item responses was generally unimodal with a high proportion of responses positioned in the central response options. The relationships between items and the subscale scores are shown in Table 39. Item–score correlations were generally high and there were acceptable correlations between the items in each subscale. Cronbach's alpha was estimated to be 0.900 for the overall scale with slightly lower values for the subscales consistent with their smaller numbers of items (Table 39). The value of alpha for the longitudinal continuity subscale was 0.474. However, when item 4 was omitted the average inter-item correlation was 0.354 and alpha was a more satisfactory 0.687 (Table 39). Thus item 4 gave results which were less consistent with the other longitudinal continuity items. Nevertheless, the subject represented by item 4 was an important concept to include in the scale, which had satisfactory overall psychometric properties.

Table 37 Professional continuity questionnaire item responses from 177 subjects with item non-response before and after imputation

Item	Item non-response	Imputed	Missing after imputation
1. For diabetic patients under routine follow-up, how many visits do they generally make over 12 months?	16	2	14
2. How many times a year does the Practice/Hospital send appointment letters reminding them to attend?	21	4	17
3. How many times a year do patients under routine follow-up care have a HbA1c measurement?	14	0	14
4. On average, what proportion of diabetic patients fail to attend their appointments?	26	10	16
5. It is difficult for diabetic patients to see me personally for their consultation if they want to.	14	0	14
6. If a diabetic patient wants to speak to me urgently about their diabetes, it is easy for them to speak to me.	14	0	14
7. I generally know little about the medical history of the patients I see for routine follow-up.	14	1	13
8. I rarely have time to address all the concerns raised by patients during their consultation.	14	2	12
9. I generally try to involve patients in decisions about their diabetes treatment.	14	1	13
10. I always have access to patients' diabetes notes during their consultation.	11	0	11
11. I always have access to patients' full medical records during their consultation.	11	0	11
12. All the information I need is easily accessible during the consultation.	12	0	12
13. The information is generally difficult to read and understand.	15	3	12
14. All staff share the same clinical records.	11	1	10
15. All staff provide consistent advice to patients.	20	2	18
16. All staff share an agreed treatment plan for each patient.	16	0	16
17. All staff share agreed guidelines for the management of diabetes.	17	1	16

Table 37 *continued*

Item	Item non-response	Imputed	Missing after imputation
18. Overall, diabetes care is poorly coordinated here.	18	2	16
19. It is difficult to speak to colleagues about a patient here.	16	0	16
20. It is difficult to obtain information about a diabetic patient from the [other setting].	16	2	14
21. When I see a patient, letters/summaries from [the other setting] are readily available.	17	1	16
22. The advice given/required by the [other setting] is clearly stated.	15	0	15
23. The patient's current medication is clearly stated.	15	0	15
24. All the information I need is provided in the letter/summary.	15	0	15
25. The Practice and Hospital provide inconsistent advice to patients.	19	1	18
26. The Practice and Hospital share an agreed treatment plan for each patient.	19	0	19
27. The Practice and Hospital share agreed diabetes treatment guidelines.	23	3	20
28. Overall, diabetes care is poorly coordinated between Practice and Hospital.	21	1	20

Table 38 Professional continuity questionnaire: distribution of item responses and mean scores for each item

Item (number of responses)	Response option						Mean response
	0	1	2	3	4	5	
1. How many visits do they generally make? (163)	0	15	78	26	32	12	2.68
2. How many times a year …appointment letters? (160)	11	56	65	19	8	1	1.75
3. How many times a year …HbA1c measurement? (163)	2	42	94	10	15	0	1.96
4. What proportion of diabetic patients fail to attend? (161)	3	13	51	59	35	0	2.68
5. Difficult for diabetic patients to see me personally. (163)	3	4	18	66	33	39	3.47
6. Patient wants to speak urgently, it is easy. (163)	0	6	13	63	45	36	3.56
7. I know little about the medical history of patients. (164)	0	2	11	54	57	40	3.74
8. I rarely have time to address all the concerns raised. (165)	5	6	42	65	35	12	2.94
9. I try to involve patients in decisions. (164)	1	1	0	66	64	32	3.75
10. I have access to patients' diabetes notes. (166)	0	0	7	46	45	68	4.05
11. I have access to patients' full medical records. (166)	5	3	15	43	50	50	3.69
12. The information I need is easily accessible. (165)	1	2	14	55	47	46	3.72
13. The information is difficult to read and understand. (165)	3	3	13	64	49	33	3.53
14. All staff share the same clinical records. (167)	1	2	7	59	25	73	3.94
15. All staff provide consistent advice to patients. (159)	1	0	17	76	54	11	3.35
16. All staff share an agreed treatment plan for each patient. (161)	0	1	29	76	44	11	3.22
17. All staff share agreed diabetes guidelines. (161)	0	0	12	69	50	30	3.61
18. Overall, diabetes care is poorly coordinated here. (161)	1	0	9	56	55	40	3.76
19. It is difficult to speak to colleagues about a patient here. (161)	1	1	4	49	49	57	3.96

Table 38 *continued*

Item (number of responses)	Response option						Mean response
	0	**1**	**2**	**3**	**4**	**5**	
20. It is difficult to obtain information from [other setting]. (163)	3	7	42	81	19	11	2.85
21. Letters/summaries from [the other setting] are available. (161)	2	12	24	80	27	16	3.03
22. Advice given/required by [other setting] is clearly stated. (162)	3	5	30	83	30	11	3.02
23. Patient's current medication is clearly stated. (162)	3	5	15	86	34	19	3.23
24. All information I need is provided in the letter/summary. (162)	8	7	46	67	24	10	2.75
25. The Practice and Hospital provide inconsistent advice. (159)	4	9	24	89	28	5	2.90
26. The Practice/Hospital share an agreed treatment plan. (158)	2	5	41	79	21	10	2.90
27. The Practice and Hospital share diabetes guidelines. (157)	1	1	26	93	20	16	3.13
28. Diabetes care is poorly coordinated. (157)	4	6	33	75	26	13	2.97

Table 39 Professional continuity questionnaire: item–score and inter-item correlations and Cronbach's alpha for subscale scores

	Responses (%)	Item–score correlation[a]	Average inter-item correlation[b]	Alpha
Professional longitudinal continuity (PLC)				
1. How many visits?		0.697	0.121	
2. How many appointment letters?		0.659	0.155	
3. How many HbA1c measurements?		0.721	0.104	
4. What proportion fail to attend?		0.423	0.354	
PLC scale	159 (90)		0.184	0.474
Professional relational continuity (PRC)				
5. Difficult for patients to see me.		0.725	0.225	
6. Patients speak to me urgently.		0.688	0.245	
7. I know little about patients' history.		0.597	0.293	
8. I rarely have time to address concerns.		0.675	0.253	
9. I try to involve patients in decisions.		0.532	0.329	
PRC scale	163 (92)		0.269	0.648
Professional informational continuity (PIC)				
10. I have access to patients' notes.		0.812	0.400	
11. I have access to medical records.		0.754	0.436	
12. Information I need is accessible.		0.850	0.378	
13. Information is difficult to read.		0.577	0.546	
14. All staff share the same records.		0.735	0.449	
PIC scale	164 (93)		0.442	0.798

Table 39 ***continued***

	Responses (%)	Item–score correlation[a]	Average inter-item correlation[b]	Alpha
Professional team continuity (PTC)				
15. All staff provide consistent advice.		0.841	0.482	
16. All staff share a treatment plan.		0.774	0.525	
17. All staff share guidelines.		0.850	0.475	
18. Care is poorly coordinated here.		0.770	0.529	
19. It is difficult to speak to colleagues.		0.692	0.580	
PTC scale	158 (89)		0.518	0.843
Professional cross-boundary continuity (PCBC)				
20. It is difficult to obtain information.		0.779	0.449	
21. Letters/summaries are available.		0.779	0.450	
22. Advice given/required is stated.		0.842	0.435	
23. Patient's medication is stated.		0.751	0.457	
24. All the information is in the letter.		0.776	0.450	
25. Provide inconsistent advice.		0.335	0.553	
26. Share an agreed treatment plan.		0.745	0.458	
27. Share diabetes guidelines.		0.725	0.462	
28. Diabetes care is poorly coordinated.		0.775	0.451	
PCBC scale	155 (88)		0.463	0.886
Total continuity in delivery of care	149 (84%)		0.243	0.900

[a]*Correlation between item score and raw subscale score.*

[b]*Average correlation between items after omitting that item.*

10.7.2 Factorial composition

The results of a factor analysis are shown in Table 40. A five-factor solution was preferred based on the distribution of the Eigenvalues and comparing analyses with different numbers of factors. The factor analysis generally supported the proposed factorial composition of the measure with items loading on factors representing grouping of items associated with cross-boundary continuity, team continuity, informational continuity, longitudinal continuity and relational continuity. However, uniqueness was estimated to be high particularly for items 4 (what proportion of patients fail to attend?) and item 9 (I try to involve patients in decisions.). Values for uniqueness were generally somewhat elevated across the items concerning either longitudinal or relational continuity. Uniqueness represents the proportion of the item's variance that is not shared with the factor structure. The finding of high values for uniqueness suggest that these items provide a less satisfactory fit to the measurement model.

Table 40 Professional continuity questionnaire: rotated factor loadings from factor analysis with five factors

Item	Factor					Uniqueness
	1	2	3	4	5	
1. How many visits?	0.176	−0.083	0.066	0.547	0.039	0.658
2. How many appointment letter?	0.093	0.012	−0.016	0.501	−0.016	0.739
3. How many HbA1c measurement?	−0.015	0.097	−0.021	0.656	0.035	0.558
4. What proportion fail to attend?	0.039	0.389	−0.016	−0.081	0.035	0.839
5. Difficult for patients to see me.	0.259	0.192	0.029	0.0863	0.616	0.508
6. Patients speak to me urgently.	0.340	0.173	0.256	0.321	0.448	0.485
7. I know little about patients' history.	0.165	0.327	0.176	−0.035	0.364	0.701
8. I rarely have time to address concerns.	0.111	0.382	0.063	−0.162	0.447	0.612
9. I try to involve patients in decisions.	0.107	0.282	0.281	−0.176	0.071	0.795
10. I have access to patients' notes.	0.097	0.183	0.724	−0.085	0.012	0.426
11. I have access to medical records.	0.274	0.146	0.725	0.076	0.082	0.366
12. Information I need is accessible.	0.237	0.188	0.756	0.032	0.054	0.332
13. Information is difficult to read.	0.160	0.320	0.221	−0.255	0.345	0.639
14. All staff share the same records.	0.190	0.317	0.562	−0.045	0.034	0.544
15. All staff provide consistent advice.	0.321	0.652	0.352	0.000	0.080	0.342

Table 40 *continued*

Item	Factor					Uniqueness
	1	2	3	4	5	
16. All staff share a treatment plan.	0.517	0.558	0.166	−0.034	−0.027	0.392
17. All staff share guidelines.	0.306	0.720	0.199	−0.001	0.162	0.323
18. Care is poorly coordinated here.	0.130	0.637	0.358	0.008	0.195	0.412
19. It is difficult to speak to colleagues.	−0.017	0.610	0.210	0.130	0.127	0.551
20. It is difficult to obtain information.	0.738	0.062	0.162	−0.167	0.236	0.343
21. Letters/summaries are available.	0.727	0.022	0.295	−0.078	0.164	0.351
22. Advice given/required is stated.	0.837	−0.022	0.248	0.059	0.133	0.216
23. Patient's medication is stated.	0.630	0.155	0.311	0.090	0.223	0.424
24. All the information is in the letter.	0.762	0.099	0.180	0.156	0.095	0.344
25. Provide inconsistent advice.	0.150	0.198	0.147	−0.197	−0.137	0.859
26. Share an agreed treatment plan.	0.707	0.370	−0.041	0.106	−0.075	0.346
27. Share diabetes guidelines.	0.662	0.450	−0.091	0.082	−0.075	0.340
28. Diabetes care is poorly coordinated.	0.743	0.281	0.010	−0.052	−0.099	0.356

10.7.3 Test-retest reliability

Repeat questionnaire responses were obtained for 63 subjects. Mean differences between the two administrations of the questionnaire and the associated 95% CIs for item responses and subscale and scale scores are shown in Table 41. There was generally close agreement between responses obtained on the two occasions consistent with excellent test-retest reliability.

Table 41 Professional continuity questionnaire: reliability of questionnaire items based on two responses 6–8 weeks apart

	Number of paired observations	Mean difference	95% CI	
			Lower	*Upper*
Professional longitudinal continuity (PLC)				
1. How many visits?	0	–	–	–
2. How many appointment letters?	52	0.06	−0.2	0.32
3. How many HbA1c measurements?	57	0.02	−0.18	0.21
4. What proportion fail to attend?	47	0.09	−0.12	0.29
PLC scale	43	−0.12	−0.84	0.6
Professional relational continuity (PRC)				
5. Difficult for patients to see me.	57	−0.32	−0.63	−0.01
6. Patients speak to me urgently.	57	0	−0.33	0.33
7. I know little about patients' history.	57	0.05	−0.21	0.32
8. I rarely have time to address concerns.	56	−0.09	−0.4	0.22
9. I try to involve patients in decisions.	57	0.09	−0.16	0.33
PRC scale	56	−0.25	−1.09	0.59
Professional informational continuity (PIC)				
10. I have access to patients' notes.	57	0	−0.24	0.24
11. I have access to medical records.	57	0	−0.27	0.27
12. Information I need is accessible.	57	0.02	−0.27	0.3
13. Information is difficult to read.	55	0	−0.28	0.28
14. All staff share the same records.	57	0.02	−0.28	0.32
PIC scale	55	0.04	−0.95	1.02

Table 41 ***continued***

	Number of paired observations	Mean difference	95% CI	
			Lower	***Upper***
Professional team continuity (PTC)				
15. All staff provide consistent advice.	49	0.1	−0.13	0.33
16. All staff share a treatment plan.	54	0.31	0.04	0.59
17. All staff share guidelines.	54	0.19	−0.05	0.42
18. Care is poorly coordinated here.	52	−0.25	−0.48	−0.02
19. It is difficult to speak to colleagues.	55	0.07	−0.23	0.37
PTC scale	48	0.21	−0.73	1.15
Professional cross-boundary continuity (PCBC)				
20. It is difficult to obtain information.	0	–	–	–
21. Letters/summaries are available.	50	0.1	−0.11	0.31
22. Advice given/required is stated.	0	–	–	–
23. Patient's medication is stated.	53	0	−0.26	0.26
24. All the information is in the letter.	53	−0.08	−0.39	0.23
25. Provide inconsistent advice.	55	−0.42	−0.71	−0.13
26. Share an agreed treatment plan.	54	0.09	−0.16	0.35
27. Share diabetes guidelines.	53	0.08	−0.15	0.3
28. Diabetes care is poorly coordinated.	54	−0.17	−0.4	0.06
PCBC score[a]	47	−0.21	−0.96	0.53
Total continuity in delivery of care[a]	37	−0.13	−2.68	2.42

[a]*Items 1, 20 and 22 were omitted.*

10.7.4 Scale scores

The distribution of scale scores is shown in Figure 5. The mean score was 64.9 with SD ±10.8. The distribution of scale and subscale scores for primary care-based and hospital-based respondents is shown in Table 42. There were 149 respondents giving total continuity-of-care scores including 127 from primary care and 22 from hospitals. The mean score was approximately 10 units higher for the primary care based respondents, who also gave higher subscale scores for longitudinal, informational, team continuity and cross-boundary continuity. There were no systematic differences between the continuity of care ratings of either doctors of nurses (Table 43). Continuity-of-care ratings did not vary systematically between the 56 practices in the survey (P=0.416) based on a mean of 2.68 respondents per practice.

Figure 5 Distribution of professional continuity scores

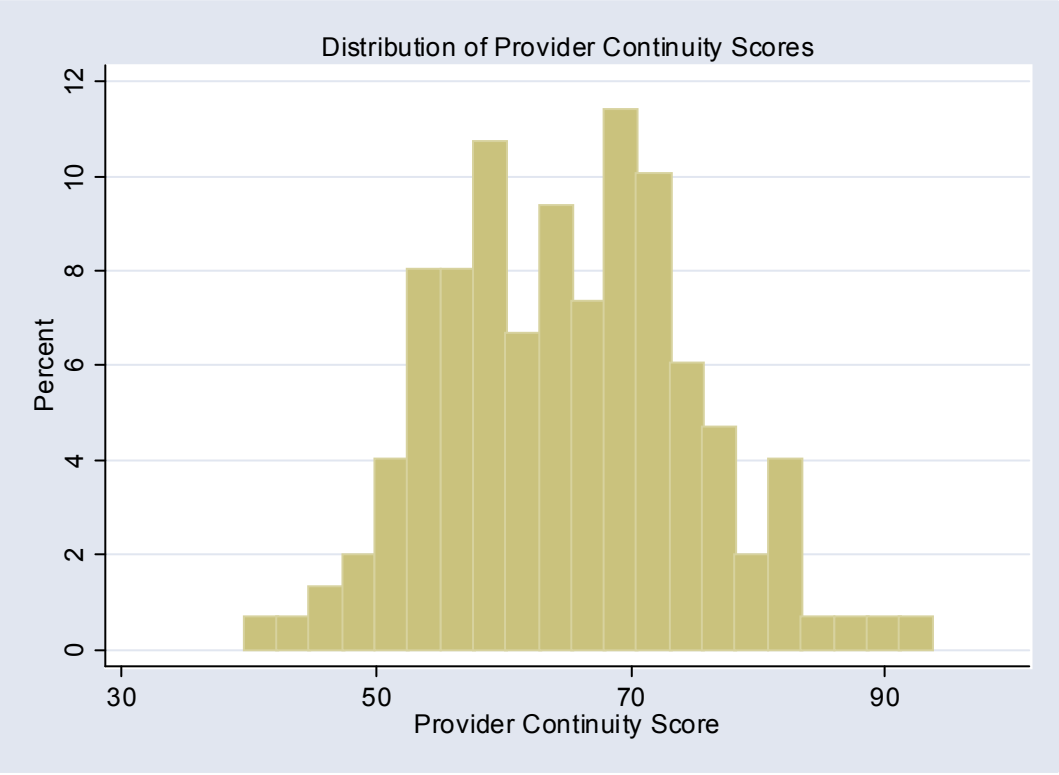


Table 42 Distribution of professional continuity scores by type of care setting

Based on 149 cases with data for total continuity scores.

Scale	Mean score (±SD)		Adjusted mean difference (95% CI)[a]	*P* value
	Primary care (n=127)	***Hospital (n=22)***		
Total continuity	66.5 (9.3)	55.5 (7.6)	−10.7 (−15.1 to −6.42)	<0.001
Longitudinal continuity	11.9 (2.9)	8.8 (2.0)	−2.8 (−5.0 to −0.7)	0.011
Relational continuity	17.8 (3.3)	16.2 (2.3)	−1.3 (−3.5 to 0.8)	0.227
Informational continuity	19.6 (3.8)	16.8 (3.8)	−2.4 (−4.2 to −0.6)	0.009
Team continuity	18.3 (3.4)	16.4 (3.5)	−1.7 (−3.4 to −0.1)	0.037
Cross-boundary continuity	15.5 (3.4)	11.2 (2.8)	−4.4 (−6.7 to −2.1)	<0.001

[a]*Adjusted for type of staff and clustering by practice or hospital.*

Table 43 Distribution of professional continuity scores by type of respondent

Scale	Mean score (±SD)		Adjusted mean difference (95% CI)[a]	*P* value
	Doctor (n=92)	***Nurse (n=54)***		
Total continuity	64.1 (9.2)	66.7 (10.8)	2.0 (−1.1 to 5.0)	0.206
Longitudinal continuity	11.1 (2.8)	12.0 (3.3)	0.6 (−0.2 to 1.49)	0.156
Relational continuity	17.2 (3.2)	18.3 (3.3)	1.0 (0.0 to 2.0)	0.057
Informational continuity	19.0 (3.7)	19.8 (4.1)	0.6 (−0.6 to 1.9)	0.326
Team continuity	18.1 (3.3)	17.9 (3.7)	−0.3 (−1.5 to 0.8)	0.576
Cross-boundary continuity	14.7 (3.6)	15.4 (3.8)	0.5 (−0.6 to 1.6)	0.356

[a]*Adjusted for type of care setting and clustering by practice or hospital.*

Based on 149 cases with data for total continuity scores. Data for one dietitian and two chiropodists were omitted.

10.8 Discussion

We have reported the development and testing of a questionnaire measure of continuity in the delivery of care. The measure has satisfactory psychometric properties and good test-retest reliability. Analysis of the factorial composition of the measure generally supports the proposed constructs or dimensions of continuity in the delivery of care. However, the items for cross-boundary continuity, team continuity and informational continuity generally appeared to give better fit than those for longitudinal and relational continuity. This is in contrast to the results from the patient

questionnaire in which data for the items concerning team and cross-boundary continuity generally had less satisfactory properties. It may be possible to develop better items referring to these concepts. However, these systematic differences between the patient and professional questionnaire suggest that different aspects of continuity of care are emphasised in the experience of patients and professionals. Thus patient responses primarily focus on the notion of the 'continuous caring relationship' and associated dimensions of relational and longitudinal continuity, whereas professionals give greater emphasis to the notion of a 'seamless service' with its associated dimensions of team continuity, cross-boundary continuity and informational continuity. Patients generally find it more difficult to evaluate these latter aspects of their care.

The assessment of professionals' experiences of continuity in the delivery of care provides information concerning professionals' perceptions of, and satisfaction with questions of coordination and consistency as they impact on the care of individual patients. Results obtained using the measure suggest that problems of continuity in the delivery of care are generally more severe in the hospital setting. This is to be expected because of the greater organisational complexity, the larger numbers of staff employed and greater staff turnover in the hospital setting. Professional satisfaction with continuity of care is not an outcome that should necessarily be valued in its own right. Instead assessments will be useful for monitoring the organisation and delivery of diabetes services. These assessments may help to identify problems that impede the delivery of services that facilitate patients' experiences of continuity of care. Further utilisation of such measures may be of value.

Qualitative data from professionals generally support, from the professional perspective, the interpretation of qualitative data from patient interviews. However, professionals' comments often referred to wider issues in clinical practice and health services organisation and delivery including questions of communication skills, team working, clinical information systems and methods of organising services for diabetic patients. These subjects each comprise a large body of knowledge in their own right. This is illustrated in the findings of a review of systematic reviews in chronic illness care (Ouwens *et al*., 2005). Ouwens *et al.* (2005) found that integrated care programmes for patients with chronic illnesses generally had certain components in common (Table 44). These components can be viewed as promoting distinct dimensions of continuity in chronic illness care. For example, longitudinal continuity is promoted through systems for clinical follow-up; relational continuity may be promoted through systems for case management and self-management support; multidisciplinary patient care teams may be viewed as promoting team continuity, whereas multidisciplinary care pathways may be seen as promoting cross-boundary continuity. This cross-referencing of ideas means that issues relating to continuity of care may not be explicitly recognised in the perspective of professionals.

Table 44 Components of chronic-disease-management programmes and continuity of care

Component (from Ouwens *et al*., 2005)	Related dimensions of continuity of care
Self-management support	Relational continuity
Clinical follow-up	Longitudinal continuity
Case management	Relational continuity
Multidisciplinary care team	Team continuity
Multidisciplinary clinical pathway	Cross-boundary continuity
Other components such as clinical information systems	Informational continuity

Section 11 Conclusions

11.1 Role of mixed methods

This study used a combination of qualitative and quantitative methods. Qualitative data were obtained from patients and their carers as well as from professionals, whereas quantitative data were obtained from patients and professionals. The information obtained from these different perspectives was generally consistent and mutually confirmatory; this is sometimes referred to as triangulation. The initial qualitative study of patients' views was used to refine the conceptual framework and provide items for a questionnaire measure. Quantitative data obtained using the questionnaire supported and confirmed the interpretation of qualitative findings in several ways. For example, qualitative data from patients, and questionnaire data from both patients and professionals, showed that experiences of continuity of care were less satisfactory in hospital settings; language differences were identified as a barrier to continuity of care in the qualitative data with confirmation from patient questionnaire data. An area of discrepancy identified by this research was between the professional view that continuity should lead to 'better' care, and the quantitative finding that health outcomes were not associated with continuity of care. This points to a conclusion that patient-centredness is not necessarily part of a causal path leading to more effective or efficient care.

11.2 Definition of continuity of care

Continuity of care encompasses two ideals:

1 the 'continuous caring relationship' between a patient and professional, characterised by closeness, familiarity and trust;

2 a 'seamless service' characterised by excellent consistency, coordination and communication between professionals and between provider organisations.

Although these two ideals are each relevant to both patients and professionals, the notion of the continuous caring relationship may be more finely judged by patients. From the patient's perspective, their relationship with a professional has a unique significance which is absent from the perspective of the professional, whose relationships are with many different patients. Conversely, the components of a seamless service may be more completely judged by professionals who have greater technical insight into the organisation and delivery of services.

11.3 Continuity in the experience of care

Patients with diabetes value experiences of good continuity of care. This comprises four dimensions:

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

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

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

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

11.4 Transitions in health and health care and continuity of care

Patients and professionals identified transitions in health, or in health care, as occasions when problems of lack of experienced continuity may arise. Changes in patients' health, changes in the patient's health professional and changes in care provider organisation all require attention to ensure that problems of lack of continuity of care are minimised.

11.5 Vulnerable groups and continuity of care

Some groups may experience particular difficulties in establishing and maintaining continuity of care. These difficulties may sometimes be related to differences in language or culture, disability or mental illness.

11.6 Measurement of experienced continuity of care

We have developed a reliable, valid, easy-to-use measure of experienced continuity of care in type 2 diabetes. Ratings of experienced continuity increase as the frequency of consultations increases, but decline as the number of individual professionals seen increases. Results obtained using the measure demonstrate systematic differences between experiences of patients attending different provider organisations. Experiences of continuity are generally less favourable in hospital than in general practice settings. There are specific features of the organisation of care, such as the identification of a named lead professional, that are associated with more favourable experiences of continuity of care.

Ouwens *et al*. (2005; 145) use the term case management in the following sense '[the] explicit allocation of coordination tasks to an appointed individual or small team who may or may not be responsible for the direct provision of care. The case manager or team takes responsibility for guiding the patient through the complex care processes in the most efficient, effective and acceptable way'. Our data support the development of the case manager function in diabetes care. In the UK context, this will often be

equivalent to the role taken by the GP or practice nurse who has responsibility for the practice's diabetic patients.

11.7 Experienced continuity of care and patient satisfaction

Experienced continuity of care encompasses patients' perceptions of the interpersonal aspects of their care and the degree of coordination of care. Dimensions of experienced continuity are therefore conceptually related to more traditional assessments of patient satisfaction. Measurements of experienced continuity of care are associated with patients' global ratings of their overall satisfaction with care received.

11.8 Continuity of care and health outcomes

In this health-care setting, experienced continuity of care was not associated with changes in glycated haemoglobin (HbA1c), blood pressure or body weight during approximately 10 months of follow-up; nor was experienced continuity of care associated with physical and mental functioning scores from the SF-12 questionnaire.

Although naïve models might suggest that experienced continuity should be associated with better health outcomes, experienced continuity may also be associated with increasing duration of illness and progression of the disease. Discontinuities in care may be associated at different times with either improvements or deteriorations in health measures.

We conclude that continuity of care is part of the pathway leading to enhanced patient-centredness in health care but is not necessarily on the pathway to increased effectiveness. Some dimensions of quality in health care are related (for example, equity is generally negatively associated with efficiency) but patient-centredness and effectiveness may not be consistently associated.

This research has not addressed questions of patient safety. It is possible that continuity of care may reduce serious adverse events and this possibility merits further investigation.

11.9 Continuity in the delivery of care

Professionals' perceptions and values of continuity in the delivery of care generally endorse those described by patients but professionals generally show greater appreciation of organisational questions and the difficulties of delivering a seamless service. Five dimensions were identified: *longitudinal continuity, relational continuity, team continuity, cross-boundary continuity* and *informational continuity.* Each dimension of continuity in the delivery of care refers to an important body of knowledge concerning the organisation and delivery of health care. A questionnaire measure was developed to measure professionals' perceptions of continuity in the delivery of care. This has excellent psychometric properties. Professionals based in hospitals generally perceive greater difficulties in delivering continuity of care.

Section 12 Recommendations

1 Aspects of the patient experience that were identified by this research are important to consider in designing services for patients with diabetes and in assessing the quality of care.

2 Patients are vulnerable to experiences of loss of continuity when their health changes or when they move between health-care organisations. It may be more difficult for some groups to establish and maintain continuity of care. Further research is required to develop and test interventions to enhance experiences of continuity through transitions in health and health care for different groups of patients.

3 Patients' experiences of continuity of care in diabetes should be monitored using the self-administered ECC-DM measure developed for this project. The instrument may also be used to evaluate the effectiveness of interventions to enhance continuity of care.

4 Further research is required to adapt the ECC-DM instrument into a form suitable for monitoring the experiences of patients with a range of chronic illnesses.

5 Organising care through an identified lead professional may enhance patients' experience of continuity of care.

6 Enhancing the patient experience of continuity of care is especially important for hospital-based services. Further research is required to develop and test interventions to enhance experiences of continuity of care in hospital-based clinics.

7 Assessment of professionals' views of continuity of care may be used to monitor service delivery and inform improvements in services.

8 Continuity of care is justified in terms of enhanced patient-centredness and acceptability of care rather than increased effectiveness. Experienced continuity of care should be valued because it represents, in the view of patients and professionals, the experience of more patient-centred care.

9 Additional research should investigate whether provider continuity is associated with patient safety or the frequency of serious adverse events.

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Appendix 1 Questionnaires

1 Experienced continuity of care in diabetes mellitus (ECC-DM, patient questionnaire)

The experienced continuity of care in type 2 diabetes mellitus (ECC-DM) measure was developed from qualitative data obtained from in-depth interviews with diabetic patients. The measure encompasses four dimensions of experienced continuity of care – longitudinal, flexible, relational and team and cross-boundary. Separate subscale scores are calculated for each dimension. Scores for longitudinal, flexible and relational continuity may be calculated for hospital care and primary care separately.

The ECC-DM measure has good psychometric properties including good test-retest reliability. The measure can be completed in about 10 minutes in self-administered format.

Scores are obtained as follows, using the item identifiers shown in the questionnaires:

Longitudinal continuity (LC) score=(LC1+LC2+LC3+LC4)×(5/4)

Flexible continuity (FC) score=(FC1+FC2+FC3+FC4)×(5/4)

Relational continuity (RC) score=
(RC1+RC2+RC3+RC4+RC5+RC6)×(5/6)

Team and cross-boundary (TCB) continuity=
TCB1+TCB2+TCB3+TCB4+TCB5

Then using the higher value of LC, FC and RC from either hospital or general-practice setting:

Experienced continuity (ECC-DM)=LC+FC+RC+TCB

See Section 7 for further information.

The questionnaire is presented in two formats.

1.1 Self-completion version: this is presented in a large font in view of the high anticipated age of many respondents.

1.2 Interview administration version

For further information on these questionnaires readers can contact Martin Gulliford (martin.gulliford@kcl.ac.uk).

1.1 Self-completion version

Section 1 General-Practice care

These questions are about your diabetes care at the General Practice/Surgery.

1. In the last 12 months, how many times have you spoken with staff at the practice about your diabetes? [LC1-gp]	*Never* ☐ *0*	*Once* ☐ *1*	*Twice* ☐ *2*	*3 times* ☐ *3*	*4 times* ☐ *4*	*5 times or more* ☐ *5*
2. In the last 12 months, how many times has the practice sent you an appointment letter for your diabetes? [LC2-gp]	*Never* ☐ *0*	*Once* ☐ *1*	*Twice* ☐ *2*	*3 times* ☐ *3*	*4 times* ☐ *4*	*5 times or more* ☐ *5*
3. In the last 12 months, how many times have you had a blood test taken for your diabetes at the practice? [LC3-gp]	*Never* ☐ *0*	*Once* ☐ *1*	*Twice* ☐ *2*	*3 times* ☐ *3*	*4 times* ☐ *4*	*5 times or more* ☐ *5*
4. If you need advice urgently how long would it take to get to speak to a doctor or nurse at the practice? [FC1-gp] (Suppose you had a problem, how long would it take?)	*In 5 days or more* ☐ *0*	*Within 4 working days* ☐ *1*	*Within 3 working days* ☐ *2*	*Within 2 working days* ☐ *3*	*Next working day* ☐ *4*	*Same day* ☐ *5*

5. How would you rate the length of time you would have to wait before you spoke to a doctor or nurse <u>at the practice</u>? [FC2-gp]	*Very poor* ☐ *0*	*Poor* ☐ *1*	*Fair* ☐ *2*	*Good* ☐ *3*	*Very good* ☐ *4*	*Excellent* ☐ *5*
6. If you have a problem with your diabetes, how well does your <u>practice</u> respond to it? [FC3-gp] (Suppose you had a problem, how well would the practice respond?)	*Extremely well* ☐ *5*	*Very well* ☐ *4*	*Fairly well* ☐ *3*	*Badly* ☐ *2*	*Very badly* ☐ *1*	*Extremely badly* ☐ *0*

The next questions are about your usual doctor or nurse at the practice. That is, the doctor or nurse who knows you and your diabetes best.

7. Who do you usually see for your diabetes care at the practice. Who knows you and your diabetes best?

☐ *Practice doctor*

☐ *Practice nurse*

☐ *I don't have a usual doctor or nurse at the practice*

8. In the last 12 months, how many times have you seen your usual doctor or nurse at the practice? [LC4-gp)

☐ *Never* *0*

☐ *Once* *1*

☐ *Twice* *2*

☐ *3 times* *3*

☐ *4 times* *4*

☐ *5 times or more* *5*

9. If you need to speak to your usual doctor or nurse about your diabetes, how easy is it for you to speak to your usual doctor or nurse at the practice? [FC4-gp]

☐ *Extremely difficult* *0*

☐ *Very difficult* *1*

☐ *Somewhat difficult* *2*

☐ *Fairly easy* *3*

☐ *Very easy* *4*

☐ *Extremely easy* *5*

10. How well does your usual doctor or nurse at the practice explain medical procedures and tests done for your diabetes? [RC1-gp]

☐ *Extremely well* *5*

☐ *Very well* *4*

☐ *Fairly well* *3*

☐ *Badly* *2*

☐ *Very badly* *1*

☐ *Extremely badly* *0*

How much do you disagree or agree with the following statements about your usual doctor or nurse at the practice?

	Agree very strongly	***Agree strongly***	***Agree***	***Disagree***	***Disagree strongly***	***Disagree very strongly***
11. My usual doctor or nurse at the practice involves me in decisions about my diabetes [RC2-gp] (e.g. discusses your treatment, diet or monitoring with you).	☐ *5*	☐ *4*	☐ *3*	☐ *2*	☐ *1*	☐ *0*
12. My usual doctor or nurse at the practice listens to what I have to say. [RC3-gp]	☐ *5*	☐ *4*	☐ *3*	☐ *2*	☐ *1*	☐ *0*
13. My usual doctor or nurse at the practice knows about my medical history [RC4-gp] (e.g. knows about illnesses and treatment you had in the past).	☐ *5*	☐ *4*	☐ *3*	☐ *2*	☐ *1*	☐ *0*
14. My usual doctor or nurse at the practice makes the best decisions about my diabetes treatment [RC5-gp] (e.g. your diet, tablets and medicines, testing, etc.).	☐ *5*	☐ *4*	☐ *3*	☐ *2*	☐ *1*	☐ *0*
15. My usual doctor or nurse at the practice is concerned about me [RC6-gp] (e.g. interested in you, and your well-being, as a person).	☐ *5*	☐ *4*	☐ *3*	☐ *2*	☐ *1*	☐ *0*

Section 2 Hospital care

These questions are about your diabetes care at the Hospital Clinic. If you do not go to the hospital clinic go to question 31.

16. In the last 12 months, how many times have you spoken with staff at the hospital about your diabetes? [LC1-hosp]	*Never* ☐ *0*	*Once* ☐ *1*	*Twice* ☐ *2*	*3 times* ☐ *3*	*4 times* ☐ *4*	*5 times or more* ☐ *5*
17. In the last 12 months, how many times has the hospital sent you an appointment letter for your diabetes? [LC2-hosp]	*Never* ☐ *0*	*Once* ☐ *1*	*Twice* ☐ *2*	*3 times* ☐ *3*	*4 times* ☐ *4*	*5 times or more* ☐ *5*
18. In the last 12 months, how many times have you had a blood test taken for your diabetes at the hospital? [LC3-hosp]	*Never* ☐ *0*	*Once* ☐ *1*	*Twice* ☐ *2*	*3 times* ☐ *3*	*4 times* ☐ *4*	*5 times or more* ☐ *5*
19. If you need advice urgently how long would it take to get to speak to a doctor or nurse at the hospital? (Suppose you had a problem, how long would it take?) [FC1-hosp)	*In 5 days or more* ☐ *0*	*Within 4 working days* ☐ *1*	*Within 3 working days* ☐ *2*	*Within 2 working days* ☐ *3*	*Next working day* ☐ *4*	*Same day* ☐ *5*

20. How would you rate the length of time you've had to wait before you spoke to a doctor or nurse <u>at the hospital</u>? [FC2-hosp]	*Very poor* ☐ *0*	*Poor* ☐ *1*	*Fair* ☐ *2*	*Good* ☐ *3*	*Very good* ☐ *4*	*Excellent* ☐ *5*
21. If you have a problem with your diabetes, how well does the <u>hospital</u> respond to it? (Suppose you had a problem, how well would the hospital respond?) [FC3-hosp]	*Extremely well* ☐ *5*	*Very well* ☐ *4*	*Fairly well* ☐ *3*	*Badly* ☐ *2*	*Very badly* ☐ *1*	*Extremely badly* ☐ *0*

The next questions are about your usual doctor or nurse at the hospital. That is, the doctor or nurse who knows you and your diabetes best.

22. Who do you usually see for your diabetes care at the hospital. Who knows you and your diabetes best?

Hospital doctor ☐ *Hospital nurse* ☐ *I don't have a usual doctor or nurse at the hospital* ☐

23. In the last 12 months, how many times have you seen your usual doctor or nurse at the hospital? [LC4-hosp]

Never	*Once*	*Twice*	*3 times*	*4 times*	*5 times or more*
☐	☐	☐	☐	☐	☐
0	*1*	*2*	*3*	*4*	*5*

24. If you need to speak to your usual doctor or nurse about your diabetes, how easy is it for you to speak to your usual doctor or nurse at the hospital? [FC4-hosp]

Extremely difficult	*Very difficult*	*Somewhat difficult*	*Fairly easy*	*Very easy*	*Extremely easy*
☐	☐	☐	☐	☐	☐
0	1	2	3	4	5

25. How well does your usual doctor or nurse at the hospital explain medical procedures and tests done for your diabetes? [RC1-hosp]

Extremely well	*Very well*	*Fairly well*	*Badly*	*Very badly*	*Extremely badly*
☐	☐	☐	☐	☐	☐
5	4	3	2	1	0

How much do you disagree or agree with the following statements about your usual doctor or nurse at the hospital?

	Agree very strongly	***Agree strongly***	***Agree***	***Disagree***	***Disagree strongly***	***Disagree very strongly***
26. My usual doctor or nurse at the hospital involves me in decisions about my diabetes [RC2-hosp] (e.g. discusses your treatment, diet or monitoring with you).	☐ *5*	☐ *4*	☐ *3*	☐ *2*	☐ *1*	☐ *0*
27. My usual doctor or nurse at the hospital listens to what I have to say. [RC3-hosp]	☐ *5*	☐ *4*	☐ *3*	☐ *2*	☐ *1*	☐ *0*
28. My usual doctor or nurse at the hospital knows about my medical history [RC4-hosp] (e.g. knows about illnesses and treatment you had in the past).	☐ *5*	☐ *4*	☐ *3*	☐ *2*	☐ *1*	☐ *0*
29. My usual doctor or nurse at the hospital makes the best decisions about my diabetes treatment [RC5-hosp] (e.g. your diet, tablets and medicines, testing etc).	☐ *5*	☐ *4*	☐ *3*	☐ *2*	☐ *1*	☐ *0*
30. My usual doctor or nurse at the hospital is concerned about me [RC6-hosp] (e.g. interested in you, and your well-being, as a person).	☐ *5*	☐ *4*	☐ *3*	☐ *2*	☐ *1*	☐ *0*

Section 3 Overall experience of diabetes care: practice and hospital care

31. In general, how well is your diabetes care coordinated? [TCB1]	*Extremely well*	*Very well*	*Fairly well*	*Badly*	*Very badly*	*Extremely badly*
	☐	☐	☐	☐	☐	☐
	5	4	3	2	1	0

Continuity of care in type 2 diabetes

Think about all the different staff involved in your diabetes care. How much would you agree with the following statements?

	Agree very strongly	***Agree strongly***	***Agree***	***Disagree***	***Disagree strongly***	***Disagree very strongly***
32. They all give me the same information and advice. [TCB2]	☐	☐	☐	☐	☐	☐
	5	4	*3*	*2*	*1*	*0*
33. They all know my medical history. [TCB3]	☐	☐	☐	☐	☐	☐
	5	4	*3*	*2*	*1*	*0*
34. They all know about my diabetes treatment. [TCB4]	☐	☐	☐	☐	☐	☐
	5	4	*3*	*2*	*1*	*0*
35. They share an agreed plan of treatment for my diabetes. [TCB5]	☐	☐	☐	☐	☐	☐
	5	4	*3*	*2*	*1*	*0*

1.2 Interview-administration version

These questions ask about your diabetes care from the general practice (surgery).

LC1-gp In the last 12 months, how many times have you spoken with staff at the practice about your diabetes?

Never	☐ 0	If you answered 'never' go
Once	☐ 1	to question LC1-hosp
Twice	☐ 2	
3 times	☐ 3	
4 times	☐ 4	
5 times or more	☐ 5	

LC2-gp In the past 12 months, how many times has the practice sent you an appointment letter for your diabetes?

Never	☐ 0
Once	☐ 1
Twice	☐ 2
3 times	☐ 3
4 times	☐ 4
5 times or more	☐ 5

LC3-gp In the past 12 months, how many times have you had a blood test (including fingerprick tests) taken for your diabetes at the practice?

Never	☐ 0
Once	☐ 1
Twice	☐ 2
3 times	☐ 3
4 times	☐ 4
5 times or more	☐ 5

FC1-gp If you need advice urgently, how long does it take to get to speak to a doctor or nurse at the practice?

Same day	☐ 5	
Next working day	☐ 4	
Within 2 working days	☐ 3	
Within 3 working days	☐ 2	
Within 4 working days	☐ 1	
In 5 working days or more	☐ 0	
I don't know	☐ 8	If this question is not applicable,
I don't go to the GP for emergencies	☐ 9	go to question FC3-gp

Continuity of care in type 2 diabetes

FC2-gp How would you rate the length of time you've had to wait before you spoke to a doctor or nurse at the practice, if you needed urgent advice?

Very poor	☐ 0
Poor	☐ 1
Fair	☐ 2
Good	☐ 3
Very good	☐ 4
Excellent	☐ 5

FC3-gp If you have a problem with your diabetes, how well does your practice respond to it?

Extremely badly	☐ 0
Very badly	☐ 1
Badly	☐ 2
Fairly well	☐ 3
Very well	☐ 4
Extremely well	☐ 5

Continuity of care in type 2 diabetes

The next questions are about your usual doctor or nurse at the general practice. That is, the doctor or nurse who knows you and your diabetes best.

LC4-gp In the last 12 months, how many times have you seen your usual doctor or nurse at the practice?

I don't have a usual doctor or nurse	☐ 0	
Once	☐ 1	
Twice	☐ 2	If you do not have a usual
3 times	☐ 3	doctor or nurse go on to
4 times	☐ 4	LC4a, otherwise LC4b
5 times or more	☐ 5	

LC4a Can I just check, does that mean there is no particular doctor or nurse at the practice who knows you and your diabetes best?

No usual doctor or nurse	☐ 0	If you do not have a usual
A usual doctor or nurse	☐ 1	doctor or nurse go on to question TCB1

LC4b Who do you usually see for your diabetes care (who knows you and your diabetes best).

Practice Doctor	☐ 1
Practice Nurse	☐ 2
Both	☐ 3

FC4-gp If you need to speak to your usual doctor or nurse about your diabetes, how easy is it for you to speak to your usual doctor or nurse at the practice?

Extremely difficult	☐ 0
Very difficult	☐ 1
Somewhat difficult	☐ 2
Fairly easy	☐ 3
Very easy	☐ 4
Extremely easy	☐ 5

RC1-gp How well does your usual doctor or nurse at the practice explain medical procedures and tests done for your diabetes?

Extremely badly	☐ 0
Very badly	☐ 1
Badly	☐ 2
Fairly well	☐ 3
Very well	☐ 4
Extremely well	☐ 5

Continuity of care in type 2 diabetes

How much do you disagree or agree with the following statements about your usual doctor or nurse at the practice?

RC2-gp My usual doctor or nurse at the practice **involves me in decisions** about my diabetes.

- Very strongly disagree ☐ 0
- Strongly disagree ☐ 1
- Disagree ☐ 2
- Agree ☐ 3
- Strongly agree ☐ 4
- Very strongly agree ☐ 5

RC3-gp My usual doctor or nurse at the practice **listens to what I have to say**.

- Very strongly disagree ☐ 0
- Strongly disagree ☐ 1
- Disagree ☐ 2
- Agree ☐ 3
- Strongly agree ☐ 4
- Very strongly agree ☐ 5

RC4-gp My usual doctor or nurse at the practice **knows about my medical history** (e.g. other illnesses and treatments).

- Very strongly disagree ☐ 0
- Strongly disagree ☐ 1
- Disagree ☐ 2
- Agree ☐ 3
- Strongly agree ☐ 4
- Very strongly agree ☐ 5

RC5-gp My usual doctor or nurse at the practice **makes the best decisions about my diabetes treatment** (e.g. medication, tests done).

- Very strongly disagree ☐ 0
- Strongly disagree ☐ 1
- Disagree ☐ 2
- Agree ☐ 3
- Strongly agree ☐ 4
- Very strongly agree ☐ 5

RC6-gp My usual doctor or nurse at the practice **is concerned about me**.

- Very strongly disagree ☐ 0
- Strongly disagree ☐ 1
- Disagree ☐ 2
- Agree ☐ 3
- Strongly agree ☐ 4
- Very strongly agree ☐ 5

Continuity of care in type 2 diabetes

These questions are about your hospital diabetes care.

LC1-hosp In the last 12 months, how many times have you spoken with staff at the hospital about your diabetes?

Never	☐ 0	If you answered 'never' go on
Once	☐ 1	to question TCB1
Twice	☐ 2	
3 times	☐ 3	
4 times	☐ 4	
5 times or more	☐ 5	

LC2-hosp In the past 12 months, how many times has the hospital sent you an appointment letter for your diabetes?

Never	☐ 0
Once	☐ 1
Twice	☐ 2
3 times	☐ 3
4 times	☐ 4
5 times or more	☐ 5

LC3-hosp In the past 12 months, how many times have you had a blood test (including fingerprick tests) taken for your diabetes at the hospital?

Never	☐ 0
Once	☐ 1
Twice	☐ 2
3 times	☐ 3
4 times	☐ 4
5 times or more	☐ 5

FC1-hosp If you need advice urgently how long does it take to get to speak to a doctor or nurse at the hospital?

Same day	☐ 5	
Next working day	☐ 4	
Within 2 working days	☐ 3	
Within 3 working days	☐ 2	
Within 4 working days	☐ 1	
In 5 working days or more	☐ 0	
I don't know	☐ 8	If this question is not applicable,
I don't go to the Hospital for emergencies	☐ 9	go to question FC3-hosp

FC2-hosp How would you rate the length of time you've had to wait before you spoke to a doctor or nurse at the hospital, if you needed urgent advice?

Very poor	☐ 0
Poor	☐ 1
Fair	☐ 2
Good	☐ 3
Very good	☐ 4
Excellent	☐ 5

FC3-hosp If you have a problem with your diabetes, how well does the hospital respond to it?

Extremely badly	☐ 0
Very badly	☐ 1
Badly	☐ 2
Fairly well	☐ 3
Very well	☐ 4
Extremely well	☐ 5

Continuity of care in type 2 diabetes

The next questions are about your usual doctor or nurse at the hospital. That is, the doctor or nurse who knows you and your diabetes best.

LC4-hosp In the last 12 months, how many times have you seen your usual doctor or **nurse at the** hospital?

I don't have a usual doctor or nurse	☐ 0	If you do not have a usual
Once	☐ 1	doctor or nurse, go on to
Twice	☐ 2	question LC4a otherwise
3 times	☐ 3	LC4b
4 times	☐ 4	
5 times or more	☐ 5	

LC4a Can I just check, does that mean there is no particular doctor or nurse at the hospital who knows you and your diabetes best?

No usual doctor or nurse	☐ 0	If you do not have a usual
A usual doctor or nurse	☐ 1	doctor or nurse go on to question TCB1

LC4b Who do you usually see for your diabetes care (who knows you and your diabetes best).

Hospital doctor	☐ 3
Hospital Nurse	☐ 4
Both	☐ 5

FC4-hosp In general, if you need to speak to your usual doctor or nurse about your diabetes, how easy is it for you to get to speak to your usual doctor or nurse at the hospital?

Extremely difficult	☐ 0
Very difficult	☐ 1
Somewhat difficult	☐ 2
Fairly easy	☐ 3
Very easy	☐ 4
Extremely easy	☐ 5

RC1-hosp How well does your usual doctor or nurse at the hospital explain medical procedures and tests done for your diabetes?

Extremely badly	☐ 0
Very badly	☐ 1
Badly	☐ 2
Fairly well	☐ 3
Very well	☐ 4
Extremely well	☐ 5

Continuity of care in type 2 diabetes

How much do you disagree or agree with the following statements about your usual doctor or nurse at the hospital?

RC2-hosp My usual doctor or nurse at the hospital **involves me in decisions** about my diabetes.

- Very strongly disagree ☐ 0
- Strongly disagree ☐ 1
- Disagree ☐ 2
- Agree ☐ 3
- Strongly agree ☐ 4
- Very strongly agree ☐ 5

RC3-hosp My usual doctor or nurse at the hospital listens to what I have to say.

- Very strongly disagree ☐ 0
- Strongly disagree ☐ 1
- Disagree ☐ 2
- Agree ☐ 3
- Strongly agree ☐ 4
- Very strongly agree ☐ 5

RC4-hosp My usual doctor or nurse at the hospital **knows about my medical history** (e.g. other illnesses and treatment you have had).

- Very strongly disagree ☐ 0
- Strongly disagree ☐ 1
- Disagree ☐ 2
- Agree ☐ 3
- Strongly agree ☐ 4
- Very strongly agree ☐ 5

RC5-hosp My usual doctor or nurse at the hospital **makes the best decisions about my diabetes treatment** (e.g. medication, tests done).

- Very strongly disagree ☐ 0
- Strongly disagree ☐ 1
- Disagree ☐ 2
- Agree ☐ 3
- Strongly agree ☐ 4
- Very strongly agree ☐ 5

RC6-hosp My usual doctor or nurse at the hospital **is concerned about me**.

- Very strongly disagree ☐ 0
- Strongly disagree ☐ 1
- Disagree ☐ 2
- Agree ☐ 3
- Strongly agree ☐ 4
- Very strongly agree ☐ 5

Continuity of care in type 2 diabetes

This section is about your overall experience of diabetes care (Practice and Hospital care).

TCB1 In general, how well is your diabetes care coordinated?

Extremely badly	☐ 0
Very badly	☐ 1
Badly	☐ 2
Fairly well	☐ 3
Very well	☐ 4
Extremely well	☐ 5

Continuity of care in type 2 diabetes

Think about all the different staff involved in your diabetes care, how much would you agree with the following statements?

TCB2 They all give me the same information and advice.

- Very strongly disagree ☐ 0
- Strongly disagree ☐ 1
- Disagree ☐ 2
- Agree ☐ 3
- Strongly agree ☐ 4
- Very strongly agree ☐ 5

TCB3 They all know my medical history (e.g. other illnesses and treatments).

- Very strongly disagree ☐ 0
- Strongly disagree ☐ 1
- Disagree ☐ 2
- Agree ☐ 3
- Strongly agree ☐ 4
- Very strongly agree ☐ 5

TCB4 They all know about my diabetes treatment (e.g. medication, tests done)

- Very strongly disagree ☐ 0
- Strongly disagree ☐ 1
- Disagree ☐ 2
- Agree ☐ 3
- Strongly agree ☐ 4
- Very strongly agree ☐ 5

TCB5 They share an agreed plan of treatment for my diabetes.

- Very strongly disagree ☐ 0
- Strongly disagree ☐ 1
- Disagree ☐ 2
- Agree ☐ 3
- Strongly agree ☐ 4
- Very strongly agree ☐ 5

END

2 Continuity in the delivery of care

This questionnaire was developed from qualitative interviews with health professionals. The questionnaire is presented in two formats: one for professionals based in general practice and one for professionals based in a hospital.

The items cover five domains:

Longitudinal continuity	L1–L4 (four items)
Relational continuity	R5–R9 (five items)
Informational continuity	I10–I14 (five items)
Team continuity	T15–T19 (five items)
Cross-boundary continuity	CB20–CB28 (nine items)

Some items have reversed scaling but, for ease of analysis, item responses are appropriately coded in these questionnaires.

Each subscale is scored by summing the item scores and then rescaling to obtain a score from zero to 25. The overall score is obtained by summing the five subscales and rescaling to obtain a score from zero to 100.

See Section 10 for further information.

General-Practice questionnaire

Regarding routine follow-up care for diabetic patients in the General Practice.

L1. For diabetic patients under routine follow-up, how many Practice visits do they generally make over 12 months?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5+ ☐
L2. How many times a year does the Practice send appointment letters reminding them to attend?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5+ ☐
L3. How many times a year do patients under routine follow-up care have a HbA1c measurement at the Practice?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5+ ☐
L4. On average, what proportion of diabetic patients fail to attend their appointments?	35% ☐	25–34% ☐	15–24% ☐	5–14% ☐	1–4% ☐	0%+ ☐

Continuity of care in type 2 diabetes

Regarding the provision of regular care to diabetic patients in the General Practice. To what extent do you agree or disagree with the following statements?

	Agree very strongly	**Agree strongly**	**Agree**	**Disagree**	**Disagree strongly**	**Disagree very strongly**
R5. It is difficult for diabetic patients to see me personally for their consultation if they want to.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
R6. If a diabetic patient wants to speak to me urgently about their diabetes, it is easy for them to speak to me.	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
R7. I generally know little about the medical history of the patients I see for routine follow-up at the Practice.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
R8. I rarely have time to address all the concerns raised by patients during their consultation.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
R9. I generally try to involve patients in decisions about their diabetes treatment.	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

Continuity of care in type 2 diabetes

Regarding the clinical information available during consultation. To what extent would you agree with the following statements?

	Agree very strongly	**Agree strongly**	**Agree**	**Disagree**	**Disagree strongly**	**Disagree very strongly**
I10. I always have access to patients' diabetes notes during their consultation.	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
I11. I always have access to patients' full medical records during their consultation.	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
I12. All the information I need is easily accessible during the consultation.	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
I13. The information is generally difficult to read and understand.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
I14. All staff share the same clinical records.	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

Continuity of care in type 2 diabetes

Regarding the coordination of care within your General Practice. To what extent do you agree with the following statements?

	Agree very strongly	**Agree strongly**	**Agree**	**Disagree**	**Disagree strongly**	**Disagree very strongly**
T15. All staff provide consistent advice to patients.	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
T16. All staff share an agreed treatment plan for each patient.	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
T17. All staff share agreed guidelines for the management of diabetes.	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
T18. Overall, diabetes care is poorly coordinated at the Practice.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
T19. It is difficult to speak to colleagues about a patient at the Practice.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Continuity of care in type 2 diabetes

Shared care between General Practice and Hospital

Regarding staff communication for diabetic patients referred to the Hospital. To what extent would you agree with the following statements?

	Agree very strongly	**Agree strongly**	**Agree**	**Disagree**	**Disagree strongly**	**Disagree very strongly**
CB20. It is difficult to obtain information about a diabetic patient from the Hospital.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
CB21. When I see a patient, Hospital letters/summaries are readily available.	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
CB22. The advice given by the Hospital is clearly stated.	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
CB23. The patient's current medication is clearly stated.	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
CB24. All the information I need is provided in the letter/summary.	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

Continuity of care in type 2 diabetes

Regarding the co-ordination of care between the General Practice and Hospital. To what extent would you agree with the following statements?

	Agree very strongly	**Agree strongly**	**Agree**	**Disagree**	**Disagree strongly**	**Disagree very strongly**
CB25. The Practice and Hospital provide inconsistent advice to patients.	☐ 0	☐ 1	☐ 2	☐ 3	☐	☐ 5
CB26. The Practice and Hospital share an agreed treatment plan for each patient.	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
CB27. The Practice and Hospital share agreed diabetes treatment guidelines.	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
CB28. Overall, diabetes care is poorly coordinated between Practice and Hospital.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Hospital professionals' questionnaire

Regarding routine follow-up care for diabetic patients in the outpatient clinic

L1. For diabetic patients under routine follow-up, how many outpatient visits do they generally make over 12 months?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5+ ☐
L2. How many times a year does the Hospital send appointment letters reminding them to attend?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5+ ☐
L3. How many times a year do patients under routine follow-up care have a HbA1c measurement at the Hospital?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5+ ☐
L4. On average, what proportion of diabetic patients fail to attend their appointments?	35% ☐	25–34% ☐	15–24% ☐	5–14% ☐	1–4% ☐	0%+ ☐

Continuity of care in type 2 diabetes

Regarding the provision of regular care to diabetic patients in the outpatient clinic. To what extent do you agree or disagree with the following statements?

	Agree very strongly	**Agree strongly**	**Agree**	**Disagree**	**Disagree strongly**	**Disagree very strongly**
R5. It is difficult for diabetic patients to see me personally for their consultation if they want to.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
R6. If a diabetic patient wants to speak to me urgently about their diabetes, it is easy for them to speak to me.	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
R7. I generally know little about the medical history of the patients I see for routine follow-up in the diabetes clinic.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
R8. I rarely have time to address all the concerns raised by patients during their consultation.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
R9. I generally try to involve patients in decisions about their diabetes treatment.	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

Continuity of care in type 2 diabetes

Regarding the clinical information available during consultation. To what extent would you agree with the following statements?

	Agree very strongly	**Agree strongly**	**Agree**	**Disagree**	**Disagree strongly**	**Disagree very strongly**
I10. I always have access to patients' diabetes notes during their consultation.	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
I11. I always have access to patients' full medical records during their consultation.	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
I12. All the information I need is easily accessible during the consultation.	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
I13. The information is generally difficult to read and understand.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
I14. All staff share the same clinical records.	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

Continuity of care in type 2 diabetes

Regarding the coordination of care within your hospital outpatient clinic. To what extent do you agree with the following statements?

	Agree very strongly	**Agree strongly**	**Agree**	**Disagree**	**Disagree strongly**	**Disagree very strongly**
T15. All staff provide consistent advice to patients.	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
T16. All staff share an agreed treatment plan for each patient.	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
T17. All staff share agreed guidelines for the management of diabetes.	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
T18. Overall, diabetes care is poorly coordinated at the Hospital.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
T19. It is difficult to speak to colleagues about a patient in the diabetes clinic.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Continuity of care in type 2 diabetes

Shared care between Hospital and General Practice

Regarding staff communication with diabetic patients referred by General Practices. To what extent would you agree with the following statements?

	Agree very strongly	**Agree strongly**	**Agree**	**Disagree**	**Disagree strongly**	**Disagree very strongly**
CB20. It is difficult to obtain information about a diabetic patient from their Practice.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
CB21. When I see a patient, letters from their Practice are readily available.	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
CB22. The advice required by the Practice is clearly stated.	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
CB23. The patient's current medication is clearly stated.	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
CB24. All the information I need is provided in the letter.	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

Disclaimer

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Addendum

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