

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

---

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

November 2005

prepared by

Richard Baker, Dept, of Health Sciences, University of Leicester

George Freeman, Dept. of Primary Health Care and General Practice, Imperial College of Science, Technology and Medicine

Mary Boulton, School of Social Sciences and Law, Oxford Brookes University

Kate Windridge, Dept. of Health Sciences, University of Leicester

Carolyn Tarrant, Department of Health Sciences, University of Leicester

Janet Low, Department of Primary Health Care and General Practice, Imperial College of Science, Technology and Medicine

David Turner, Dept. of Health Sciences, University of Leicester

Eileen Hutton, Former Chair, Patient Partnership Group, Royal College of General Practitioners

Stirling Bryan, Health Services Management Centre, University of Birmingham

## Acknowledgements

We thank Sarah Redsell, Savita Katbamna, Keith Stevenson, and Arch Mainous for providing advice on aspects of the study.

We particularly thank John Bankart for his advice and assistance in the statistical analysis of the cross sectional survey (Chapter Six).

We also thank the following research staff for their assistance towards the end of the study: Shona Agarwal, Krishna Bhatti, Ahuti Pancholi, Emma Sullivan, Janet Vaux and Liu Yang. Each contributed in different ways to enable us to complete the study on time despite the delays that occurred due to the changes to ethics and research governance procedures during the course of the study. Their creative and committed assistance was crucial.

We also thank Vicki Cluley and Raj Gill for clerical assistance, including the transcription of interviews. We thank Arwen Sadler and staff at ASTS transcription services, Nisha Parbat, Andrew Petersen (data entry).

We are also grateful to the staff of the Local Research Ethics Committees and NHS research governance office who gave us continuing advice as the new procedures were introduced.

Two other groups must receive a special mention.

### ***The Patient Advisory Group***

The active members of the Patient Advisory Group were:

Mrs Eileen Hutton (Chair)

Mr John McLellan

Mrs Ann Damerell

Mrs Diane Wildbur

Mrs Gilma Pizarro-Duhart

Mr Trevor Seeman

Members recruited through adverts in the National Press, local contacts, and snowball sampling. The group proved to be a great asset to the study, being committed to supporting the research and willing to provide input and advice at all stages. Members came from different backgrounds and had a range of experiences of using health care, and so brought varied and useful perspectives to bear on the issues discussed during meetings.

## ***Continuity of care: the views of patients and carers***

The members met at approximately six-monthly intervals over the duration of the study. Meetings were chaired by Eileen Hutton, and all meetings were attended by one or more of the wider research team (GF, JL, KW, CT). The meetings covered:

1. Introduction to the study
  - members advised on study process, definitions of terms, and recruitment of participants
2. Discussion of initial findings from the interview study, and process of longitudinal data collection
  - as a result of the meeting, group members offered to keep records of primary care consultations, which provided the basis for developing record collection booklets for the longitudinal study. Group members also provided extensive feedback on booklets under development
3. Discussion of findings on advanced access policies and organisational issues in continuity of care
  - members provided their perspectives and recommended publication
4. Development of conjoint questionnaire
  - Patient Advisory Group members reviewed and offered feedback on aspects of the conjoint questionnaire. Following the meeting, members also took part in cognitive pre-testing of the conjoint questionnaire
5. Development of the cross sectional survey questionnaire
  - members completed a draft version of the questionnaire and offered feedback.

### ***Service Liaison Group***

A Service Liaison Group was also convened, composed of NHS managers in various organisations and posts. However, because it was difficult to arrange convenient dates for the meeting of the Group, we undertook individual interviews of the Group members. They provided us with essential information about service priorities and perspectives, and we are grateful for their input. Their names are not recorded here in order to preserve their confidentiality should any material from the interviews eventually be published.

## Contents

<i>Acknowledgments</i> .....	2
<b>Executive Summary</b> .....	<b>7</b>
<b>Chapter 1 Introduction</b> .....	<b>10</b>
1.1 <i>What is continuity?</i> .....	10
1.2 <i>Continuity and developments in health service organisation</i> .....	11
1.3 <i>The importance of other aspects of care</i> .....	15
1.4 <i>The study</i> .....	16
<b>Chapter 2 Design and context</b> .....	<b>19</b>
2.1 <i>Design of the study</i> .....	19
2.1.1 <i>Phase 1</i> .....	19
2.1.2 <i>Phase 2</i> .....	20
2.2 <i>Context</i> .....	20
2.3 <i>The participating practices and their organisational context</i> .....	22
2.4 <i>Model of continuity of care</i> .....	22
<b>Chapter 3 The qualitative study</b> .....	<b>29</b>
3.1 <i>Aim</i> .....	29
3.2 <i>Method – Leicestershire</i> .....	30
3.2.1 <i>Recruitment of participants</i> .....	30
3.2.2 <i>Participants</i> .....	31
3.2.3 <i>Data collection: the interview</i> .....	33
3.2.4 <i>Data processing, analysis and interpretation</i> .....	35
3.3 <i>Methods – London</i> .....	36
3.3.1 <i>Recruitment of participants</i> .....	36
3.3.2 <i>Participants</i> .....	37
3.3.3 <i>Data collection: the interview</i> .....	39
3.3.4 <i>Data processing, analysis and interpretation</i> .....	39
3.4 <i>Results: Findings and interpretations</i> .....	41
3.5 <i>Leicestershire interviews</i> .....	41
3.5.1 <i>Patients’ and carers’ views of types of continuity</i> .....	41
3.5.2 <i>Patients’ and carers’ priorities other than continuity</i> .....	43
3.5.3 <i>Identification of contexts &amp; circumstances</i> .....	45
3.5.4 <i>Matching preferences to primary care services</i> .....	51
3.6 <i>London interviews</i> .....	54
3.7 <i>Discussion</i> .....	57
3.7.1 <i>Implications for the next phases of the study</i> .....	58
3.7.2 <i>Implications for service providers</i> .....	59

## **Continuity of care: the views of patients and carers**

<b>Chapter 4 The longitudinal study.....</b>	<b>60</b>
4.1 Aims.....	60
4.2 Sample and methods.....	60
4.3 Findings.....	65
4.3.1 How far were patient preferences met?.....	65
4.3.2 How far did patients experience continuity?.....	67
4.3.3 Patients' use of primary care... ..	69
4.3.4 A note on other health care providers .....	84
4.4 Conclusions.....	85
4.5 Post script.....	86
<b>Chapter 5 The conjoint study .....</b>	<b>88</b>
5.1 Introduction .....	88
5.2 Methods.....	89
5.2.1 Questionnaire development and piloting.....	89
5.2.2 Framing the choices .....	91
5.2.3 Pilot study .....	92
5.2.4 Econometric model.....	92
5.2.4 Interpretation of the models .....	94
5.2.5 Full postal survey .....	95
5.3 Results .....	97
5.3.1 Sample details .....	97
5.3.2 Characteristics of the sample .....	97
5.3.3 Regression models using only difference terms .....	99
5.3.4 Regression models using interaction terms .....	101
5.4 Discussion .....	107
5.4.1 Key findings.....	107
5.4.2 Implications.....	107
5.4.3 Methodological issues .....	108
5.5 Conclusions.....	109
<b>Chapter 6 The cross-sectional survey.....</b>	<b>110</b>
6.1 Introduction .....	110
6.2 Methods.....	111
6.2.1 The survey questionnaire .....	111
6.2.2 Administration procedure .....	113
6.2.3 The practice and localities .....	113
6.2.4 Analyses .....	115
6.3 Results .....	115
6.3.1 The respondents .....	115
6.3.2 The practices .....	121
6.2.3 Aspects of continuity and patients' choices .....	121
6.2.4 Modelling .....	124
6.3 Discussion.....	146
6.3.1 Weaknesses and strengths of the study .....	146
6.3.2 Findings .....	147
<b>Chapter 7 Discussion and conclusions .....</b>	<b>150</b>
7.1 Introduction .....	150
7.2 Main findings.....	150
7.2.1 Views of patients and carers .....	150
7.3 Strengths and weaknesses.....	152
7.3.1 Strengths .....	152
7.3.2 Weaknesses.....	153

## **Continuity of care: the views of patients and carers**

7.4 How this study has advanced our knowledge & understanding	156
7.5 The findings and development of the model of continuity .....	158
7.6 Implications .....	160
7.6.1 The service.....	160
7.6.2 Policymakers .....	161
7.6.3 PCTs .....	162
7.6.4 Professionals .....	163
7.6.3 Research .....	163
7.8 Conclusion .....	164
<b>Chapter 8 References .....</b>	<b>164</b>
<b>Appendices.....</b>	<b>171</b>

### **Publications**

Several papers have either been published or accepted for publication, or are being prepared to report the elements of the study. They represent the ongoing evolution of our views in the light of reflection on, and further analyses of, the data collected in the study.

Windridge K, Tarrant C, Freeman G, Baker R, Boulton M, Low J. 2004. Problems with a 'target' approach to access in primary care: a qualitative study. *Br J Gen Pract* 54:316-3.

Low J. 2004. Continuity of care from the patient's point of view: context, process and relation. *Family Medicine* 36:61-4.

Boulton M, Tarrant C, Windridge K, Baker R, Freeman GK. How is continuity of care produced? 2006. A mixed methods longitudinal study in primary care. *Br J Gen Pract* 56:749-55

Baker R, Boulton M, Windridge K, Tarrant C, Bankart J, Freeman GK. Interpersonal continuity of care: A cross sectional survey of primary care patients' preferences and their experience. *Br J Gen Pract* (accepted)

Turner DA, Tarrant C, Windridge K, Bryan S, Boulton M, Freeman G, Baker R. Do patients value continuity of care in general practice? An investigation using stated preference discrete choice experiments. *Journal of Health Services Research & Policy* (accepted).

## ***Executive Summary***

---

### **Introduction**

Three aspects of continuity are believed to influence the extent to which patients experience continuity of care:

1. *Informational continuity* – the use of information on past events and personal circumstances to make current care appropriate for each individual.
2. *Management continuity* – a consistent and coherent approach to the management of a health condition that is responsive to a patient's changing needs.
3. *Relational continuity* – an ongoing therapeutic relationship between a patient and one or more providers (Haggerty *et al*, 2003)

Although continuity of care is often regarded as a defining characteristic of primary care, other attributes of care may be equally or more important to patients, for example quick access, availability of special clinical expertise, or someone with time to listen as they explain their problems.

In recent years, developments in the provision of primary care may have reduced the continuity of care. For example, the growing role of nurses in primary care, the introduction of alternative services including walk-in centres and NHS Direct, and the continuing increase in size and complexity of general practices could potentially impair informational and relational continuity, and therefore also management continuity.

Following a listening exercise and the completion of a scoping review, the NHS SDO R&D Programme commissioned this study to explore the current role of continuity in primary care to enable policymakers and providers to plan their services to meet the preferences of patients. The specific aim of the study was to determine the views of patients and carers about the importance of continuity compared to other aspects of care.

### **Methods**

The study adopted a multi-method approach, having four components:

1. A qualitative study in which 79 patients and carers were asked to describe their views on continuity in primary care and the choices they made with respect to different features of care.
2. A longitudinal study in which 36 were followed up over an extended period of time to investigate their pattern of use of primary care, and the choices they made at different times and in different circumstances.
3. A stated preference discrete choice experiment (SPDCE) (also known as a conjoint analysis) involving 666 patients to investigate the relative importance of different attributes of primary care under different hypothetical consulting conditions.
4. A cross sectional survey involving 1437 patients to investigate the patient and service characteristics that influence choices for primary care.

The study took place in two locations in England – West London and Leicestershire – since it was anticipated that the service structures and other characteristics of localities would influence the available features of primary care.

---

### **Findings**

1. Patients are well aware of the clash between personal continuity and quick access in primary care. Patients value all three aspects of continuity of care described by Haggerty *et al* (2003). In common with professionals they often tended to take the term continuity to mean personal or relational continuity although they recognised other aspects when prompted and sometimes volunteered these. Quite early in our study we found that patients were volunteering concerns, unprompted, about their increasing difficulty in seeing the doctor of their choice.
2. Patients and carers have clear views on when they need personal continuity. They want it for more serious and more impactful problems. They are much less concerned when they perceive themselves as fit and by exercising choice according to the circumstances, patients are co-producers of experienced continuity.
3. Patients do not confine their view of continuity to primary care. They see no reason why the NHS should not join up in any way or aspect that their health problems require. This was particularly evident in some of the interviews with more seriously ill patients whose care required but did not always get *good cross-boundary continuity*.
4. These days, patients expect *good informational continuity*. At interview and in survey responses they told us how they expected their primary care professionals to have their records available and their resulting frustration if this does not happen. In the SPDCE and cross sectional survey, great



## ***Continuity of care: the views of patients and carers***

importance was given by respondents to the professional having information on the patient's medical history.

5. Patients also value *personal/relational continuity*. We used the words 'seeing a person you know and trust' to describe the positive therapeutic relationship which is the key feature of *relational* or personal continuity. Patients particularly value relational continuity of care if they are in poorer health or for problems with great impact on their lives (Chapters Five and Six).
6. Continuity of care, both informational and relational, becomes generally more important as patients get older, become more ill and feel more vulnerable. The SPDCE (Chapter Five) showed that patients gave high priority to the availability of records and were prepared to wait for such an appointment. They would also wait a shorter time to see someone they knew and trusted, even when they had new and unexplained symptoms.
7. Some patients are more successful than others in obtaining care with the attributes they prefer. The groups who are disadvantaged in this include those from non-white ethnic groups, the socially isolated, and those not in work. It is possible that patients in these groups are less effective in negotiating for their care, although the structure and organisations of services may also present more barriers for them to overcome.
8. There are differences between locations (London and Leicestershire) in the extent to which patients' preferences are met. Patients in London were less likely than those in Leicestershire to experience relational continuity, informational continuity or longitudinal continuity even when they preferred these attributes of care.

---

## **Implications**

PCTs must balance access targets with an equally valued priority for relational continuity. They should also monitor relational continuity in their communities. The annual national primary care patient survey should be modified to include questions on relational and informational continuity. In addition to improving relational continuity, efforts to improve informational and managerial continuity of care are also needed. Practices themselves need to prioritise relational continuity. This needs team work and staff awareness and training. It also means that every practice policy, for example to maximise performance to gain points within the Quality and Outcomes Framework (QOF), should consider the effects on relational continuity. It should be made easy for patients to express their choice of professional, and they should be encouraged to access this person or people at all times. The revision of the QOF should improve the incentives for offering relational continuity, and for improving delivery of informational continuity.

Particular attention must be given by practices and PCTs to those patients who find it difficult to negotiate for the attributes of care they prefer.

# **The Report**

---

## Chapter 1 Introduction

### **1.1 What is continuity?**

Prior to the planning of this study, a scoping literature review was commissioned by the SDO Programme (Freeman *et al*, 2000). The review searched several bibliographies to identify relevant articles published 1966-2000. The review was not restricted to continuity in primary care, and 95 articles were identified for inclusion of which 17 specifically addressed primary care. The authors of the review concluded that there was no common understanding of what continuity of care represents. They found that researchers had used a variety of definitions of continuity, or no definitions at all. To address this problem, they suggested that a minimum definition of continuity should include the following elements:

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

To achieve this central element, the service needs:

- excellent information transfer accompanying the patient (*continuity of information*)
- effective communication between professionals and services (*cross-boundary continuity*)
- to be flexible and adjust to the needs of the individual over time (*flexible continuity*)
- care from as few professionals as possible consistent with needs (*longitudinal continuity*)
- to provide one or more named individual professionals with whom the patient can establish and maintain a therapeutic relationship (*relational or personal continuity*).

The review suggested that continuity should most appropriately be considered as a relational idea (Saulz, 2003). The context is not only the individual relationship between the doctor, nurse or other health care professional and the patient at a particular point in time, but also the relationship between the patient and their own life-stage, their long-term as well as short-term goals, and the social context (family, employment and so on) within which they live. Thus, different patient groups will hold different views about what continuity is and its value, and individuals will hold different views as they go through different life stages. Given these considerations, measurement of continuity is clearly problematic. With respect to primary health care, the scoping report concluded that more provider continuity was associated with greater satisfaction and lower costs, with relational continuity being

## ***Continuity of care: the views of patients and carers***

more relevant but much more difficult to measure, although at least a moderate level of longitudinal continuity is necessary for patients to make therapeutic relationships with professionals.

In undertaking a review to provide common definitions for continuity, Haggerty *et al* (2003) built on the SDO Programme scoping review. This more recent review identified 583 documents which primarily fell into five domains: primary medical care (226 documents), mental health care (109), disease specific care (92), nursing (74), and other (61), with 21 dealing with measures of continuity. The authors of the review defined continuity as the degree to which a series of discrete health care events is experienced as coherent and connected and consistent with the patient's medical needs and personal context (that is, comparable to experienced continuity in the Freeman *et al* (2000) scoping review). They identified two key elements and three types of continuity. The elements distinguish continuity from other attributes of health care, the first element being care of an individual patient and the second being care over time. They say that continuity is not an attribute of health care providers or organisations but how individual patients experience integration of services and co-ordination. The types of continuity they described are:

1. *Informational continuity* – the use of information on past events and personal circumstances to make current care appropriate for each individual.
2. *Management continuity* – a consistent and coherent approach to the management of a health condition that is responsive to a patient's changing needs.
3. *Relational continuity* – an ongoing therapeutic relationship between a patient and one or more providers.

The reviews of Freeman *et al* (2000) and Haggerty *et al* (2003) have brought much needed improved clarity to the concept of continuity. In undertaking the study described in this report, our thinking has been informed by these definitions, although our focus has been on what patients and carers have had to tell us about their views and choices.

### ***1.2 Continuity and developments in health service organisation***

Continuity of care has long been regarded as a defining characteristic of general practice (RCGP, 1996) and as an important feature of other primary health care services. However, general practice has undergone radical change over the past 30 years, and continues to change in response to new policy developments. Continuity may, therefore, no longer be as important as it once was.

Services have changed. Thirty years ago, primary health care consisted of general practice, with specific services being provided by community nurses, community midwives, and health visitors. That largely primary medical service has now given way to a more

## ***Continuity of care: the views of patients and carers***

pluralistic primary health care service in which a much larger number of non-medical staff provide a much wider range of services. Alternative providers now include walk-in centres in many parts of the country, the telephone service NHS Direct, and a growing number of alternative practitioners. In the 1998 annual patient survey, 19% of respondents reported using one or more of six alternative services in the previous year: 11% accident and emergency (A&E), 4% private doctors, 4% physiotherapists, 2% chiropractors, 1% counsellors, 3% family planning clinics (Airey *et al*, 1999). The importance to patients and carers of continuity with such providers is not clear, and the way the advice of multiple providers is assimilated also requires clarification.

Practices have also changed. Most doctors now work in groups of four or more (Figure 1.1), with extended primary care teams that include more nurses, and in some practices also counsellors, social workers, physiotherapists and others (Figure 1.2). An increasing proportion of consultations are with nurses. Consultations with nurses for people with minor illnesses have been shown in randomised trials to be acceptable to patients (Kinnersley *et al*, 2000; Venning *et al*, 2000). However, although patients tended to report higher levels of satisfaction with nurse consultations, the impact in terms of their views of primary care services as a whole has not been investigated – in particular, is the reduction in continuity that is usually necessary as a trade-off acceptable to patients and carers, and if so, which patients and carers, and under what circumstances? The new contract for general practitioners has replaced the system by which patients registered with a named general practitioner by registration with the practice, and responsibility for out of hours services has been transferred from general practices to primary care trusts (PCTs).

Patients too have changed, and continuity may no longer be as important to them as it was in the past. More of them have been better educated and have more disposable income, and arguably have adopted more consumerist attitudes towards health care (Meerabeau, 1998; Harrison *et al*, 1997). The new range of primary care services provides them with more choice, and they expect increased involvement in decisions about their care.

## Continuity of care: the views of patients and carers

Figure 1.1. Percentage (%) of GPs in solo or 4+ practices (England)

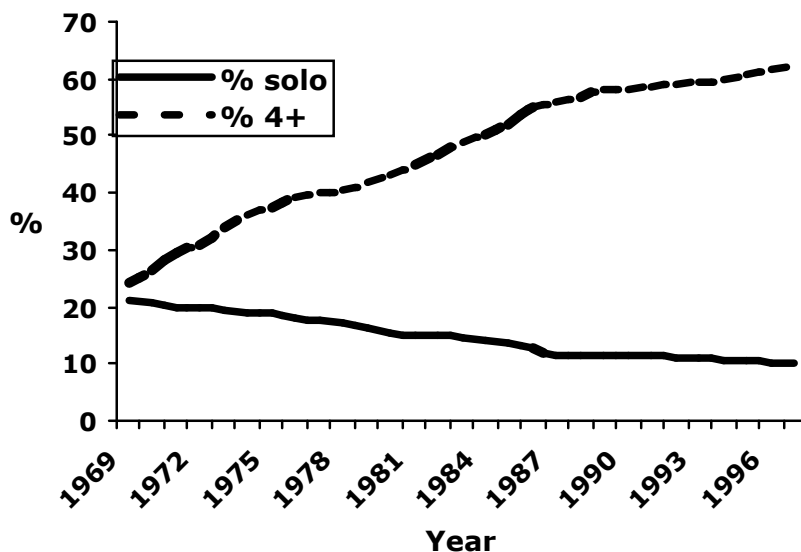
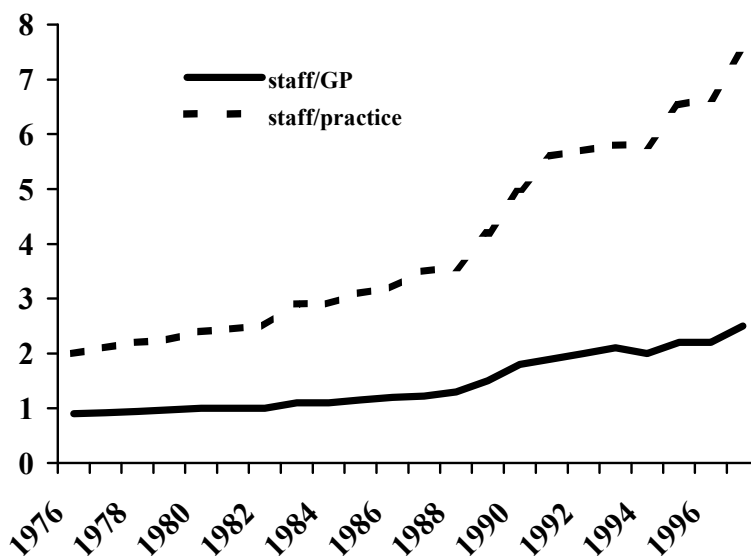


Figure 1.2. Mean number of staff per GP and per practice, 1976-97 (England)



The changes in primary health care and in society make a re-evaluation of the place of continuity necessary. Should decisions about the design of services rest on nostalgia for a no longer relevant shibboleth? On the other hand, if continuity remains important to a

## ***Continuity of care: the views of patients and carers***

substantial proportion of patients, will policy based on the assumption that continuity is no longer important be detrimental to patients' clinical outcomes and experiences of care?

In 1999, the SDO R&D Programme (NHS Service Delivery and Organisation National R&D Programme 2000; Lomas *et al*, 2003) carried out a national listening exercise in order to understand what issues were most important to those delivering and organising services and to those receiving them. Focus groups were held throughout the country involving a total of 354 people, including service users, health care professionals, health service managers, researchers and others. Of the ten areas of particular concern identified, continuity was one. Participants in the focus groups noted that service users wanted to experience greater continuity of care both within health service organisations and across the boundaries between them.

In this report, we describe a study to determine the views of patients and carers about the importance of various types of continuity compared to other aspects of care.

What is known about the views of patients and carers about continuity in primary care?

As the scoping exercise has shown, evidence for the importance of continuity other than in influencing satisfaction is scanty (Freeman *et al*, 2000). Surprisingly little is known of how patients view continuity in different contexts and at different times in their lives and it is necessary to study this specifically. Relational continuity is associated with patient satisfaction and trust in the doctor (Mainous *et al*, 2001; Baker *et al*, 2003; Hjortdahl and Laerum, 1992). The association was confirmed in a recent systematic review of 22 original studies, although it was suggested that future research should investigate whether the association holds for all patients or only those seeking a ongoing relationship with a professional (Saultz and Albedaiwi, 2004). The association may in part be explained by patient choice – the relevant studies were not experimental and patients may be choosing to see doctors they trust and with whom they are satisfied. Nevertheless, there is an association between size of practice and satisfaction, including satisfaction with continuity (Baker and Streatfield, 1995). Relational continuity is also associated with enablement (Howie *et al*, 1999). Enablement is a potentially important measure of the outcome of consultations in primary care, but the theoretical basis of the concept is not yet developed and there is likely to be some overlap with satisfaction.

In a review undertaken in the development of a theory of continuity, Gray and colleagues (2003) reported that in addition to satisfaction, aspects of continuity were associated with improved preventive care, diagnosis, adherence to advice, and patient education, and reduced hospital admissions. However, caution is needed in interpreting these findings. There is very little evidence to suggest that aspects of

## ***Continuity of care: the views of patients and carers***

continuity are associated with improved clinical outcomes, and effects on the process of care tend to be limited at best (Koopman *et al*, 2003; Mainous, 2004). In a study conducted in Belgium, the association between longitudinal continuity and health care costs was explored with a sample of 4,134 members of two health insurance companies (De Maeseneer *et al*, 2003). Provider continuity was found to be associated with lower total health care costs after controlling for sociodemographic and patient variables. A similar finding was reported in a study undertaken in US HMOs involving patients with selected chronic conditions (Raddish *et al*, 1999). In another US study involving Medicaid patients, clinician continuity was associated with lower likelihood of hospital admission (Mainous and Gill, 1998).

In a recent US study, a higher value was placed on continuity by patients who reported worse self-reported health status, were covered by Medicaid or Medicare insurance, had less education, a higher number of chronic conditions and medications, were female, and were at the extremes of age (Nutting *et al*, 2003). However, continuity is not always regarded by patients as important. In a Dutch survey, patients regarded being able to see their familiar general practitioner as more important when the condition was serious (Schers *et al*, 2002). We have shown that patients report that they find it possible to receive personal care in consultations with unfamiliar professionals, but when the condition is complex they prefer care in the context of a continuing relationship (Tarrant *et al*, 2003).

### ***1.3 The importance of other aspects of care***

Continuity is not the only attribute of primary care that may be important to patients. Other attributes include access, range of services, cost, and quality among others. Human communication, care tailored to the individual, and a focus on the person as a whole are regarded as important attributes of primary care (Tarrant *et al*, 2003). Cost is relatively unimportant in the UK NHS, and it is difficult for patients to assess the technical quality of care (McKinley *et al*, 2004). However, patient access to care has been the subject of research as well as concern. In the 1998 national patient survey in which 100,000 adults were asked about their experiences of general practice, 81% of the respondents (65% response rate) reported consulting a GP in the past 12 months (Airy *et al*, 1999). Access was one of the most heavily criticised aspects of care. One in four had to wait more than four days to see a GP of their choice, and 5% had to wait 8 days or longer. In responding to the target included in the NHS Plan of 48 hours for access, the National Primary Care Development Team has made improvement in access a priority, and is exploring the use of alternatives to consultations with GPs, for example nurse consultations or consultations by telephone.

In an SDO Programme scoping review of access to health care (including but not restricted to primary care), Gulliford *et al* (2001)

## ***Continuity of care: the views of patients and carers***

reported a significant mismatch between professional expectations, patients' needs and patterns of uptake of services. Policy responses have shifted from trying to change people's behaviour to trying to address people's concerns more directly. Problems of access include under-use of services by some groups (for example, failure to take up preventive measures such as immunisation or cervical screening), inappropriate use of services such as use of accident and emergency departments for minor illness, and patient dissatisfaction with access. The review noted that difficulty with obtaining general practice appointments was a key concern in the NHS, pointing out that in one study 55% of patient reported having to wait more than two days for an appointment for a non-urgent problem. The advanced access techniques of the National Primary Care Development Team, based on the idea that 'today's work must be done today' were noted as a potentially successful means of scheduling appointments.

The national patient survey undertaken in England in 2004 provides more evidence about the issues of access and continuity (Healthcare Commission, 2004). The survey was sent to 850 patients aged 16 and over in each PCT, a total of 249,538 people, of whom 122,133 (49%) responded. Of the respondents, 88% had visited their health centre or surgery in the past 12 months. 6% had often been put off attending and 16% sometimes put off because of inconvenient opening times. 29% of people requesting an appointment had been seen on the same day, and another 25% within two working days (another 7% were seen without an appointment and 17% had a pre-planned appointment). Over half thought they were given an appointment as soon as they thought necessary, while 30% thought their appointment should have been a bit sooner and 13% felt it should have been a lot sooner. 44% of respondents who waited for more than a day for an appointment did so because they were unable to get an earlier appointment with any general practitioner at their practice. However, 41% said that the main reason they had to wait was that they wanted to see their choice of doctor, indicating that at least some patients were making trade-offs between fast access and seeing someone they know. The findings of this survey highlight the importance of taking other attributes of primary care into account when investigating patients' views of continuity.

### ***1.4 The study***

The aim of the study is to determine the views of patients and carers about the importance of various types of continuity compared to other aspects of care. The specific objectives are as follows:

1. to describe the views of patients and carers about the meaning, value and importance of various types of continuity of care
2. to identify the context and circumstances in which various types of continuity of care are given greater or lesser weight in relation to other valued aspects of primary care (e.g. access,



## ***Continuity of care: the views of patients and carers***

specialist knowledge, gender of provider, language of provider, trust in provider)

3. to examine how this influences the way patients use the range of primary care services available to them
4. to determine the proportions of people in different groups who hold particular views about the importance of continuity
5. to determine the trade-offs people are willing to make between continuity and other aspects of care.

In an investigation of the importance of continuity, a variety of factors must be acknowledged:

1. Patients make use of a range of providers in primary care.
2. Carers also develop relationships with primary health care services, but although the difficulties carers experience have been documented in several studies, their needs are often overlooked.
3. Discontinuity may also play a role in promoting errors in care, but conversely, obligatory longitudinal continuity may impair the quality of care if the practitioner does not perform adequately. Some patients may wish to consult different professionals for different problems, or change to another professional altogether.
4. Organisational context is likely to influence patients' perceptions of the importance of different aspects of continuity, or their ability to obtain the care that they most prefer, and change in organisational forms may impact on the extent to which patients' experience continuity. Thus, a walk-in centre may not be locally available, or not open at convenient times. Complementary therapists may not be accessible to rural communities, and the range of traditional services available from the small local practice may be limited. Furthermore, organisations may have features that make them more or less able to provide continuity, or manage the trade-off between continuity and other aspects of care more effectively. For example, an organisational culture that emphasises the need for inter-professional co-operation and attention to the experience of users may be more likely to design services that meet the wishes of patients for attributes of care such as continuity. On the other hand, large and complex organisations may be less able to respond to the needs of different patients. Co-ordination between organisations or health professionals will influence perceptions of continuity. In a study of patients' and carers experiences of care across the interface with secondary care, failures in continuity were found to generate a state described by respondents as 'limbo', in which they felt they had ceased to make progress towards recovery or adjustment to an altered state of health (Preston *et al*, 1999).

## ***Continuity of care: the views of patients and carers***

We have conducted a multi-method study in which quantitative data have a role to play, but qualitative methods also have an important role in describing patients' views and experiences. The study has four main components. These are:

1. A **qualitative investigation** of the views of samples of patients and carers.
2. A **longitudinal study**, also largely qualitative, in a sample of patients
3. A **conjoint analysis**
4. A large **cross sectional survey**.

These studies are described in the following chapters.

## Chapter 2 Design and context

### **2.1 Design of the study**

We undertook a multi-method study with four main components broadly grouped into two phases. These were:

#### **Phase 1**

- a qualitative investigation of the views of samples of patients and carers. The initial findings of this component were used to inform the development of questionnaires for the other two components (see Chapter 3)
- a longitudinal study of a selected subgroup of patients to follow-up prospectively their use of primary care services in relation to their views on continuity of care (see Chapter 4);

#### **Phase 2**

- a conjoint analysis (see Chapter 5)
- a cross sectional survey (see Chapter 6).

#### **2.1.1 Phase 1**

Views on the meaning and relative importance of different aspects of continuity of care were elicited through semi-structured interviews with patients and carers, recruited in Leicestershire and London from local practices and other providers (e.g. NHS walk-in centres, complementary therapists). Patients were sampled to ensure a range of socio-demographic and lifestyle factors.

The interviews sought to describe the way patients and carers perceive and value continuity of care, including what they value about continuity, what they see as the costs, compromises and trade-offs required to maintain continuity and when and how they are willing to compromise. The analysis was used to develop an initial theory or model about the role, value and importance of different types of continuity of care, to individuals in different contexts and circumstances. The findings of the interviews were also used to inform the development of the questionnaires for the conjoint analysis and cross sectional survey.

Further information was collected from a sub-group of participants who had taken part in the interviews over an extended period of time. They were asked to keep a record of their contact with primary health care providers, and for permission to review their GP notes about their recent consultations.

## ***Continuity of care: the views of patients and carers***

### **2.1.2 Phase 2**

To investigate the trade-offs that patients and carers are willing to make, a postal questionnaire based on the conjoint method of eliciting preferences was completed by a sample of 646 patients and carers, and administered to 20 patients from minority ethnic groups. A small sample of patients and carers was also interviewed about the decision-making process behind their responses. The term conjoint analysis refers to a number of different approaches, all of which use people's statements of how they would respond to different hypothetical situations. It requires respondents to rate, rank or choose between alternatives. The analyst designs a set of hypothetical alternatives based on a limited set of 'important' attributes, and obtains from the respondent an indication of the relative preference for each alternative. The simplest indicator of preference involves the selection of one alternative from two options, and the exercise is repeated with the values of the alternatives being systematically altered. Choice based approaches have been used previously in health care settings (Ryan *et al*, 1998; Bryan *et al*, 1998) with encouraging results concerning test-retest reliability (Bryan *et al*, 2000). A choice based approach was adopted. Attribute identification and level assignment were based on the results of the qualitative component of the study and informed by the model.

We also undertook a cross sectional survey of patients' and carers' views and priorities, to identify whether different groups of people hold different views about the importance of various aspects of primary care (including continuity). A total of 1437 people completed the survey questionnaire that was developed from the analysis of the initial interviews. The participants were random samples of people identified from the registers of the participating practices.

The responses to the questionnaires were analysed to determine the proportions of people in different groups (and with particular personal characteristics) who hold particular views about the relative importance of the elements of continuity. Multivariate analyses were undertaken to further elaborate the model developed from the qualitative study.

The findings of the four elements of the study (qualitative, longitudinal, conjoint analysis and cross sectional survey) have been summarised in Chapter 7, which also includes a discussion of the implications for providers, policymakers and researchers.

## **2.2 Context**

Since aspects of continuity will be influenced by organisational context, the study was undertaken in two centres – Leicestershire and London.

## ***Continuity of care: the views of patients and carers***

### ***Leicestershire***

900,000 people live in Leicestershire and Rutland, in a mix of rural communities, market towns, and the suburbs and inner-city of Leicester. There are six primary care trusts (PCTs). The principal A&E service is based in one acute hospital in Leicester. There are also several community hospitals and (in Loughborough) a walk-in centre. The population of rural Leicestershire is affluent, but the inner-city has areas of high deprivation (Jarman scores 41-51; the IMD2004 in some localities is over 50). The inner-city has a high proportion of people from ethnic minority communities, particularly south Asians, and local languages include Hindi, Gujarati, Punjabi, Bengali and Urdu. There are 150 general practices in Leicestershire and approximately 450 GPs.

### ***West London***

When the project began (November 2001) the health service structures were at a point of change. The primary care groups were in process of dissolution, and negotiations were yet to settle upon new boundaries for their successors. Similar shifts were at play in hospital trusts: the organisational framework was in flux.

In the absence of clear boundaries in the health domain, we chose to make use of boundaries that were available through the local government structures. The physical area of the part of London contained within the administrative boundaries of the Royal Borough of Kensington and Chelsea (RBK&C) was chosen as the location of the initial round of qualitative interviews. This choice satisfied two conditions:

1. The relative stability of administrative systems allowed us to access a reliable list of GPs in the area. It also offered clear organisational structures that we hoped to make use of in later stages of the research.
2. The social make up of this borough reflected the sociodemographic variety required for the study. The population includes some of the richest people in the country, and some of the poorest; some of the longest established communities, and some of the newest and most transient populations; over 100 different languages are spoken in the schools in the area, reflecting the diverse ethnic make up of the population.

Every practice in Leicestershire and RBK&C received a letter asking them if they might be interested in taking part in the study. Those who expressed interest were contacted to explain the study and clarify basic information about the practice (whether inner city, suburban or rural, size, and levels of deprivation in the local population). The sample selected for inclusion in the study included a mix of practices by location, size and deprivation.

### **2.3 The participating practices and their organisational context**

We collected information about organisational context through interviews with key practice staff, usually the lead general practitioner, and supplemented this information by interviews of health service managers who had volunteered for the Service Liaison Group.

The practice interview was based on a questionnaire in six sections. The details investigated included: (1) the locality, numbers of patients, main ethnic groups of patients, whether training, having a personal list system; (2) numbers of GPs; (3) other practice staff (nurses, counsellors etc); (4) the appointment system; (5) practice culture; and (6) information about other local services. The four practice culture questions were based on Kralewski *et al's* (2003) questionnaire. This US instrument was developed to measure the organisational culture of medical group practices, and we selected four questions from the collegiality and cohesiveness scales of the questionnaire as most relevant to the provision of continuity of care. Each question requested the respondent to indicate the degree to which the question statement describes the practice culture, with responses being in the form of four-point options, 'not at all' to 'a great deal'. We calculated the mean of the responses to these four questions to indicate practice culture. We also included a single question on the importance attached by the practice to personal continuity with a five-point response option, 'not at all important' to 'extremely important'.

Table 2.1 summarises features of the participating practices. Of the Leicestershire practices, 25% reported a walk-in centre or minor injuries unit in their locality, but in London all but one practice reported that one or more of these services were available locally. Table 2.2 presents more detail about alternative local services. Practices with code numbers of 100 or above were situated in London, and these practices reported a greater number of alternative local services, although the variety of services available was similar in London and Leicestershire.

## Continuity of care: the views of patients and carers

**Table 2.1. Features of the participating practices.**

<b>Practice ID</b>	<b>Leics 1 Lond 2</b>	<b>Locality</b>	List size (small <6000; med 6000- 12000; large 12000+)	<b>Deprivation (IMD 2004 high = &gt;30, med = 10-30, low = &lt;10)</b>	<b>Local walk- in centre or minor injuries unit</b>
01	1	Inner city	Med	High	N
02	1	Urban/ suburban	Med	High	N
03	1	Inner city	Med	Med	N
04	1	Rural	Small	Low	N
05	1	Urban/ suburban	Small	Med	Y
06	1	Urban/ suburban	Large	Low	N
07	1	Inner city	Large	Med	N
08	1	Rural	Small	Med	N
10	1	Urban/ suburban	Med	High	Y
11	1	Inner city	Small	High	N
12	1	Rural	Large	High	N
13	1	Urban/ suburban	Small	Low	Y
14	1	Urban/ suburban	Med	Low	N
15	1	Inner city	Large	Med	N
16	1	Urban/ suburban	Large	Med	Y
100	2	Inner city	Med	High	Y
200	2	Inner city	Med	High	Y
300	2	Urban/ suburban	Med	Med	Y
400	2	Urban/ suburban	Small	Low	Y
500	2	Urban/ suburban	Small	Med	Y
600	2	Urban/ suburban	Med	High	N
700	2	Urban/ suburban	Small	Med	Y
800	2	Urban/ suburban	Large	Low	Y
900	2	Inner city	Med	Med	Y
1000	2	Inner city	Small	High	Y
1100	2	Inner city	Med	Med	Y
1200	2	Inner city	Med	Med	Y

## ***Continuity of care: the views of patients and carers***

**Table 2.2. Alternative services in practice localities (WIC - walk-in centre)**

<b>Practice ID</b>	<b>Services ** (In London - services within 3 miles of practice)</b>
01	city hospital (A&E), sexual health/family planning clinic
02	local hospital (no A&E)
03	city hospital (A&E), sexual health/family planning clinic
04	minor injuries unit (6 miles)
05	WIC, minor injuries unit, sexual health/family planning clinic, local hospital (no A&E), alt therapy/comp medicine centre
06	local hospital (no A&E)
07	city hospital (A&E), sexual health/family planning clinic
08	local hospital (no A&E), alt therapy/comp medicine centre
10	WIC, minor injuries unit, sexual health/family planning clinic, local hospital (no A&E), alt therapy/comp medicine centre
11	city hospital (A&E), sexual health/family planning clinic
12	local hospital (no A&E)
13	WIC, minor injuries unit, sexual health/family planning clinic, local hospital (no A&E), alt therapy/comp medicine centre
14	city hospital (A&E), sexual health/family planning clinic
15	city hospital (A&E), sexual health/family planning clinic
100	2 WIC, 3 A&E, sexual health/family planning clinic, complementary therapy centre
200	2 WIC, 2 A&E, sexual health/family planning clinic, alt therapy/comp medicine centre
300	WIC, 3 A&E, sexual health/family planning clinic
400	WIC, minor injuries unit, (A&E 3 mile)
500	WIC, sexual health/family planning clinic, (A&E 3 mile)
600	2 A&E, sexual health/family planning clinic, (WIC 3 mile)
700	2 WIC, 3 A&E, minor injuries unit, sexual health/family planning clinic
800	WIC, minor injuries unit, (A&E 4 mile)
900	2 WIC, 2 A&E, sexual health/family planning clinic, alternative therapy/complementary medicine centre
1000	WIC, 3 A&E, minor injuries unit, sexual health/family planning clinic
1100	2 WIC, 3 A&E, minor injuries unit, sexual health/family planning clinic
1200	WIC, 3 A&E, minor injuries unit, sexual health/family planning clinic

\*\* In all areas patients have access to some alternative or complementary therapy providers



## ***Continuity of care: the views of patients and carers***

The responses to the practice culture questions are shown in Table 2.3. The mean score in response to the question on the importance attached to providing personal continuity by the practice was 3.59 (on a scale 1- not at all important to 5-extremely important), 11 practices tending to regard personal continuity as rather unimportant or were indifferent to it, and 11 regarding it as important to extremely important.

**Table 2.3. Responses to the questions on practice culture.**

	<b>mean</b>	<b>range</b>
There is a great deal of informal consultation among members of the practice	3.18	1-4
There is a great deal of sharing of clinical information among members of the practice	3.41	2-4
There is a strong sense of belonging to a group	3.14	1-4
There is an identifiable practice style that we all adhere to	3.09	1-4
Mean score	3.20	1.5-4

The mean list size of the participating practices was 8978, range 1760 to 33,000. The mean number of general practitioner partners was 4.91, of whom a mean of 1.50 were part-time partners. Practices also included a mean of 1.64 other GPs who were not partners, and a mean of 2.29 practice nurses and 10.36 receptionists and administrative staff. All practices had several other staff who were members of the primary health care team, and in different practices these included midwives, community nurses, health care assistants counsellors, psychologists, phlebotomists, podiatrists, physiotherapists and health visitors. Ten practices reported that 90% or more of their patients were from white ethnic groups, seven between 60 and 89%, and four less than 60%. Thirteen were training practices. Practice appointment systems fell into three broad categories. One ran an open access system; around a third of the other practices operated the advanced access system only, and the remainder a more traditional mixed system in which it was possible for patients to book appointments in advance. No practice reported operating their own out-of-hours service, all using either a local cooperative or commercial service.

The staff (n=10) who took part in interviews as members of the service liaison group served either strategic health authorities, PCTs or practices. They all had a role in the management of services. The staff at strategic health authority level reported that their focus was on meeting national targets. There had been a shift away from the individual GP/patient model of primary care, towards a coherent, managed service aimed at the population. Continuity (not necessarily

## ***Continuity of care: the views of patients and carers***

relational/personal) was seen as relevant only for some groups e.g. those with ongoing health problems, or asylum seekers or the homeless. Staff at PCT level reported that they were primarily concerned with meeting access targets, the demands of the new contract, and the introduction of flexible working (extended roles, team communication). They reported viewing relational/personal continuity as the exception not the rule in primary health care, and that it was not necessarily the GP's role to provide continuity. At the level of the practice, management staff reported that access was a priority; choice was also a priority in some contexts, but even where prompt access is the main priority, continuity often has important role (e.g. if patients will not use the service until trust has been built up, or if an episode of care needs completion).

The interviews of the service liaison group were limited in number, and we have not included interview quotations in order to protect individuals from identification. Nevertheless, it is clear that in this sample, there is a different view of the importance of continuity at different levels in the service. Those at higher levels give priority to meeting targets, but those at the lower levels appear to be attempting to provide sufficient flexibility to meet patients' preferences for continuity.

### ***2.4 Model of continuity of care***

The model of continuity of care initially emerged from the qualitative interviews, and is described here in order to underpin the reports of the component studies that follow. The model looks at the effects of variation at four distinct levels on how people use (and are satisfied with their use of) primary health care in relation to continuity of care and other competing priorities. Throughout the study, we have made a particular effort to use consistently a set of concepts, categories and questions as well as particular areas, and practices within those areas, which will allow us to explore these levels and their interconnections and effects in order to test and refine the model further.

#### ***(a) The wider environment of available primary care services***

This is the outer context of the range of sources of primary health care available to people in a given area, including GP practices, A&E departments, walk-in centres and complementary and alternative practitioners (homeopathy, acupuncture, chiropractic, etc). It reflects health policy (e.g. walk-in centres) and wider social and cultural trends (e.g. complementary and alternative practitioners). At issue is the extent to which increasing the range of alternative providers of primary health care affects patients' and carers' views and actions regarding continuity, and in what circumstances (e.g. if walk-in centres are available, are people more likely to value access over continuity for minor acute problems?).

## ***Continuity of care: the views of patients and carers***

### ***(b) The immediate environment of the primary health care provider***

The immediate environment is made up of the characteristics, organisation and culture of the provider (typically a GP practice) that provide the immediate opportunities and constraints on how people are able to balance or accommodate their preferences in the way they use the service. These preferences are in relation to a wide range of aspects of primary health care, including speed of access, convenience of access, gender/ethnicity/language of provider, trust in and qualities of the personal relationship with the provider, the provider's specialist knowledge, etc.

The extent to which individuals are able to meet their preferences is constrained or facilitated by service characteristics and organisation such as size of the provider's practice, gender/ethnic composition, appointment system, consulting hours, staff, etc and by the culture and values of the provider, for example in relation to identifying personal doctors, or encouraging continuity. The model suggests that providers both constrain the options available to patients and shape their (future) preferences with regard to continuity, access, choice of provider, etc. On this basis we might hypothesise that people are likely to prefer what they have experience of (e.g. quicker access or greater continuity) and that this will cut across patient characteristics. We might also hypothesise that providers can change patient preferences by changing their characteristics, organisation and culture if they do so in a way that brings patients along with them.

### ***(c) The characteristics of the patient her- or himself***

These include the socio-demographic and life stage/lifestyle characteristics of the patient as well as their views on the meaning, value and importance of various types of continuity and their general preferences for personal/informational/longitudinal continuity in particular classes of situation (e.g. acute minor condition, chronic condition, as a carer, etc). Socio-demographic characteristics and life stage/lifestyle shape priorities and concerns but these are also shaped by past experience of their provider and the 'habits' and expectations that they develop.

The model suggests that different patients have different preferences with regard to continuity in particular classes of situation which shape how they try to use primary health care and their satisfaction with how they actually use it. Whether they are able to achieve their preferences and how they feel about this in particular consultations depends on particular circumstances at a consultation - the final level of variation.

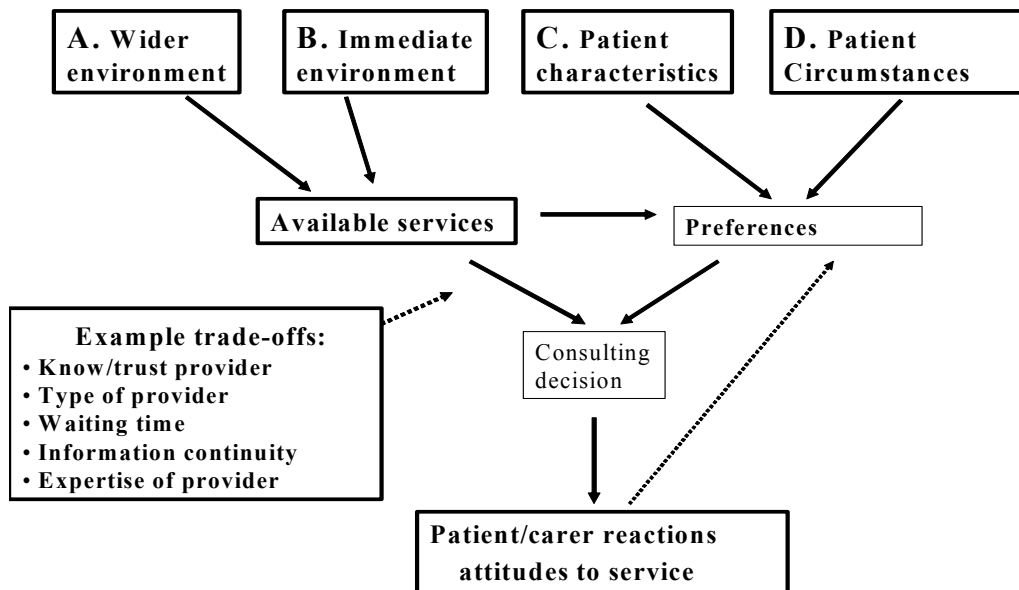
### ***(d) Particular circumstances of a consultation***

Patient preferences in the case of a specific consultation will be shaped by the type of health problem and personal pressures/priorities at the

## **Continuity of care: the views of patients and carers**

time, and provider constraints, including appointment system, practice culture and the availability of doctors or other practitioners at the time. These influences will also shape what patients get with regard to the attributes of primary care such as access, continuity, or specialist knowledge. They will also shape patient 'satisfaction' with what they get and help change or reinforce expectations and preferences for the future.

**Figure 2.1. An outline of the model of patients' and carers' views and choices with respect to elements of continuity in primary health care.**



## Chapter 3 The qualitative study

### **3.1 Aim**

The aim of this component of phase 1 was to address the first aim of the study, namely to describe the views of patients and carers about the meaning, value and importance of various types of continuity of care in relation to other valued aspects of service provision such as access. We also planned to begin to identify the contexts and circumstances in which various types of continuity are given greater or lesser weight in relation to other valued aspects of primary care, in order to inform the development of a model describing relationships among factors that potentially influence people's needs or preferences for types of continuity in primary care (see Chapter Two). The analysis aimed to produce preliminary findings on the extent to which people make trade-offs between continuity and other aspects of primary care when deciding how to consult. It was also designed to identify which variables should be included in a conjoint analysis of the trade-offs people make and a cross sectional survey of whether particular demographic or diagnostic groups have particular patterns of need for continuity.

Understanding when patients prefer various types of continuity of care is most useful if it can be used to predict situations when a particular type of continuity is essential, for instance when it is essential for someone to consult a known and trusted professional who has detailed knowledge of the patient and the way their health condition(s) have evolved. This aim was borne in mind during analysis.

We report separately the studies undertaken in Leicestershire and London since different orientations to the research were in play. Complementary questions were asked in each site, but different analytical techniques and epistemological positions were in use. This reflects the different characteristics of the sites and the range of expertise available in the multidisciplinary team. It also had the effect of more clearly revealing the contradictions that exist in the work and experience of primary care. As a result, the research team became more aware of the inherent differences of perspective – e.g. of patient, of medical practitioner, of manager or policy maker – and the conflict of interests at play in the health care setting. During the process of accommodating these differences, the team were forced to acknowledge the importance of a number of gaps that had to be taken into account in which local participants not only had the freedom to act, but in fact were obliged to act. This led us to see more clearly where questions of praxis, ethics and responsibility must still have their place.

## **3.2 Method – Leicestershire**

### **3.2.1 Recruitment of participants**

The practices were recruited as described in Chapter Two. Practice managers were asked to select a sample of ten patients and carers from a range of ages and with a range of health status (including good health), and write to invite them to be visited at home by a researcher who would ask them about what was important to them when they used primary care services. The invitation letter came from the senior partner in each practice, on practice notepaper, and was accompanied by an information leaflet and consent form which could be returned by post to the researchers if the patient or carer wished to participate. Recruitment was monitored so that criteria set out in a maximum variation sampling frame were met (Box 3.1), in order to ensure that a wide range of interviewees were represented in terms of gender, age, ethnicity, health status, caring status, living arrangements, social class and employment.

#### **Box 3.1. Sampling frame**

Sampling sought to ensure at least one interviewee in each group.

Age group (yrs):	11-17; 18-29; 30-59; 60-79; 80+
Gender	Male; Female
Ethnicity:	White; Black; Asian; Other
Carer?	Non-carer, not disabled; Non-carer, disabled; Carer for young child <10 where child has no significant medical problem; Carer for child with a medical condition; Carer for adult
Location	Inner city; Urban/suburban city; Market town; Industrial/mining/other town/large village; Rural village, or isolated rural house
Employment	Has paid employment; Unemployed and not retired or caring or 'home-making'; Retired or full-time home-maker or other unpaid occupation
Occupation	'Professional'; Non-manual clerical etc; Manual
Qualifications	None; Up to but not including A level or equivalent; A level or equivalent but not more; beyond A level, including degree or postgraduate
Living situation	Lives alone; Lives with partner/family/other; Lives in institution
Health status	Chronic health condition requiring ongoing management; Good health

As recruitment progressed it emerged that there was a lack of interviewees from ethnic minority backgrounds, of those who used primary care services very rarely, and of teenagers. Further

## ***Continuity of care: the views of patients and carers***

recruitment therefore took place via community and other groups, by posting invitations on a notice board, and by snowball sampling.

### **3.2.2 Participants**

The Leicestershire participants were 56 interviewees whose ages ranged from 13 to 85 (Table 3.1). There was a mix in terms of age, gender, ethnicity, occupation, education, use of a car, and living arrangements, although the sample did not include any Black participants and relatively small numbers in the younger age groups. They varied in their health status from those who were healthy to those living with long term limiting conditions, and a range of caring responsibilities were represented including full time and part time care for one or more than one dependent adult(s), care for child(ren) with long-term conditions, and parental responsibilities.

Use of primary care services also ranged from those who had weekly consultations at a GP practice to those who said they avoided using a GP practice. Over 90% of interviewees had consulted a GP in the past 12 months, 80% had consulted a practice nurse, over 60% a pharmacist, over 50% a dentist, and around 35% an alternative practitioner. Services or individuals that had been consulted in the past year by less than 35% of interviewees were: community nurse or nurse practitioner, A&E, NHS Direct, podiatrist/ chiropodist, physiotherapist, psychologist or counsellor, out-of-hours service, health visitor, family planning clinic, walk-in centre, walk-in hospital clinic, voluntary organisation, and midwife.

## ***Continuity of care: the views of patients and carers***

**Table 3.1. Characteristics of interviewees (Leicestershire)**

<b>Characteristic</b>	<b>Subgroups</b>	<b>Number of interviewees</b>
Age (years)	11-17	4
	18-29	8
	30-59	22
	60-79	19
	80+	3
Gender	Male	21
	Female	35
Ethnicity	White	48
	Black	0
	Asian	6
	Other	2
Carer status*	Non-carer, not disabled	25
	Non-carer, disabled	8
	Carer for young child <10 where child has no significant medical problem	13
	Carer for child with a medical condition	2
	Carer for adult	12
Location	Inner city	11
	Urban/suburban city	20
	Market town	3
	Industrial/mining/other town/large village	11
	Rural village, or isolated rural house	11
Employment*	Full time paid work	9
	Part-time paid work	12
	Retired, unemployed or unpaid occupation	29
	Student	7
Qualifications**	None	13
	Up to but not including A level or equivalent	9
	A level or equivalent but not more	6
	Beyond A level	17
Living	Lives alone	5
	Lives with partner/family/other	49
	Lives in institution	2
Health status	Chronic health condition needing ongoing management	31
	Good health	24

\* totals may add to more than 56 because categories are not mutually exclusive

\*\* not all interviewees provided this information



## ***Continuity of care: the views of patients and carers***

### **3.2.3 Data collection: the interview**

Data collection, sampling and analysis in Leicestershire aimed to explore preferences and priorities across as wide a range of participants as possible, in order to identify any priorities not already anticipated on the basis of previous literature, and to begin to make cross-case comparisons. The methodological approach therefore reflected both deductive (testing whether participants held preferences already identified in previous research) and interpretive or inductive elements (using open-ended questions and inviting accounts of issues identified by participants as important).

Leicestershire interviews took place in patients' and carers' homes except on three occasions, when they were held at the patient's GP practice. The interviews in Leicestershire were conducted and audio taped by CT and KW, and explored how patients perceived continuity of care, and when they saw various aspects of it as particularly important (for instance consulting the same professional on two different occasions, consulting a known and trusted professional, having continuity of information). Interviewees were invited to give accounts of their encounters with primary care services including their GP practice, and the interviewer explored whether there were particular priorities on each occasion using a prompt guide which was initially based on literature about patients' preferences and which became progressively more focused during data collection in order to reflect issues raised by interviewees at the same time as enabling exploration of those priorities which seemed most salient to them, as described in Bryman (2001), for example. A prompt guide for the final version is shown in Box 3.2.

## ***Continuity of care: the views of patients and carers***

### **Box 3.2. Topic guide for interview, Leicester interviewees**

NB These topics were incorporated in whatever order suited the interviewee's narrative.

#### **Introduction**

Thanks, use of tape recorder, info sheet, in confidence, anonymised reporting, can withdraw at any time), aim of study.

#### **1. About your GP's practice**

How long registered? How often do you see a GP/nurse these days?

Was there any particular reason why you chose this practice?

What are the good and bad things about it?

How does it compare with previous practices?

#### **2. About your experiences in the last year**

For the illnesses/problems experienced in the past year:

what were **main priorities**? (Being seen quickly/choice of service or person etc, explore what lies behind priorities)

what happened? / who did you consult?

what led to you consulting this person?

have you consulted this person before?

what were the advantages and disadvantages of seeing this person?

if any problems, what would have helped?

For services used in the last year (if not arising above), ask:

What led to using this service, any contact between them and GP

how was it different from seeing own GP?

explore whether 'gaps'

what were the advantages and disadvantages?

#### **3. About your views**

(a) *Continuity of carer*

Have you ever had to see a GP you didn't know?

Have you ever had to see a GP you didn't want to see?

Would you have waited to see your own GP if you could?

Have you ever **chosen** to see a different GP?

Explore whether circumstances when would wait to see own GP

minor problem, ongoing problem, a personal problem?

When would it be particularly important? When would it not matter / prefer not to?

## ***Continuity of care: the views of patients and carers***

Box 3.2 continued

### *(b) Continuity of care*

In the practice, does / did info about you seem to get passed to who needs it, explore implications

When seeing other HCPs outside the practice, does / did info about you get passed to your GP / whoever needs it? Explore

Explore whether ever felt that the people you see didn't seem to know about you and what problems / treatment you have had in the past,

Explore number of people involved in care (too many, OK, too few)

Explore conflicting vs. coherent info

When is it important, when unimportant, that care is well co-ordinated

### *(c) Other services*

Views on NHS direct, walk-in centres, internet services

## **4. Ending**

Sum up. Ask to summarise what are the most important things about a practice.

Explore whether anything else is important, not covered already

Thanks etc

### **3.2.4 Data processing, analysis and interpretation**

Demographic data were reduced, following discussion among team members, into six 'life stages' which reflected interviewees' current main focus: stages were young working person/student (under 30 years with no children or under 30 and working full time), parent of young child if under 65 (not working full time, with pre-teen children), middle age, full time work (aged 31-65, full time work), middle age, no full time work, no caring responsibilities, carer (31-65, no full time work, carer), older people (over 65).

All interviews were transcribed verbatim, and each transcript was checked and anonymised by the relevant interviewer. With the Leicestershire interviews, open codes were generated by CT and KW through familiarisation with the transcripts (describing text referring to particular attributes of primary care, for instance) and the transcripts were read repeatedly, refining the coding system until no further codes were required. After discussion with other team members, codes were focused into categories and a coding scheme was devised. Categories reflected demographic characteristics of the interviewees, characteristics of their practice, aspects of primary care (including continuity), which they described as priorities (or not) on a given occasion, and descriptions of the contextual background to any given

## ***Continuity of care: the views of patients and carers***

decision about whether and how to consult. Over the course of the interview administration and analysis, there was a move towards a more structured coding frame and a more structured interview schedule with questions that were nevertheless open-ended and allowed the respondent to answer in their own terms. NUDist software was used initially, and when the coding frame had developed to the point at which no further changes were required (after 35 interviews), charts were used to summarise contexts within which particular preferences were expressed for types of continuity, and/or for other aspects of care. This was done to facilitate discussion of progress among team members who did not have access to NUDist software, and to enable visual representation of cross-case comparisons.

### **3.3 Methods – London**

#### **3.3.1 Recruitment of participants**

When the project began (November 2001) health service structures were at a point of great change and uncertainty. The primary care groups were in process of dissolution, and negotiations were yet to settle upon new boundaries for their successors (primary care trusts). Similar shifts were at play in strategic, mental and hospital trusts: the organisational framework of the national health scene was in flux.

In the absence of clear boundaries in the health domain, we chose to make use of the more evident boundaries that were available through the local government structures. In this way we were able to define and enter our research field.

The physical area of the part of London contained within the administrative boundaries of the Royal Borough of Kensington and Chelsea (RBK&C) was chosen as the location of the initial round of qualitative interviews. This choice satisfied two conditions:

1. The relative stability of administrative systems allowed us to access a reliable list of GPs in the area. It also offered clear organisational structures that we hoped to make use of in later stages of the research. We planned to connect with service providers in order to establish a viable channel for our research results later in the process.
2. The social make up of this borough reflected the variety aspired to by the research proposal. The population includes some of the richest people in the country, and some of the poorest; some of the longest established communities, and some of the newest and most transient populations; there are over 100 different languages spoken in the schools in the area, and this reflects the diverse ethnic make up of the population.

We sought to identify a range of participants as described in the sampling frame (Box 3.1). All GP units (practices) listed within RBK&C were invited to participate in the research. The GPs that responded

## ***Continuity of care: the views of patients and carers***

were visited one by one, the project was explained to them, and patients were recruited and interviewed in a cumulative way until a saturation point was achieved. Each practice had a different way of engaging with the research, but all required a relation to be negotiated between the particular GP and the practice manager. Variations occurred between these two poles, but all the patients that were written to were purposively selected by the practice to reflect something particular about continuity of care as it manifested at that moment.

Approaching the patient in this way linked the research tightly with the GP unit. It also aligned the research question with the perspective of a section of the GP population. Each encounter between interviewer and interviewee occurred in a highly configured space: the carefully constructed natural environment of a hand picked selection of GP patients in a specific area of London, 2002.

### **3.3.2 Participants**

In London, patients were recruited and interviewed in a cumulative way until a saturation point was achieved with regard to experiences of continuity of care. The London participants were 23 interviewees (Table 3.2). Although the majority of participants were from the majority white population, the sample included several Black participants and six people from other ethnic groups, although no South Asians. Overall in the Leicestershire and London samples combined, 16 (20.3%) patients were of non-white ethnic origin, 6 being South Asian, 4 black, and 6 other non-white ethnic groups. Six London respondents were carers, eight were not employed although neither retired nor committed to home making, and the sample included people who had a variety of educational experience, living arrangements and level of health. The sample did not include many younger persons.

## ***Continuity of care: the views of patients and carers***

**Table 3.2. Characteristics of the London interviewees**

<b>Characteristic</b>	<b>Subgroups</b>	<b>Number of interviewees</b>
Age (years)	11-17	0
	18-29	1
	30-59	9
	60-79	12
	80+	1
Gender	Male	9
	Female	14
Ethnicity	White	13
	Black	4
	Asian	0
	Other	6
Carer status*	Non-carer, not disabled	17
	Non-carer, disabled	1
	Carer for young child <10 where child has no significant medical problem	1
	Carer for child with a medical condition	0
	Carer for adult	5
Location	Inner city	23
	Urban/suburban city	0
	Market town	0
	Industrial/mining/other town/large village	0
	Rural village, or isolated rural house	0
Employment	In paid work	6
	Retired, unemployed or unpaid occupation	16
Qualifications	None	6
	Up to but not including A level or equivalent	3
	A level or equivalent but not more	7
	Beyond A level	6
Living	Lives alone	8
	Lives with partner/family/other	13
	Lives in institution	2
Health status	Chronic health condition needing ongoing management	5
	Good health	17

### **3.3.3 Data Collection: the interview**

London interviewing and analysis took an actor network approach (see <http://www.lancs.ac.uk/fss/sociology/css/antres/ant-a.htm> for bibliography) to the data. Each case was explored in depth to reveal the threads of the particular network the patient was situated in. Each interview began with a description of the network in which the research was situated. We nominated the NHS as the originator of the funds which had been channelled into the University sector via the SDO. We described these funds as having then been distributed amongst teams of researchers, themselves made up of partnerships between disciplines and institutions. The aim of the interview was stated as eliciting the patients' 'point of view' of continuity of care. Continuity of care was then described by the researcher (JL) in terms of continuity throughout the life of the patient, and throughout the life of a particular incident (diachronic and synchronic continuity).

The 'point of view' of the patient was taken literally by this method. A patient was defined as one particular person drawn from a set of many different people (the universal set of people registered with an NHS GP in a limited geographic area). The point of view of the patient was defined as what could be observed from their perspective in the network of care. We were not primarily interested in the 'opinion' of the patient, although this is an element of material. We were mostly interested in what could be witnessed by someone who was in the position of a patient as they entered and moved through an episode of care. This always involved a person in a relation with someone else more or less attached to organised procedures, but each of whom acted from another specific position in the network. In taking this view, we were able to access the *dynamics* of the process, the *trajectories* taken by patients, as well as to hear something important about the *nature of relations* that signified something in particular to each different interviewee.

This approach had three benefits. First, it avoided mistaking the patient's voice as a pure voice of truth (something established in Balint's work [Balint, 1957]), and situated it in a particular place in a complex structure in which it could be heard as a partial voice of truth on a particular occasion. Second, it allowed us to understand the particularity of the suffering that took place, and to hear what the patient attributed this to. Third, it rendered material to make a map of the local networks that were actually operating at the time of the research.

### **3.3.4 Data processing, analysis and interpretation**

Interviews were recorded and transcribed. Every interview was transcribed and submitted to an extended period of analysis. Placement students from undergraduate and post graduate social science degrees at Surrey and Brunel Universities were brought into

## ***Continuity of care: the views of patients and carers***

the team and participated in this part of the research. The students made extensive use of the N-Vivo programme in a concatenated method of analysing the data. This system of working established a dialectical process of analysis. The students were closely supervised by the researcher, and met regularly to discuss the interviews. The team brought theoretical questions to the data from the fields of sociology, psychology, anthropology, and psychoanalysis. Key questions from the data were also discussed with the medical experts in the department, which generated another dialectical process between social science and medicine.

Issues arising from the interviews were also used to build a link with service providers in the locality. For example, one interview (see Low 2004, included as an appendix to this report) opened up links that we were able to follow into old age psychiatry and social services. This provided us with very good information about the particular local set up of services that are linked at the point of provision but which are separate at the point of supply. This set of links came in useful again later in the research when the research attempted to generate another dialectical process with local policy makers and practitioners.

So, the interview material provided a rich source of information about the local scene of service provision; served as an excellent point of dialogue between medical and social scientists; gave a strong base for sharpening concepts and testing ideas against the data; and maintained the pressure on the researchers to find ways of articulating the common essence of the interviews. The process of work implicated expertise from a number of different perspectives and this helped us to avoid reifying elements of the data, it also brought our own perspectives more clearly into view, and clarified the different positions that were taken in interpreting the data.

The process of research described here was very productive - it forced us to come up with the idea of a gap. We were obliged to include gaps into the research model in order to preserve the differences which were evident in the data. During the course of our work we experimented with a number of different ways to name these gaps. Ideas such as 'x-factor', 'soul', 'human dimension', 'ethics', 'praxis', and even 'zero' were all explored as ways to better understand the problems and questions at stake in local health care work.



### **3.4 Results: Findings and interpretations**

The following sections give an initial overview of interviewees' views of types of continuity, followed by peripheral and central priorities other than those to do with continuity of care. The framework for presenting the findings has been developed from the Leicestershire interviews (Section 3.5) and is verified by the findings of the London interviews (Section 3.6). However, the London interviews have added an additional layer of understanding to the meaning of continuity from the patient's and carer's perspective which is illustrated by a recently paper (Low, 2004), included in full in the Appendices. The section explores whether, and how, patients describe making decisions among priorities on particular occasions when this is possible and examines accounts of what happens when this is not possible. This exploration begins to reveal the contexts in which continuity of care is likely to be particularly important and to suggest an initial model of the variables that are likely to influence need for continuity.

### **3.5 Leicestershire interviews**

#### **3.5.1 Patients' and carers' views of types of continuity**

##### ***Continuity that did not depend on an individual practitioner***

Continuity, or its lack, formed a central feature of many participants' accounts of experiences of primary care. Interviewees' accounts of continuity or discontinuity did not always involve 'personal' continuity (i.e. consulting the same GP, or a known and trusted GP, on different occasions), but could be described in a number of different ways:

##### ***(a) transfer of information (or its lack) within or between services or professionals***

... you go and see the nurse about it and she'll say, "Well I'll put it on your notes." but then when you go and see them they say, "Oh well have you tried this?" and you're thinking, "Yeah and it should be on my notes, surely you've ..." and you don't feel like they read them sometimes ... (female, 30-59 yrs, chronic health problem, unable to work)

I mean cos you've got everything there on the computer anyway in front of 'em, they know what you're on or whatever, all your drugs and that, and I was just grateful to know I was all right and that, you know, with being on warfarin and other things; cos you've got to be so careful what you do ... (female, 30-59, chronic health problem)

## **Continuity of care: the views of patients and carers**

### **(b) continuity of management through regularity of check-ups, teamwork, or having services under one umbrella (usually in terms of geographical location).**

I wanted them to have a logbook that said to them, "We ought to visit this patient every three months to see what the improvements are and write a note in the logbook" (male full time carer for severely disabled adult daughter)

Every six months now, it was twelve months and then ... my blood count went up a bit so he keeps an eye on me now every six months. .(male, 60-79, chronic health problem)

... actually our practice has got a ... dedicated counsellor there so you can be referred through to talk to the counsellor, so that's quite good ... you go down there and it seems to be part of that particular environment and you see them coming and going whereas if you were going somewhere else it's a bit strange, you know. (female, 30-59, chronic health problem)

### **(c) consistency of treatment or advice**

... I've had a few doctors that I've been to ... and it's just one doctor would say something and the other doctor would say summat else and you just don't know who to believe.(female, 18-20, good health)

## **Continuity that depended on consulting the same professional**

### **(a) The 'same' GP**

Individual practitioners were described as instrumental in whether or not care was experienced as continuous; in some cases it was sufficient to consult the same practitioner on more than one consecutive occasion, even when that practitioner was previously unfamiliar.

I got a poisoned knee about 6 or 7 years ago .. - I couldn't get up - so I had two home visits from the same doctor, and ... I went to see him following on because he'd actually been out to see me ...

SO HOW WOULD YOU HAVE FELT IF YOU'D HAD A DIFFERENT DOCTOR ON EACH OF THOSE THREE OCCASIONS

That would have been unsatisfactory because each doctor diagnoses slightly differently. One can't expect otherwise. And one wouldn't necessarily have the feeling that you were following ... through a procedure in the same way. (Male, 30-59, good health)

### **(b) The 'personal' GP**

Many patients described their experience of continuity as being provided through consulting a known and trusted health professional, with whom they had a *history of positive and productive interactions*.

## ***Continuity of care: the views of patients and carers***

I've always stuck to Dr S ... I just suppose through (my husband) going to him so much, cos he used to see him quite regularly ... we got quite friendly with him, and I liked him, and he tried everything ... Dr S sent him everywhere he could ... (female, 60-79, chronic health problem)

Successful shared histories of interaction were characterised by an interviewee giving examples of their GP or practice knowing that their requests for consultations were legitimate and that they tried not to abuse the system, and examples of reciprocation where a GP was seen as having taken care to ensure that the correct treatment was received.

They know whether you're a fooler-along, shall we say, or a mucker-about, you know what I mean, or whether you're genuine; and they know I won't bother them if I'm not bad and that. So I mean the doctor'll phone you back within twenty minutes and if need be he'll come out. They're ever so good ... we've never had any problems with this practice (*female, 30-59, chronic health problems*)

He's very good, if me blood results come back, something's a bit bad, he rings me. I don't have to go and see him every time something's wrong, he's always ringing me, I think it's to give me some confidence, you know, that he's, oh they're marvellous down there, it's a wonderful place. (*female, 60-79, chronic health problems*)

The importance to patients of a successful relationship with their health care provider(s) was apparent in the descriptions of several interviewees of the dilemmas they faced when they lost faith in the expertise of their GP (e.g. through her/his increasing age) but 'loyalty' made it hard to change provider.

We moved within Leicester, we could have stayed at our GPs but I wasn't impressed so we took the opportunity to move (GP practice) at the same time ... we felt that (previous GP) should have retired ... she couldn't see what she was doing and she caught (son) with the scalpel...

...WOULD YOU HAVE THOUGHT ABOUT GOING TO THE OTHER GPS (AT THAT PRACTICE)?

Probably not,...I think at the time I would have been uncomfortable about transferring ... within the practice. (*female, 30-59, chronic health problem*)

The significance (for understanding when continuity is important) of patients' motivation for a successful shared interaction history will be further explored later in this chapter.

### **3.5.2 Patients' and carers' priorities other than continuity**

Continuity of care was not the only priority that emerged from analysis of the interview transcripts, and it is necessary to outline these other priorities in order to move to a discussion of how people tried to weigh up the relative importance of aspects of continuity. Box 3.2 shows the attributes of primary care that were perceived as important for at least

## ***Continuity of care: the views of patients and carers***

some interviewees on at least some occasions. The list provided a starting point for the design of the conjoint questionnaire described in Chapter Five, and provided confirmation that interviewees had a wide range of priorities, which included aspects of continuity of care.

### ***Box 3.2: Attributes of primary care emerging from interview analyses as important***

Access issues:

- a) Proximity of service
- b) Ease of telephone access
- c) Time spent in waiting room
- d) Timing of appointment (e.g. convenient or not)
- e) Timing spent waiting after deciding to consult (same day appointment, or no. of days waiting)
- f) Frequency of contact
- g) Availability of home visits

Continuity issues

- a) 'own' GP, same GP, known GP
- b) paper or computer records, transfer of information
- c) continuity across professionals, teamwork
- d) professional-patient information transfer

Interaction quality (patient-professional)

Expertise

Trust/confidence

Reputation

Gender, ethnicity

Community links

Cost versus 'free' service

Quality of environment, experience of procedure

Access, individual expertise, and interpersonal skills, as well as continuity featured frequently in patients' accounts, and often engendered strong feelings.

## ***Continuity of care: the views of patients and carers***

### **(a) Access:**

IF I ASKED YOU TO TRY TO SAY WHAT'S MOST IMPORTANT TO YOU, WHEN YOU GO TO THE DOCTORS ...

The waiting times more than anything. Fitting in that you're not going to have to wait around for hours and you can go in and get seen ... (female, 18-20, chronic health problem)

### **(b) Individual expertise:**

Expertise was almost universally important – there was only one example of an interviewee (a teenager) who said that she did not mind whether or not a practitioner (a dentist in this case) was appropriately qualified. Other interviewees described expertise either in terms of expecting an acceptable level of professionalism, or in terms of specific skills of individuals:

(WHAT IS IMPORTANT TO YOU ...?)

Well, to obviously prescribe me with whatever is wrong with me and make sure it's something right and not something else that they're prescribing me with, and just making sure that, you know, that they do their job really and they tell me what's really wrong with me and stuff. (female, 18-20, good health)

... he came recommended by a friend ... it was his medical skills really. He'd been extremely quick on picking up a difficult diagnosis of a colleague of mine ... he was very on the ball and that was the decider for me. (female, 30-59, chronic health problems)

### **(c) Interpersonal skills:**

However, expertise was not sufficient on its own, as described by the next interviewee who implied that in some situations high levels of expertise were not always the most crucial feature of care so long as interpersonal skills were good:

I think somebody who is approachable and gives you time and makes you feel that you're important to them while you're with them, and they come over as caring. And dare I say it; they needn't necessarily be the most capable person ... (male, 60-79, good health)

### **3.5.3 Identification of contexts & circumstances in which continuity is important**

Having outlined patients' and carers' descriptions of their priorities, the next stage was to explore the influences on when different types of continuity were particularly important, relative to other priorities. There were several 'levels' of contextual variable which could influence patients' preferences.

## **Continuity of care: the views of patients and carers**

### **(i) The particular circumstances of a consultation**

The most obvious influence on patients' and carers' priorities was to do with the nature of the immediate reason for seeking health care. This level of influence will be described before moving on to look at other potential predictors of preference for continuity relative to other features of care. First, there were situations in which *discontinuity of health professional* was a priority, for example when anonymity was preferred because a problem was embarrassing.

#### HOW DID YOU DECIDE WHERE TO GO?

Cos I didn't know anyone at the family planning clinic and I sort of get – er – like embarrassed if you know people, and you have to tell them (Teenager, seeking emergency contraception)

Discontinuity of health professional was also a priority where expectations of a practitioner's expertise with respect to the particular reason for consulting were not met:

I went to see Dr A. and she gave me a cream and sent me away and it didn't do anything, and I went back to her 'cause I thought I'd see what she thought and she didn't do anything. And so I actually said to the receptionist 'I really want to see a different doctor' and ... that's when they diagnosed I'd got toxic poisoning ..' (female, 18-20, good health)

However, there were many occasions upon which interviewees described preferences for personal continuity, and many patients emphasised the importance of personal continuity when consulting about ongoing problems, particularly where their problem had emotional or psychological components.

you want a particular doctor, who has been treating you for a long number of years, he knows your illness (male, 60-79, chronic health problem)

because of everything that's happened to me, I've been a bit depressed, or it's maybe things that's ongoing with the bowel problems ... there is one specific doctor I ask for... (male, 30-59, chronic health problem)

Most patients tended to feel that personal continuity was a low priority when the consulting problem was 'impersonal' and /or easily resolved, and to prioritise quick or convenient access over personal continuity when consulting with minor acute problems.

I don't see my optician half as much (as GP) ... I find it's more impersonal ... if it's your eyes and it's just a simple check up and it's a routine thing ... you don't get a sense of relationship. You just get a sense of, "I'm just going to run these checks and you're out of here." That's it. (Female (18-29), talking about optician, in contrast to GP with whom she shares a history of successful management of a mild long-term condition)

I'd prefer to see my own GP but ...I'd probably prefer to be seen quickly if it was just a minor thing...I'd rather get it sorted as quickly as I could. (male, 18-29, good health)

## ***Continuity of care: the views of patients and carers***

However, there were many examples of patients expressing general preferences for personal continuity, which were not clearly related to the immediate reason for a specific consultation.

I would prefer to see him (family GP) every time but if I can't, and I can't see somebody else that I know in the practice, and I don't know anybody as well as him, then I would see a different doctor. And for the children as well, I mean I see different doctors for the children and it's been fine, but you always worry .... (Working mother of three children)

The fact that many patients expressed general preferences for personal continuity, suggests that it may sometimes be necessary to go beyond the level of the immediate reason for a consultation in order to predict whether, and to what extent, particular types of continuity matter. One advantage of using charts was that patterns of preference or priority could be examined via 'sorting' summarised data by age, gender, life stage, carer status, or health status. This helped to reveal other contextual details (i.e. other than immediate reason for consulting) that might be associated with particular patterns of preference, particularly those at level of the socio-demographic, life stage, and health characteristics of the patient her- or himself.

### ***(ii) Patient characteristics and experience***

#### **(a) The importance of becoming an 'expert' user: individual experience**

The first finding to emerge from this process was that increasing experience of services had a potential impact on views, choices and expectations of health care. For example, people in the healthy young working person/student life stage (with less experience by virtue of age) and those who were in good health (with less experience by virtue of fewer consultations) tended to be more likely to focus on choice of provider, interpersonal skills (including receptionists' skills), or quick or convenient access than on continuity, and tended to have less to say about health care as it affected them personally than those who were older or less healthy.

.. first of all I would look at my problem and decide which was the system of medicine most likely to help it. So would it be acupuncture, would it be herbalism, would it be homeopathy ...(male, 30-59, good health)

I think their communication and kind of people skills are really, really important because even if you don't know the doctor that you're seeing, if they're good at putting you at ease then it doesn't matter as much that you don't know them (female, teenager, good health)

WHAT WOULD YOU SAY WAS SORT OF TOP OF YOUR LIST FOR WHAT YOU'RE LOOKING FOR FROM PRIMARY CARE FROM A GP PRACTICE?

Time I think, time. To be unhurried.... Right from reception, because if there's time there's less likelihood of there being inaccuracies, if people are rushing, you know. So yeah, time (female, 30-59, pregnant, good health)

## ***Continuity of care: the views of patients and carers***

Those who were more experienced in their use of primary care services usually (but not always) talked about strategies they had learned to use in order to get what they needed while maintaining a good relationship with the practice or practitioner. They described developing expertise in coping with the organisational features of a particular practice or other service and ways in which they had learned to 'bridge gaps' for themselves, as illustrated by the elderly man who visited the receptionists personally in order to get the appointment he wanted (see box), or by knowing what time to telephone to maximise the chance of getting an appointment, or by looking over the receptionist's shoulder to see which GP had the shortest list of appointments on that day before choosing who to consult.

So people like me, (laughs) most of the old men, will go personally to the surgery, ... and you get the eye of the receptionist you know, and say look I have got this problem and do you think I could see the doctor. Suppose .. the particular receptionist with whom you are more friendly, or she is more friendly with you, is not on duty, then you will get a negative response. (male, 60-79, chronic health problems)

Conversely, when a patient had not had the opportunity to become expert (either because they were healthy and did not use the service often, or because systems had changed and they had not had time to become familiar with them), dissatisfaction or unmet priorities could feature when they needed to gain access to services.

### **(b) The importance of becoming an 'expert' user: family experience**

A further finding was that increasing expertise in using services was usually associated with a history of other *family members'* use of services.

... the senior partner there, you know, she cared for my father as well so she knows all the sort of the family side of it and my mother's quite happy to go to see her, and that's it. (female, 30-59, mild chronic health problem, carer)

When accounts were sorted by not only the interviewee's own health status, but also by the health status of other family members on whose behalf the interviewee consulted, it was possible to predict when continuity of care from a known and trusted provider would be most likely to be a very high priority. Increasing experience and more extensive shared histories of interaction with health care services were by definition associated with increasing amounts of ill health. This factor was the key to understanding when continuity of care was most important. Charting of preferences in the context of health status of a *patient and his/her family* revealed that the need for personal continuity was most likely where there were family members (including the interviewee him or herself) who had longer term, limiting conditions (i.e. health problems that were not resolved after one consultation and were described by the interviewee as 'limiting' in terms of their quality of life), and this was strongly influenced by the



## ***Continuity of care: the views of patients and carers***

type of shared history between the GP, that patient and his/her family. The next section returns to the issue of whether a shared history of interactions was perceived as positive or negative, and highlights the central importance of this where there is a longer term, limiting health problem in the family.

### ***(iii) Shared histories***

#### **(a) 'Positive' shared histories**

First there was the situation in which the interviewee had a 'positive' shared history of interaction with their GP and practice as a whole. In other words they described a history of interactions in which mutual expectations were met. This meant that they described being given appropriate access, advice and/or treatment, and outlined how they reciprocated by not abusing the system, only consulting when necessary, communicating honestly with their provider, and following his or her advice. A positive shared history of this kind was seen as confirming the patient's belief that they used services legitimately - this was particularly important where long-term conditions were concerned, as this often meant frequent use of primary care - and confirming the patient's view that they could trust their provider's expertise and have confidence in him/her/them.

I was sitting there one evening at seven o'clock and my appointment had been at six, and Dr. X was still there. He'd obviously had one or two serious patients and I said to the practice nurse, of course I know one or two of them now, I said, "I will go home if you like and have another appointment as it's not urgent." And she said, "If you don't mind sitting here, Dr. X will see before he goes home." I find that absolutely incredible, when he's done a long working day. ... He's a GP in the best sense of the word (female, 60-79, chronic health problem)

It avoided the patient having to re-tell their story:

I hate repeating myself anyway, it just winds me up, it makes me feel like people are being ignorant, having to sit there and (pause) repeat yourself, so that's basically how I feel about doctors, I'd rather see the same one so I'm not sitting there every time I go repeating everything I've just told the doctor previously. So I feel fairly strongly about that (female, 18-20, chronic health problem)

It facilitated appropriate care and treatment and was sometimes the only way of getting appropriate care, and it enabled family care:

(My husband) had a bout of depression, a couple of years ago ... and he wouldn't have a doctor, wouldn't go to the doctor, used to sit here all day staring at that rug and I thought, "I can't stick this." Anyway my doctor collared him one day when he took me down and had him in and had a talk to him, ... and now he's all right (female, 60-79, chronic health problems).

## ***Continuity of care: the views of patients and carers***

It provided emotional reassurance and meant that communication of information (in both directions) was perceived as more effective, and was associated with positive relationships with more than one member of the practice concerned:

HOW WOULD IT FEEL FROM YOUR POINT OF VIEW IF YOU SAW A DIFFERENT DOCTOR?

M: Well it wouldn't be the same would it? You'd be embarrassed ... when you get used to one person you can talk to 'em better than you can a fresh 'un; cos you don't know ... you've got to see a doctor two or three time before you get what he's like (male and his wife, 50-69, chronic health problems)

Those interviewees with the severest, most limiting and most complex problems were the most likely to need a positive shared history, achieved through personal continuity in order to get appropriate care, regardless of the immediate circumstances of the consultation.

ARE THERE ANY OCCASIONS WHEN YOU WOULD BE HAPPY TO SEE ANOTHER GP?

I wouldn't be quite happy because Dr. K knows me very well, with all my myriad problems. He's very thorough, he's very conservative, he doesn't dish out medicines for the sake of, he will take the trouble to go through the computer lists and see what you can take and what you can't. In my experience he's only made two small slip ups in eighteen years, and that's rather remarkable considering what I've had wrong with me..(female, 60-69, chronic limiting problems)

The situation was slightly different for less serious and less limiting longer term conditions. A positive shared history was still important because it was seen as promoting trust in the organisation as a whole (e.g. the practice), promoting better management of a health problem, avoiding the need to re-tell their story, and helping patients to feel at ease which promoted communication.

### **(b) 'Negative' shared histories**

The situation was very different when a patient with a long-term, limiting health problem in the family did not experience positive history. Typically, the interviewee felt that she or he had been badly let down by the practice or the GP; for instance by not having the opportunity to initiate a 'positive' relationship, or, if they had established a positive relationship, by not being able to get access to it. The effects of this were dramatic for this group of patients, and included extreme distress, exhaustion, worry, potential errors, mismanagement, a 'crisis' or reactive style of managing family health problems as opposed to a proactive, preventive style, greater use of A&E departments, confusion about diagnosis or treatment, repeated first encounters (having to re-tell their story without progressing) and having to re-start treatment regimes.

It is clear from the above discussion that positive shared histories have particular importance when patients or their families have

## ***Continuity of care: the views of patients and carers***

severe, or complex, ongoing problems. However, where nobody in the interviewee's family had experience of a longer term health problem interviewees tended not to describe any type of shared history with particular members of a GP practice. Where the GP practice was concerned, patients' priorities were likely to focus on quick or convenient access, having enough time during consultations to (a) ensure that the practitioner had understood their problem (this required interpersonal skill too) and (b) minimise the chance of mistakes, and good record keeping within the practice. Some interviewees were aware that their priorities could change if their, or members of their family's health status changed. They spoke of the need for confidence in an organisation as a whole, should they need longer term care:

I think that continuity of care becomes most important when you fall seriously ill. If by continuity of care one understands that to mean that the interested parties are talking to one another, and are providing the same information and are able to sort of transfer their information between one another .. then that is where it becomes crucial ... you need to have confidence in the organisation that you're dealing with even if you don't have a particular individual beforehand.(male, 30-59, good health)

### **3.5.4 Matching preferences to primary care services - the strategies patients used to make consulting decisions, and the factors that influenced whether patients could meet their preferences**

It is clear from the analysis described above that different patients hold a range of priorities under different circumstances, and that some of the factors that influence patient preferences can be identified. However, patients have to make consulting decisions based on the range of primary care services available to them, and it may not always be possible for patients to match all their priorities each time they consult.

One further aim of the analysis was to explore the strategies people use to make consulting decisions, particularly where they are constrained by the range of services available into making choices between one or more valued aspects of care. An exploration of patients' decision-making processes was felt to be important, given that the conjoint questionnaire involves asking participants to make trade-offs between aspects of primary care, which may or may not reflect real-life decision making.

The interview analysis asked - to what extent did patients describe making trade-offs when deciding whom, and when, to consult? In other words, did patients describe weighing up features of each available consulting option and consider the extent to which they are prepared to give up one feature of care in order to get another feature of care, if they could not have both? For example there might be

## ***Continuity of care: the views of patients and carers***

circumstances under which patients are prepared to give up quick access in order to see a known and trusted professional; or situations when people choose good interpersonal skills because they want reassurance rather than clinical diagnosis or treatment. Previous research suggests that where possible people will use decision strategies that minimise cognitive load, particularly when decisions are complex or stressful, (Mano 1992) and trade-offs are relatively cognitively demanding.

Interviewees in this study often described 'intuitive' decision-making, or habit, in that they did not describe considering a range of choices but consulted by habit, simply visiting their 'usual' provider. So the range of available primary care services with which people were familiar was an important consideration when understanding patients priorities and service use. This was particularly the case when patients were consulting for familiar or routine problems.

I just went to my family planning clinic ... that's where I generally go for smear tests and things like that, and consequently I've just always gone back there. I don't think it's a particularly amazing surgery or anything, I just, that's where I've always gone.' (female, 18-29, good health)

When patients did consider different possibilities for consulting, they often used relatively simple strategies, and considered only a limited range of options. For instance it was common that lexicographic-type strategies were described (comparing options in terms of one or more ordered preferences):

The doctors don't come out now, you ring this number and they ask what's the matter and they decide whether you need paramedics or whatever, so my husband dialled 999 because it's the quickest (female, 60-79, good health)

I've had women's problems and I've seen a man 'cos "well I really need to see a female doctor". (The receptionist said): "well there's none for like two weeks", so I tell 'em "oh male doctors are all right, which one am I seeing?" "which one would you prefer?" "one that I know preferably. I don't wanna see like this new bloke .... I want to see someone that I've seen before". (female, 18-29, good health)

Overall, analyses of decision-making suggested that patients may not seek out the full range of consulting options, or weigh up all the features of each option, when making consulting decisions. Instead they often use simple strategies, and consider a limited range of consulting options, in order to reduce cognitive load. It was only when patients had conflicting priorities that they described having to make trade-offs, for example, between quick access and seeing the GP of their choice, and these decisions were often seen as difficult.

Last week I got up every day to make an emergency appointment, but then I thought 'no I won't be able to see Dr P, forget it', so I didn't, I'd rather wait. (female, 18-29, chronic health problem)

## ***Continuity of care: the views of patients and carers***

Analysis suggested two main reasons why patients might be faced with difficulties in meeting all their priorities. There could be a mismatch between the priorities (in other words, some patients may feel that they need to match a number of priorities, some of which may conflict), or there may be a mismatch between the attributes of the available primary care services (such as the organisational structure of the practice) and the priorities of the patient. For example, this terminally ill man needed both quick access and to consult a (known) GP rather than a nurse, but the practice emphasis was on quick access:

I need to get it seen straight away because ... my cancer is sort of in an advanced stage and I don't like to be messed around like this, you know. I like to get seen or given reassurance by the doctor ... I don't like to go through this phase again, see the district nurse, or nurse upstairs and then come back again cos I haven't got the strength to be honest. I haven't got that sort of energy to come, keep on coming again and again, right? I'd rather have somebody who knows my history and can do something about it or give me some sort of reassurance ... (male, 30-59, chronic health problem)

Alternatively the problem might lie in the patient's circumstances as in the case of an interviewee who could not walk far, could not afford a taxi to the practice, and did not live on a bus route and therefore had to rely on a relative to give him a lift to the GP. His visits were therefore determined by his relative's availability and he could not choose when or whom to consult.

Examination of accounts of occasions when not all priorities could be met thus highlighted three different groups or levels of variable that could affect patients' preferences and their ability to access care that met their preferences, some of which have been discussed in previous sections of this chapter: (a) the wider environment of the range of primary care services that the patient knew about, (b) the characteristics of a particular practice (or other organisation) and (c) the patient's own characteristics and circumstances.

On occasions when practice characteristics (such as management structure or inflexible appointment systems) presented a barrier to achieving appropriate care, there were some accounts describing how service providers were able to be flexible in meeting interviewees' needs. This was presented in accounts in terms of the actions of caring or concerned individuals within the practice as in the case described in Section 3.5.4 of the elderly man who circumvents the practice's appointment system by visiting the practice so that he can speak to a known receptionist, or the following quote, which illustrates the practice's responsiveness and flexibility to the patient's needs, and additionally, the notion of reciprocity in the patient's relationship with the practice:

## ***Continuity of care: the views of patients and carers***

..when me father was ill they say, "Well come to the back door, just give a knock at such and such a time." and that was to get him in and out without having to wait, it was when his health was failing... And it didn't take long, it wasn't holding the queue up long, it got him dealt with without upsetting him, which is important. But we took him instead of them coming for a visit which again was benefiting them (male, 60-79, good health)

On other occasions inflexibility of service provision, combined with lack of room for manoeuvre on the part of the patient or carer, gave rise to undesirable outcomes. For instance, the introduction of the 24/48 hour access policy was welcomed on occasions when urgent help was needed, but on other occasions was seen as a serious barrier to getting appropriate care, especially where the practice concerned had interpreted the access policy restrictively so that appointments could not be booked in advance, and had set in motion procedures that limited telephone access to particular times of day or days of the week.

### ***3.6 London interviews***

The interview material revealed clear and particular accounts of the ways different people were involved with elements of the care network. It emphasized the complexity of the network of relations, the difficulty of finding a good map of these relations, and the value of a good guide. It also showed how people improvised their own way through the system, and how this implicated family members, social bonds, TV personalities, private health systems, and specific life histories. It showed how and when the patient was particularly aware of the actions of the GP and other professionals and how this affected the process. It also revealed something else too.

Issues arising from the interviews were also used to build a link with service providers in the locality. For example, the interview described in the published paper (Low 2004, included in the appendices) opened up links that we were able to follow into old age psychiatry and social services. This provided us with very good information about the particular local set up of services that are linked at the point of provision but which are separate at the point of supply. This set of links came in useful again later in the research when we attempted to generate new links in the network to include the medical school more directly in the local scene. So, the interview material in London provided an additional, rich source of information about the local

## ***Continuity of care: the views of patients and carers***

service provision and helped us to set the patient's experience in the context of the network of care. It pointed to a common factor that patients and carers, particularly those with chronic conditions with multiple co-morbidities referred to in dealing with the complex network responsible for their health care. Over the course of our project the research team have experimented with a number of different ways of naming this common feature of the interviews, for example the human dimension, going the 'extra mile', or personal care - an act that is required of a practitioner in the course of his or her work but that cannot be prescribed, predicted or prevented. They each pointed to something in excess of any rules, protocols, or indicators that might be written, something, indeed, very difficult to pin down in words but nevertheless possible to know about and to transmit. What follows is a short account drawn from one of the interviews which we think illustrates this point rather well (the names and some details have been changed to preserve confidentiality).

Mr FT, a man in his late 60s, is an exile from Persia. He refused my request to tape record the interview so what follows is drawn from memory and the brief notes I was able to make when I met him. The account is written in two parts, first looking onto the case from the interviewers point of view, then from within the case, from Mr Ts' own point of view.

It was written with the idea that it would be acted. This idea arose when I realised that my colleagues in the department of general practice were in the habit of using actors as part of the teaching practice. It seemed practical and useful to provide a text for teaching drawn directly from the interviews. It also seems a very appropriate method of treating the data. This was especially important for the question of continuity of care where something of the personal dimension is at stake, and something very difficult to put into words is invoked. The scope of history, geography, and personal pain are all available from this brief account, and provide a good illustration of the way the body is implicated in the human condition.

1. Mr T is a man that follows his doctor's orders, and is grateful to have an ally such as this in a hostile world. He suffers from things inside his body: from nerves. But also from things outside his body: his landlord. He has depression, he is stressed, he has cancer. He has had major operations. He suffers from angina, from back pain, atherosclerosis, and, again, nerves.

Ten or twelve years ago the landlord, the council, the housing department all seemed to gang up together to make his life a misery: they all seemed bent on making him leave his home. The ensuing battle, he says, destroyed his life. He is no longer able to read: a tragedy as reading had been his one great pleasure in life.

He has a bad knee, and a bad back and is no longer able to go to the library when he wants to. He has somewhere in the region of two to three thousand

## ***Continuity of care: the views of patients and carers***

books at home, and he spends much time at home defending his right to live in peace.

He has been with Dr N for eighteen years, and claims to have been one of his first patients.

2. 'I find Dr N one of the best GPs: a helpful, hopeful, angel. But he is busy – because he is so good. Even at a hospital a good consultant is like a jewel - a *diamond*. They get busy and they go to Harley Street to make money....

I have had a ten, a *twelve* year struggle. I used to read a lot, but now, now I get fed up. I read philosophy, law, medicine. I read in Farsi, Arabic, Turkish, French, German. I used to be a lecturer - I taught.... But. Khomani. He stopped all that. He stopped civilisation. The Shah was a bad dictator I know. Oil and Arms. Oil and arms. I am a member of the human rights movement. Amnesty International.

I had a cancer, angina, a slipped disc *and* arthritis in my shoulder.

The other doctors here - I don't know them, but I don't complain if I see them. But when you are here for 18 years, the GP - he understands everything. When he takes my blood pressure - everything. Others, it is difficult to explain everything again and again. They don't know everything that's going on.

Of course there are lots of shortages. In the hospital - I go a lot to Casualty, and it always takes two or three hours waiting. You have to wait in corridors to find a bed.

The S & T Hospital didn't diagnose my shingles. They didn't know! The junior doctors didn't know! They were straight from college! Dr N was on holiday, and I felt it an emergency so I went to the hospital because they have my records, there is an X-ray right there. It was ten days.

When people look at me, people think I'm a big strong guy. But inside I'm very weak.

Dr N saw me after ten days, and it took him five minutes to diagnose me.

They gave me an antibiotic, but Dr N had to change it to a better one. My body cannot ... [fades away].

It happened a few months ago, in November, or December last year. All the doctors here were fully booked up, so I went to the hospital. I thought that the hospital would have everything. The reception couldn't help me here. He was a nice doctor at the hospital. But he did not diagnose the shingles!

I'm an intelligent well educated man, I know when something is going wrong. I know already better than many. I've been going for 18-20 years to Boots on the High Street. We know each other, they give a good service. Even when they change, they look in the records, and they are good. Most of the people working there have humanity. They are kind. They are good people.

Nurses, they are angels. I come to see the nurses here for flu vaccinations, blood tests. Usually C, but others come in part time, and this morning she was South African.

I see M, the councillor, regularly. Once or twice a month. I've been coming for a few years. And I go for physiotherapy at the S & T Hospital for my shoulder.



## ***Continuity of care: the views of patients and carers***

I've been renting thirty years in my flat, but ten or twelve years ago someone else bought it and took over as landlord. I was not in the country when the sale happened, and my lawyer didn't apply to buy it for me. The guy who bought it, bought it very cheap, and the building is now worth ten times the price he paid. So he wants to get rid of me.

I am very, very, satisfied with the Judge. I would be homeless without him.

N is a good Doctor. You don't have to be ill to go and see him.

I have family in the USA, in Paris. They call me. We talk. ... [fades away].

### ***3.7 Discussion***

In interpreting the findings of this phase of the study, it must be borne in mind that it was more difficult to recruit practices in areas of both Leicestershire and London where the majority population was from ethnic minority groups. In addition, no teenagers were recruited through the sampling process we used in GP practices. These deficits were partly remedied by snowball sampling and recruiting via non-GP practice avenues, so the requirements specified in the sampling frame were largely met.

The diversity within the samples represents one strength of this phase of the study, particularly in terms of diversity of patients' experiences of primary care services, diversity in terms of social advantage, range from inner city (including London) to rural environments, and 'carer' status. The finding that experience of long-term, limiting health problems predicted need for continuity (at least in the context of a 'positive' rather than 'negative' shared history of interactions) is rendered more powerful by its emergence regardless of this diversity.

A further strength is in the use of qualitative methodology in two different contexts (London and Leicester). The use of complementary approaches served not only to verify the findings but also to highlight a key issue that might not otherwise have emerged.

The findings can be related to theories from social science that explain aspects of the relationship between patients and the professionals who care for them. There is a body of work suggesting that patients' priorities change with increasing awareness of mortality. Lockenhoff and Carstensen, (2004) report that older people, or those with life-threatening illness, are less socially motivated by the need for information than healthier or younger people, and more highly motivated by the need for emotional meaning. Analyses of interview transcripts in the current study has led us to suggest that patients are indeed highly motivated to maintain a successful relationship with their GP or other practitioner, and that the strength of this motivation apparently is greater in those with longer term, limiting health problems: this is consistent with Lockenhoff and Carstensen's argument. In a related area, Stokes *et al* (2003) outlined the need to maintain an image of oneself as a 'good patient', who consults only

## ***Continuity of care: the views of patients and carers***

when necessary; and the expectation that in return the provider will take seriously their responsibility to give appropriate treatment or advice. They also pointed out that it is only when violations of patients' expectations occur that strong unspoken assumptions underlying relationships such as those between provider and patient are revealed, and that this partly explains the extreme levels of distress experienced in that situation. This is consistent with the 'atrocious' stories heard by interviewers in this phase of the current study when patients with long term limiting problems did not have the opportunity to develop a 'positive' shared history with a service and/or professional.

Lockenhoff and Carstensen's theoretical stance predicts that the motivation to maintain the relationship may be greater than the motivation to acquire health-related *information*, and a frequent feature of the accounts of those with long-term limiting health problems in the family was the assertion that although informational continuity and expertise are important, they cannot replace the positive shared history that follows from consulting a known and trusted provider. This makes intuitive sense given that what matters to patients with a complex, limiting health problem is that the relevant information is correctly *applied*, and patients cannot apply this information themselves. Therefore, their efforts are focused on maintaining the link with a professional who can apply the information efficiently.

### **3.7.1 Implications for the next phases of the study**

One implication of the interview phase is that the longitudinal stage should explore preferences for continuity in a sample of people with a range of health status in order to investigate the extent to which limiting health problems play a predict choices and trade-offs in use of services. A further issue that merits exploration in later phases is that some interviewees described how their preferences and priorities are shaped by experiences of family members; again the longitudinal study and the survey will provide opportunities to explore this phenomenon further.

The identification of several levels of variable with a potential impact on interviewees' priorities has implications for the way a model of continuity of care will develop through the associated series of studies. The conjoint survey will be able to test these in the sense that variables at one level (patient characteristics) will be determined by the individual participant's inherent characteristics; but variables at other levels can be manipulated. At the 'practice environment' level participants can be asked to imagine that they have to choose among particular organisational features (e.g. various combinations of being able to consult on the same day, or being able to consult a known and trusted professional, or having informational continuity etc). At the 'immediate circumstances of the consultation' level they can be asked to imagine different reasons for the consultation. The cross sectional

## ***Continuity of care: the views of patients and carers***

survey will also be able to incorporate variables at all levels, either via sampling strategies (to ensure a range of wider primary care environments) or via the items in the survey (to ensure a range within the other three levels).

### **3.7.2 Implications for service providers**

There are important messages to be derived from the interview stage alone. These are:

- Services are used by families. The professional-personal interface does not occur only between one patient and one provider, but between families (or other groupings of connected individuals) and any or all members of a practice.

When someone is consulting in connection with a person with a long term, limiting health problem (physical or psychological), it is likely to be particularly important that they have access to a known and trusted professional of their choice. This may also be important for those with non-limiting longer term problems.

- 'Patient choice' is currently the focus of much attention. This is usually in the context of being able to choose a particular provider (e.g. Walk-in centre versus GP practice versus pharmacist, or choice of hospital for operations). However, interviewees' accounts suggest that it is extremely important to provide choice among various aspects of care *within* a given provider (e.g. the opportunity to choose to wait to consult a known and trusted GP, or to choose quick access). In addition, it is clear that patients may not seek out the full range of consulting options, or weigh up all the features of each option, when making consulting decisions. Instead they often use simple strategies to choose the best option from a limited range. Where patients are very anxious or concerned they are particularly likely to find choice between a range of primary care service options problematic, and instead prefer a single option that meets their needs.
- The role of receptionists should not be ignored. Practices should consider implementing policy in flexible ways that are responsive to the needs of individual patients, and training receptionists to ask patients whether they prefer to wait to see a particular practitioner, or to see any practitioner more quickly.
- There are some patients for whom urgent access to a GP who knows them and their condition is vital. They are likely to be those with longer term conditions (not necessarily permanent) which limit quality of life (e.g. in advanced terminal illness, or mental health problems). The number of such patients is likely to be small, and their identity is likely to be known to GPs, so a

## ***Continuity of care: the views of patients and carers***

'flagging' system could be considered and shared with receptionists.

## Chapter 4 Longitudinal study

### ***4.1 Aims***

The second stage of the qualitative study followed a sub-sample of interviewed patients to examine, prospectively, their use of primary care services over an extended period of time. Its aims were (1) to explore how patients used primary care services in relation to the preferences for continuity of care they described in their interviews and (2) to examine how aspects of primary care organisation and culture constrain or facilitate patients' ability to achieve their preferences.

### ***4.2 Sample and methods***

A sub-sample of 30 patients was recruited from among those who had been interviewed in the first stage of the qualitative study and an additional 6 patients were recruited to extend the range of patients included, giving a total of 36. Patients were recruited from a variety of practices in Leicester and London to include individuals with diverse socio-demographic characteristics, health statuses and disabilities, living arrangements and caring responsibilities. The characteristics of the patients are given in Table 4.1 and the characteristics of the practices from which they were recruited are given in Table 4.2.

Patients who agreed to take part in the longitudinal study were given a set of Consultation Record Booklets and self-addressed return envelopes and asked to fill in one of the booklets each time they consulted a GP or nurse or used other primary care services (see Appendices). These were defined as including: 'Your GP practice (e.g. GP, practice nurse, health visitor, midwife, district nurse, chiropodist/podiatrist, counsellor) and Other primary care services (e.g. pharmacist, 'out of hours doctor', NHS walk-in centre, NHS Direct telephone service, NHS Direct Online, accident & emergency (A&E), family planning centre, GU clinic, alternative therapy or complementary medicine). Patients were asked to continue completing and returning booklets for every primary care contact they had over a six month period or until they had returned 10 booklets.

## ***Continuity of care: the views of patients and carers***

**Table 4.1 Characteristics of Sample**

<b>Gender</b>	<b>Number</b>	<b>Per cent</b>
Male	14	39
Female	21	58
Missing	1	3

<b>Age</b>	<b>Number</b>	<b>Per cent</b>
11-17	1	3
18-29	2	6
30-59	12	33
60-79	15	42
80+	3	8
Missing	3	8
Total	36	100

<b>Ethnicity</b>	<b>Number</b>	<b>Per cent</b>
White British	29	81
White Other	2	6
Asian	4	11
Missing	1	3
Total	36	100

<b>Work status</b>	<b>Number</b>	<b>Per cent</b>
Employed	8	22
Retired or on illness benefit	12	33
Household responsibilities	7	19
At school or university	6	17
Missing	3	8
Total	36	99

## ***Continuity of care: the views of patients and carers***

<b>Carer</b>	<b>Number</b>	<b>Per cent</b>
Yes	4	11
No	29	81
Missing	3	8
Total	36	100

<b>Health</b>	<b>Number</b>	<b>Per cent</b>
Very good or good	18	50
Fair	6	17
Poor or very poor	8	22
Missing	4	11
Total	36	100

<b>Long-term illness (limiting)</b>	<b>Number</b>	<b>Per cent</b>
Yes	18	50
No	12	33
Missing	6	17
Total	36	100

**Table 4. 2 Characteristics of Practices used by Sample**

<b>Number of Partners</b>	<b>Number</b>	<b>Per cent</b>
1	2	10
2	1	5
3	2	10
4	4	19
5	3	14
6	1	5
7	1	5
8	2	10
9+	0	0
Missing	5	24
Total	21	102

## ***Continuity of care: the views of patients and carers***

<b>Locality</b>	<b>Number</b>	<b>Per cent</b>
Inner city or urban	11	52
Suburban or town	2	10
Rural or semi-rural	3	14
Missing	5	24
Total	21	100

<b>Deprivation</b>	<b>Number</b>	<b>Per cent</b>
Very low, low	6	29
Medium or mixed	5	24
High, very high	3	14
Missing	7	33
Total	21	100

<b>Appointment system</b>	<b>Number</b>	<b>Per cent</b>
Open access or advanced access	3	14
Majority same day appointments	4	19
Equal number same day & booked appts	1	5
Majority booked in advance appointments	3	14
Other mixed	2	10
All appointments booked in advance	3	14
Missing	5	24
Total	21	100



## ***Continuity of care: the views of patients and carers***

<b>Personal list</b>	<b>Number</b>	<b>Per cent</b>
Yes	6	29
No	9	43
Missing	6	29
Total	21	101

<b>Value put on personal continuity</b>	<b>Number</b>	<b>Per cent</b>
1 (very low)	0	0
2 (low)	1	5
3 (medium)	7	33
4 (high)	3	14
5 (very high)	5	24
Missing	5	24
Total	21	100

Patients were also asked for permission to approach their GP for a copy of their notes for the previous year. These showed all contacts with the practice including telephone calls, home visits and surgery or clinic attendance with named GPs, nurses and counsellors.

Data analysis involved examining all three sources of information – the initial interviews with the patients, the consultation record booklets completed by the patients and the practice notes provided by the GPs – both independently and in relation to each other.

Consultation record booklets were examined to identify the extent to which patients' preferences for consulting particular individuals within particular time frames were met at the level of individual consultations. Those consultations where patient preferences were not met were examined to identify the patient and practice characteristics associated with them.

Practice notes for the previous year were examined to determine the extent of personal or relational continuity that individual patients experienced. This involved calculating the number of consultations (face-to-face or telephone) each patient had with GPs and with other members of the primary care team, the number of professionals seen and the proportion of consultations which were with their 'main' GP. Those patients who did not experience personal continuity were examined to determine their own and their practice characteristics.

## ***Continuity of care: the views of patients and carers***

The face-to-face interviews, the consultation record booklets and the practice notes were then considered together for individual patients to explore further how patients use primary care services in specific circumstances, the efforts they made to realise their preferences in relation to continuity of care and the factors which constrained or inhibited them in doing so. This qualitative analysis proceeded along the lines described by Ritchie and Lewis (2003). A typology was developed to describe the patterns of use of primary care services. Explanations for these patterns were developed in terms of the way patients negotiated the constraints created by the organisation and culture of primary care practices.

### ***4.3 Findings***

#### **4.3.1 How far were patient preferences met in specific consultations?**

A total of 151 usable consultation record booklets were returned by 30 patients. Table 4.3 shows patients' preferences, and how far they were met, in the consultations described in the consultation record booklets. In the majority of consultations, patients saw the particular person they wanted to see at the time they wanted to see them (55 consultations, 36%) or at a pre-booked appointment (31 consultations, 21%). In a further 40 (26%) consultations, the patient did not have a preference for whom they saw and were able to see someone within the time they wanted. By contrast, in 10 consultations (7%) the patient did not see the person they wanted to see and in 11 (7%) consultations the patient saw the person they wanted to see but had to wait longer than they wanted in order to do so. In only 2 (1%) consultations did the patient wait longer than they wanted and still not see the person they wanted to see.

## ***Continuity of care: the views of patients and carers***

**Table 4.3 Patient preferences and how far they are met in individual consultations**

	<b>Saw the person they wanted to see</b>	<b>Did not mind who they saw or a range of people were acceptable</b>	<b>Did not see the person they wanted to see</b>	<b>Total</b>
<b>Appointment at the time wanted</b>	55 (36%) consultations	26 (17%) consultations	3 (2%) consultations	84 (56%) consultations
<b>Appointment later than the time wanted</b>	9 (6%) consultations		2 (1%) consultations	11 (7%) consultations
<b>Pre-booked or regular appointment</b>	31 (21%) consultations	10 (7%) consultations	5 (3%) consultations	46 (30%) consultations
<b>Willing to wait more than 10 days for appointment</b>	6 (4%) consultations	4 (3%) consultations		10 (7%) consultations
<b>Total</b>	101 (67%) consultations	40 (26%) consultations	10 (7%) consultations	151 (100%) consultations

Those who did not see the person they wanted to see were parents (3 consultations) or middle-aged people not working (7 consultations), attending for a routine check (5 consultations) or for symptoms of a new problem (2 consultations) or a change in an established long-term problem (3 consultations). They attended urban or inner city practices (patients in 9 consultations) which favoured same-day appointments (patients in 3 consultations). [nb data missing for 2 practices accounting for 5 consultations]

Those who had to wait longer than they wanted to see their chosen provider had attended for symptoms of a new problem (6 consultations), a change in an established long-term problem (3 consultations) and follow-up or routine management (2 consultations). Their practices were urban or inner city (10 consultations), booked most appointments in advance (8 consultations) and placed a high value on personal continuity (8 consultations).

## ***Continuity of care: the views of patients and carers***

### **4.3.2 How far did patients experience personal/relational continuity?**

A summary of patients' consultation records were provided by practices for 31 patients. These set out the patient's contact with the practice, including the date of the contact, whether it was a face-to-face consultation, a telephone consultation or a home visit and with whom the patient consulted. Most practices sent a print-out of the records they held on their computer which also included the notes made by the person consulted, for example on the problem presented, advice given, treatment plans and prescriptions.

**Table 4.4: The extent of personal or relational continuity in patients' use of general practice (surgery attendance, telephone consultations, home visits) over the course of a year**

#### **(i) Number of consultations in the year**

<b>Number of Consultations with GP</b>	<b>Number of patients</b>	<b>Number of Consultations with other HCP (eg nurse)</b>	<b>Number of patients</b>	<b>Total Number Consultations with any HCP</b>	<b>Number of patients</b>
0-4	5	0-4	21	0-4	2
5-9	13	5-9	8	5-9	10
10-14	6	10-14	0	10-14	4
15-19	2	15-19	2	15-19	9
20+	5	20+	0	20+	6
Total	31	Total	31	Total	31

#### **ii) Number of different practitioners seen in the year**

<b>No of GPs seen</b>	<b>Number of Patients</b>	<b>No of other HCPs (eg nurses) seen</b>	<b>Number of Patients</b>	<b>Total No of HCPs seen</b>	<b>Number of Patients</b>
0	1	0	4	0	1
1	10	1	15	1	3
2	6	2	7	2	4
3	6	3	1	3	7
4	4	4	3	4	4
5	2	5	1	5	5
6+	2	6+	0	6+	7
Total	31	Total	13	Total	31

## ***Continuity of care: the views of patients and carers***

### **(iii) Proportion of GP consultations with main GP**

<b>Proportion of GP Consultations with main GP</b>	<b>Number of patients</b>
<30%	3
30-39%	0
40-49%	2
50-59%	3
60-69%	2
70-79%	4
80-89%	4
90-99%	2
100%	10
Total	30*

\*one patient did not consult anyone for himself over the year

Table 4.4 shows the number of consultations with GPs and other members of the primary care team over the course of a year, the number of different professionals seen and the proportion of consultations with the 'main' GP. The number of contacts with GPs ranged from 0 to 40 (median 5-9); the number of contacts with practice nurses and other health care providers in the practice ranged from 0 to 15 (median 0-4); the total number of contacts ranged from 0 to 41 (median 10-14). The number of different GPs seen ranged from 1 to 6 (median 2); the number of practice nurses, counsellors and other health care providers seen ranged from 0 to 5 (median 1); and the total number of different providers seen ranged from 1 to 9 (median 4).

Two thirds of patients saw the same GP for at least two thirds of their GP consultations and a third saw the same GP for *all* GP consultations over the year. At the other extreme, 5 patients did not see any one GP for even half their GP consultations. This included three middle-aged people (30-59/60) with limiting long-term problems who were not working because of their health problems, a middle-aged full-time carer of her disabled husband and one young person (18-20) in full-time education who was in good health. They consulted between 7 and 19 times in the year and saw between 5 and 8 different health care professionals. The practices they attended had between 4 and 8 partners, had appointment systems which allowed both same-day appointments and appointments booked in advance, and with one exception, rated personal continuity as only moderately important (3 or 4 on a 5 point scale).

## ***Continuity of care: the views of patients and carers***

### **4.3.3 Patients' use of primary care in relation to their views regarding continuity of care**

A complete set of interview, consultation record booklets and practice notes were available for 22 patients; two of the three sources of information were available for a further 12 patients. In this Chapter we describe how these 34 patients used primary care services over the period of a year, the efforts they made to realise their preferences in relation to continuity of care and the factors which constrained or inhibited them in doing so.

A typology of practice use was developed, bringing together patients accounts of their preferences for personal continuity of care and the degree of personal continuity displayed in their actual use of primary care services. Five distinct patterns were identified which are briefly described below.

- Committed:** A strong preference expressed for personal continuity which was sustained
- Supported:** No strong preference for personal continuity expressed but personal continuity sustained nonetheless
- Frustrated:** A strong preference expressed for personal continuity but this was not sustained in practice
- Pragmatic:** A higher priority given to other considerations than personal continuity which was not sustained
- Strategic:** A strong preference for personal continuity expressed in relation to a particular dimension of care but a higher priority given to other considerations in other dimensions with personal continuity sustained across a more complex picture.

In the rest of this Chapter we will describe these five patterns of primary care use and how they were produced by the interplay of patient preferences and their efforts to realise them and the structure, organisation and culture of primary care practices. We will conclude by considering some of the implications of these patterns and the factors which produce them.

#### ***Committed***

Patients in this group had a strong preference for personal continuity and were able to sustain it. They included patients who rarely consulted (e.g. 2 or 4 times a year) but always saw the same GP and patients who consulted very frequently (e.g. more than 20 times a year) and saw the same GP on more than 70% of occasions.

## **Continuity of care: the views of patients and carers**

For some patients, particularly older middle class patients with chronic conditions, personal continuity appeared to come easily and unproblematically: they expected to see their 'own' GP when they consulted and they almost always did. As Mrs A illustrates in the following example, however, this current ease in seeing their 'own' GP was often the product of a good deal of effort in the past, over many years, to establish and maintain a personal relationship with their chosen GP. These patients had sought out and found a GP with whom they got on well and after many years of mutual commitment and loyalty, regarded themselves – and were regarded by their GP – as his or her patient. In later life personal continuity was also often facilitated by an infrastructure of regular appointments, booked with their own GP weeks or months in advance, to monitor chronic conditions such as blood pressure or diabetes. The frequency and regularity of these appointments gave patients the opportunity to raise with their own GP any new problems they experienced without having to seek a 'new' appointment and so risk having to choose between seeing their own GP and seeing a GP quickly.

### **Committed – case example 1**

*Mrs A was a widow aged over 80, in good health but with arthritis and heart problems and a range of minor complaints. She regarded it as very important to have a personal relationship with her doctor: "We should all know our bank manager" she said in her interview, "and our bank manager should know us. And we should all know our doctor and we made a point of that."(p7) She had put an effort into this over the past 10 years, visiting her GP every fortnight with her husband who had a range of chronic problems. She felt her GP was equally engaged in their relationship as was evident, for example, in his response to her husband's recent death: "John was I think quite – he was devastated." At the time of her interview, she continued to make regular appointments with her GP, ostensibly to collect medication for high blood pressure: "since Edward died I've come, probably about every three or four weeks. I try to come in once a month. I feel secure then. I mean I also get a medication. I've got medication as well, I get that when I come in."*

*Over the previous year she had had 16 consultations with her practice, 13 with her own GP and 3 with the practice nurse. These were routine consultations, booked monthly in advance, to monitor her blood pressure but in which she also raised a number of other chronic and acute conditions. For example, the reasons listed for consulting in booklet 1 include 'BP check, pills needed; discussed possibility of wheel chair; wart to be blasted; itchy rash on top of back.' In each booklet she indicated that she wanted to see one person in particular – 'Dr J because he has been my (and my husband's) GP for years.' (bl1). The notes made by her GP in turn included comments of a non-medical nature which indicate his concern for her welfare more generally. For example, for the consultation that Mrs A described as a 'pre-holiday check up', Dr J noted her BP and added 'Well. Off to Aix.'*

## **Continuity of care: the views of patients and carers**

*Their relationship appears to be mutually rewarding and sustained by its own momentum.*

Not all patients for whom personal continuity was important were able to achieve it so easily. Patients in busy practices in more deprived or mixed urban areas often had to make special efforts to sustain personal continuity and their ingenuity and energy in doing so attest to the very high value they placed on it. In their accounts of their use of primary care services, both in their interviews and in their consultation record booklets, these patients indicated a number of long term strategies and more immediate tactics which they used to see their 'chosen' GP and to sustain the personal continuity they valued. In the following example, Mrs B suggests that her initial strategy had been to find a GP who was sufficiently accessible that she could see her easily enough to build up a loyal and trusting relationship with her. Having managed to do so, she was then faced with the problem of seeing an increasingly senior and popular GP within a reasonable time. Her main tactic at the time of the study was to trade off quick access to medical care for personal continuity with her preferred GP: while she was very unhappy with the length of time she had to wait to see her 'chosen' GP, she nonetheless did so because personal continuity was so important to her. Other tactics she described included 'holding her ground' against the receptionist who would not give her access to her GP and learning the new rules for telephone consultations and using them to her advantage. Perhaps most significant, however, was the effort her 'chosen' GP herself made to maintain personal continuity, over-riding the receptionist and practice rules on occasion and showing both flexibility and commitment to Mrs B in seeing her as an emergency patient.

### **Committed – case example 2**

*Mrs B was an older married woman, retired, in fair health but with a variety of chronic and acute problems. Personal continuity was very important to her as she indicated repeatedly in her consultation booklets: 'My 'own' GP has been wonderfully supportive over several years and knows the many health problems that I have. Hence, whenever possible, I would always choose to consult her.'(bl2) This was not easily achieved, however, and over the years she had developed a number of strategies and tactics to increase her chances of achieving it. Most significant of these was to find a GP who was reasonably accessible and establish a relationship with her. In her interview she explained: "I am registered under Dr B, she sees me once a year for my diabetes assessment .The reason that I went to Dr C instead of Dr B is that every time I wanted to see Dr B I had to wait a heck of a long time. . . Dr C was the third doctor [junior partner and so more accessible at that time]. . ." (p8). With retirements, Dr C had become the second partner and Mrs B had accepted that she would have to make compromises on occasion: 'She is somebody that I really trust. But if I can't see her – because now she is so popular,*



## **Continuity of care: the views of patients and carers**

*everyone wants to see her – I will sometimes, if it is not all that important, then I will see the third one, whoever it is.” (p 9) Soon after the longitudinal study started, Dr B retired and Dr C became her ‘own’ as well as her ‘preferred’ GP.*

*Over the course of the year, Mrs B had had 19 consultations with her practice, including 15 GP consultations, 11 with Dr C, 2 with Dr B and 2 with Dr Y, and 4 consultations with the practice nurse.*

*In her consultation record booklets, Mrs B always indicated that she wanted to see a particular person (her GP on 8 occasions and the practice nurse on 2). In each case she was successful, though her accounts convey the considerable effort she made to achieve this success and the price she paid in terms of much longer waiting times. For example, in booklet 4 she described how she had attended the practice for a routine blood test and while there had tried to book an appointment with her chosen GP regarding a chest infection she had mentioned in an earlier booklet. ‘The receptionist told me that there were no appointments for at least two weeks and that the diary didn’t go beyond that. Eventually, after a discussion, she told me to go home and my GP would telephone; which she did at 10:45 giving me an appointment at 11:15. My GP was very efficient and kind as always.’ (bl4) She later added ‘I did have a problem with a particular receptionist. She has been a permanent member of staff for many years and is very sour and can be, as today, unhelpful. . . . I held my ground and did not take ‘No’ for an answer. Hence the telephone call from my GP.’*

*This conflict with the receptionist continued and in booklet 6 Mrs B wrote that she had telephoned the practice to make an appointment to talk about painful arthritis in her hands, a swelling in her nose which had been cauterised and problems with her diabetes testing kit. She had been told that there were no appointments available for a week and had booked an appointment for 8 days ahead. She was very unhappy and angry about this situation, complaining that the receptionist had not asked if her problem was urgent, that she had not been told that only a limited number of telephone calls were available each day and that the practice had taken a very long time to answer the phone. In the next booklet, however, she wrote that she had asked for a telephone appointment with her GP which could only be booked for the next day. ‘My preferred doctor telephoned and booked an early appointment for the following day.’ In this way she managed to get an appointment with her own GP only 2 rather than 8 days after her first request.*

Other strategies and tactics that patients used included being flexible in making appointments, making friends with the receptionists and learning when to ring to make an appointment and what to say to get it.

## **Continuity of care: the views of patients and carers**

### **Supported**

Some patients did not place a particularly high value on personal continuity – seeing it instead as one among several potentially important considerations – but nonetheless regularly saw the same GP when they consulted their practice. Mrs C provides an example of a healthy woman who found herself seeing the same GP for a series of minor acute problems largely without specifically intending to do so.

### **Supported – case example 1**

*Mrs C was a middle-aged woman in paid employment and in good health. She consulted a GP only 7 times over the course of the year, seeing the same GP on each occasion. She completed three consultation record booklets over a three month period which indicated a preference for quick access to any GP in the practice. In the first booklet she noted swollen glands and cold sores as her reason for consulting and indicated that she did not mind who she consulted but 'I wanted to see someone before I went to work'. In the second booklet, she identified 'severe migraine' as her reason for consulting and again did not mind who she consulted. The third booklet referred to a follow-up visit the next day where she indicated that she wanted to see the same GP as she had seen the previous day and for the first time described him as her 'own' or usual GP. Her practice, which was an urban practice with 4 partners, operated an appointment system which could accommodate her wish for same-day appointments (early appointments bookable in advance, late appointments available for the same day) and, despite only a moderate value placed on it (3), also provided her with personal continuity of care.*

While she received personal continuity, it is not clear whether or not she *experienced* it as such.

In the following example, Mrs D, a middle-aged woman disabled by a number of chronic health problems including severe asthma, illustrates how personal continuity can come to be taken for granted when it is achieved without much effort.

### **Supported – case example 2**

*Mrs D was a middle-aged woman with adult children, not working because of her poor health. She had been registered with her practice for over 20 years and had got to know the doctors and receptionists very well.*

*Although she preferred to 'stick to one or two doctors because they get to know you' (p3), Mrs D had confidence in all the doctors in the practice and indicated that there were no circumstances in which she would wait to see one of her preferred GPs. 'If you need to see a GP, you need to see a GP. You're not fussy who it is with, you know what*

## ***Continuity of care: the views of patients and carers***

*I mean? If they're at the surgery, they've got to be good. . . .  
They've got to be a proper GP.'*

As someone with severe asthma, Mrs D valued quick access to a GP and appreciated the way this was provided by her practice: 'I mean if I phone and say I'm bad, I can get a five minute appointment in a morning or whatever. Or like I take bad this afternoon, . . . if I ring the surgery, whatever doctor was on call, if need be, would come out to see you. They're very good.' (p3-4)

Her account also suggested that the mutual knowledge and trust that had developed between her and the staff at the practice played an important role in the way she accessed care. Because she was known to the practice, she said, the GPs were willing to prescribe over the telephone and the receptionists were willing to fit her in with an appointment. With regard to the latter, she commented on their key role as gatekeepers and the value of being known to them: 'The girls on the desk are excellent as well. . . . Even on the desk and that they get to know you. They know whether you're a fooler-along, shall we say, or a mucker-about and that, or whether you're genuine and they know I won't bother them if I'm not bad.' (p4)

Over the course of the year she had 40 GP consultations, 39 with the same GP; 20 of these contacts were documented in the consultation record booklets she completed. These show that she booked regular appointments every two weeks with her own GP to monitor her warfarin prescription and in the context of these consultations also discussed a range of other problems including her asthma and other respiratory problems, dry skin and wax in her ear. On the rare occasion when she experienced new acute symptoms – sore throat and blocked nose and head – outside the infrastructure of these appointments, she indicated that she wanted a same day appointment to see a doctor: 'Have to be careful with colds and infections because of asthma and have to check what you can have because of warfarin'. She did not mind who she consulted – 'All the doctors at the practice could have helped.' – but nonetheless was given a same-day appointment to see her usual GP – 'It was just that Dr E had a free appointment.'

Patients in this group took little initiative in the way they used primary care services, leaving the choice of GP to the receptionists who booked appointments or to the systems in place for organising routine monitoring of chronic conditions. They appeared unaware of the personal continuity they received or took it for granted because it happened so 'naturally'.

### ***Frustrated***

Some patients who placed a high value on personal continuity were not able to sustain it over the longer term. While they looked for

## ***Continuity of care: the views of patients and carers***

continuity as a feature of their interaction with primary care services, they took no steps to produce it when they ceased to receive it. These patients were more isolated than others, no longer working due to ill health or retirement, and may have lacked the confidence, skills and emotional resources needed to manage the bureaucracy of primary care. In the following example, Mr E, a registered methadone user, described the importance of personal continuity in helping him stay 'stable' and in treatment. He relied on the commitment of his GP and the CAPS clinic with whom he had established a good personal relationship to provide it for him and appeared to feel helpless to do anything when they no longer did so.

## **Continuity of care: the views of patients and carers**

### **Frustrated case example 1**

*Mr E was a middle-aged man, registered as a methadone user and not well enough to work. He used a number of primary care services, most notably a GP practice and the Community Assessment and Primary Services (CAPS) (run by the Community Mental Health Trust). He valued continuity in both contexts, in part because he was "sick and tired of having to tell the story over and over again. Having to re-fill assessment forms in." (p 5) and in part because he wanted someone he could trust to look after and support him in a variety of contexts (p 1). As he noted on his first booklet, 'I would always prefer my regular GP as I have built up a good relationship with them over the years I have been a patient here.' (b1) The strength of this relationship had been demonstrated in various ways over the years, for example when his GP had intervened when he had had difficulties with the local pharmacists ("the doctor [rang and gave] them a bollocking as it were. And the next time I went, he was, he couldn't do enough for me" p 4).*

While Mr E valued personal continuity, he did little more to sustain it than book regular appointments with his GP and with the psychiatrist at the CAPS clinic, in the expectation that he would see the same health care provider. This happened to some extent at the GP practice and each time his usual GP was away, she made provisions with the regular mental health nurse to cover for her. On the first occasion this happened, Mr E noted in his booklet 'I would have preferred my own GP. Partner took GP's place (holiday leave). Fortunately the practice nurse sorted prescriptions so we didn't have to see alternate GP'. At the next monthly consultation, he noted that 'I wanted to see my GP, to make sure prescriptions were all in order, as I have had problems at certain pharmacies in past' and managed to do so on that occasion. This was not the case, however, on the subsequent two occasions, a development about which he was not happy.

Continuity was even more difficult to sustain in the CAPS counselling service where a high turn over of staff meant he was unable to see the psychiatrist [or clinical psychologist] with whom he had originally established a good relationship. He noted in his penultimate booklet: 'Five different doctors over the last eight months is too much for me. It leaves me feeling negative that none of the doctors truly knows me, except for the case notes that they quickly flick through.' (b1 7).

As this example makes clear, wanting and expecting personal continuity was no guarantee of getting it. This was the case even when appointments were booked well in advance, a tactic that many patients used specifically to ensure that they saw their 'own' GP. In this example, it may have been the low status of the patient or his failure to conform to the expectations of the sick role which made it easier for his doctors to disengage. Condition-specific clinics which provide a more routine and standardised service may be a form of

## **Continuity of care: the views of patients and carers**

what Goffman calls 'batch care' and which tends to depersonalise patients, making it easier for doctors to hand them over to another practitioner. In these circumstances, doctors rely on good communication with each other – through verbal briefings or good written records – to be able to provide further care. However, the above example suggests that, where patients are looking for the personalised care and commitment provided by a doctor they regard as their own, this is not sufficient. Neither management continuity provided by known colleagues in the practice nor informational continuity provided by detailed case notes were perceived to be adequate substitutes for personal continuity. This is not always the case, however, as an example in the following section suggests. Where patients have a more 'technical' orientation to health care, informational continuity may be accepted as a satisfactory basis for continuity of care.

### **Pragmatic**

Personal continuity was not the only consideration for patients when using primary care services and for some patients other considerations, including speed and convenience of access, gender of the provider or personal experience of motherhood, were more important. The majority of patients who displayed this pattern were young, healthy, employed patients who largely consulted about minor acute problems. Many of these patients were primarily concerned to get an appointment at a time which could be fitted in with the many other demands on them and did not mind which of the GPs at the practice that they saw. Ms T provides an example of a patient who acknowledged that there could be benefits in seeing the same GP but who in practice gave greater priority to speed or convenience when arranging a consultation.

### **Pragmatic – case example 1**

*Ms T was a single young working woman in good health despite a non-limiting long term condition (depression). When interviewed she commented that she had recently consulted on several occasions about a continuing problem and had 'luckily' seen the same GP each time. In this case, she said, it had been helpful to see the same GP 'because I don't have to explain the whole thing again' but normally 'if it's just a numerous amount of illnesses or whatever, then it don't matter who you see.' (p4) She also observed that GPs themselves 'tell you to ask for them' when booking a follow-up appointment but added that such advice did not necessarily help in practice. 'Too many patients' meant it was difficult to get an appointment so 'sometimes you can't see the same doctor that you want to see. You just get shoved onto another doctor that's got an empty space somewhere.' (p5) Her own priorities were 'fitting in' around her working hours and not having 'to wait around for hours. You can go in and get seen and sort of come out again.' (p3) She regarded all GPs as much the same – 'it doesn't matter, so long as they are professional in what they do*

## **Continuity of care: the views of patients and carers**

*and they're not treating you any different to anybody else' (p3) – and so concentrated on making her appointment at a time convenient to her work and other activities. This was accommodated by her large, city practice which booked a quarter of their appointments on the same day.*

The consequence of this approach was a rather chaotic use of primary care services. Over the course of the year she had consulted 9 different health care professionals (6 GPs, 2 practice nurses and a clinical psychologist) for 6 different problems (depression, headache, sore throat, haemoptysis, cervical smear and tinea) on 15 different occasions. The problem for which she consulted most frequently was psychological (what she described as post-traumatic stress disorder and her GPs as depression) for which she saw 4 different GPs on 8 separate occasions. She completed only 4 consultation record booklets, all for consultations regarding PTSD/depression, the final ones indicating growing dissatisfaction with being 'palmed off with unnecessary tablets.' (bl4)

Mr F provides an example of a patient with a different attitude to consulting and what could be described as a 'taxi queue' approach to using primary care: he was happy to take the next appointment available with whomever it was. At interview, he indicated that this was based on his faith in informational continuity as the foundation for continuity of care and outlined ways in which he, his doctors and the practice made effective use of it.

### **Pragmatic – case example 2**

*Mr F was a single, middle-aged father in full-time employment and in good health despite a limiting long term condition (a chronic bowel problem). While he acknowledged that there were some problems for which he would like to see the same GP (cf the Strategic group, below), these were not currently bothering him and at the time of interview he did not mind which GP he saw when he needed medical attention. His concern was largely with the technical competence of the individual from whom he sought help and he regarded all qualified doctors as having – or being able to access – the necessary expertise. He commented, for example that 'our practice use a lot of locum doctors as well and a lot of training GPs and even a training GP has qualified. So whoever you go to see is qualified. . . .' (p4) Perhaps because of this experience, he also commented on the futility of trying to see the same GP, pointing out that 'surgeries have a turnaround of doctors anyway. Just because you've got a preference on the doctor, if that doctor leaves, you've still got to go and see another one.' (p13) In this context, what he mostly appreciated was the opportunity the practice offered for him to be seen quickly when he felt it was necessary: 'if you feel it's an emergency, you might have to wait an hour or you might have to wait an hour and a half but you can have a five minute appointment and that is very good.' (p4)*

## **Continuity of care: the views of patients and carers**

*Over the course of the year, Mr F consulted the practice 6 times, seeing 3 different GPs on 4 occasions and a clinical assistant (for BP monitoring) on 2 occasions. He completed three booklets, for three different problems, which illustrate the 'taxi queue' approach he described at interview. In the first booklet he reported a visit to the local A&E department to deal with 'sand and grit in face and left eye'. He wanted immediate treatment for the problem ('my eye needed immediate treatment due to grit getting under eyelid') and did not mind whom he consulted ('anyone qualified to give eye treatment'). In the second booklet he reported a visit to his GP practice for 'pain in upper back'. Again he did not mind whom he consulted but wanted to be seen within two days and at a suitable time, noting that 'I was working late shift at work and required a morning appointment and was given an appointment for the following morning.' In the third booklet he reported a consultation for a blood pressure check which he wanted in order to follow up the results of workplace screening that indicated he had high blood pressure. Again, he did not mind whom he consulted but wanted to be seen in the next couple of days.*

*Although his use of primary care appeared fragmented, Mr F did not find this problematic, largely because of the faith he had in practice records (p13) and the ability of GPs to use the information passed on to them. He made an effort in this direction himself, noting that 'I'm one of these people that, I do take notice of what I've been told and try to stick to it as much as possible and if they [the new doctor] are unsure I'll explain to him what I think the problem is or if I've had similar problems in the past. And they do have the thing of, they can look at the records anyway and they can, some of it will come up on the screen as well, and it might take a little bit longer but eventually we, hopefully, we get there.' (p5) His faith in informational continuity also underpinned his positive attitude towards new arrangements he understood were to be introduced by his practice, which involved a team leader and two other GPs responsible for a group of patients. 'So within reason, you're going to see someone within that team and I would imagine then that you're gonna get the same sort of care ' (p13).*

Included in this group were two patients who illustrate the way in which patients' attitudes and behaviour can change over time as they gain experience and confidence. One patient, Mr G, a middle-aged man with young children and working part-time, did not consult anyone for himself over the course of the year but did take his mother-in-law to a Walk In Centre specifically to get quick access to a health care provider for a diagnosis of her symptoms as they occurred. When the 'illness nurse' was not able to give a diagnosis, he made an appointment with his mother-in-law's own GP who, to his surprise, saw her immediately and referred her to a stroke clinic (with a diagnosis of TIA). The GP was also able to accommodate to his need for a follow-up appointment after 3:00 pm (so he could accompany his mother-in-law) and so he booked to see that particular GP again. In



## ***Continuity of care: the views of patients and carers***

the sequence of consultation booklets he completed, he conveyed the impression of someone discovering a whole new way of using primary care services. The other patient was a teenaged boy (CK) who was told by his mother to see a doctor 'for advice about dizziness'. For the first two consultations, he 'wasn't bothered' who he saw or when he saw them and was given tablets and a blood test. At the third consultation, however, 'mum wanted my own GP' and he was given advice and asked to make another appointment for two weeks time. Like the patient in the previous example, this patient's indifference to personal continuity may have been based on his own good health and lack of experience of primary care services and looked like changing as he learned how to use the system more effectively.

Also included in this group were two patients who gave priority to speed and convenience of appointments but who were dissatisfied with and critical of the care they received as a result. These patients were older than the others in this group and had chronic health problems or cared for someone with chronic health problems. Mr J, for example, was a single man aged 30-59, not working because of chronic health problems, including asthma. He did not want to be restricted to a single GP of his own (though he identified three he preferred), indicating that he wanted to be able to choose which GP to consult according to his immediate concerns and also that 'transport problems' made personal continuity difficult. In his booklets he noted that the speed or timing of the appointment was most important to him and over the course of the year he saw 4 different GPs on 11 occasions. At the end of his last booklet he indicated that he was less than satisfied with the consultation and that the GP he had seen would not be his first choice next time. He closed by adding 'I tend to feel like I am on a conveyor belt in a rush to get rid of me'. Similarly, Mrs S, a 60-79 healthy carer of her disabled husband, was less than happy with her experience with her practice. She complained that her husband has suffered from lack of continuity of care but also stated that she was unhappy with always seeing their 'usual' GP who did not see past her husband's MS. She too had problems with transport and in her booklets gave priority to speed and convenience of access to a GP, particularly when her husband fell ill. Over the course of a year, she saw 4 different GPs on 5 occasions.

### ***Strategic***

Patients in the final group wanted to see (and saw) their own GP for a particular set of health issues but gave a higher priority to other considerations when consulting for other problems. Included in this group were several patients who looked for personal continuity with their GP in relation to their chronic health problems but who gave a greater priority to quick or convenient access when they experienced minor acute problems. This could give rise to a large number of consultations with a large number of different health care professionals as the following example illustrates.

## **Continuity of care: the views of patients and carers**

### **Strategic – case example 1**

*Mrs L was a 30-59 year old mother of children aged 5-10, in poor health and consequently off work on incapacity benefit (which she later described as fibromyalgia). She had been with her large city practice (7 partners) for many years, since before her children were born, and had come to regard Dr E as her 'own' GP. At interview, she indicated that she preferred to see him when she consulted except for 'women's problems' for which she preferred to see the female partner, Dr D: 'I go and see Dr E. The only time I don't see Dr D is if it's female related problems cos I don't, . . . I feel more comfortable talking to a woman about it because I always feel that they know exactly what you're talking about.' (p5) She saw this 'divided loyalty' as potentially problematic and disruptive to her relationship with Dr E but he had reassured her that he understood and accepted it: 'He said "I understand that there are things that you perhaps feel more comfortable talking to a woman doctor about." Which is nice because I felt I was betraying him by going to someone [else] . . . because he's been so brilliant with us as a family with all the problems that we've had with my illness and other things . . . He's a very good doctor, he's very, very understanding and he'll pull the stoppers out to get things done if it needs to be done.'*

Her two children (aged 8 and 10) had been attending the practice since they were born and her daughter was beginning to show the same preferences as her mother. However, Mrs L felt that with her children's health, it was more important to see a doctor quickly than to wait to see their 'own' GP if he were not immediately available: 'With children you want to see a doctor or speak to somebody and be reassured if you've got a problem and if you can't get in to see the doctor, it's a bit of a nuisance.' (p5)

Her practice notes indicated that, over the course of a year, Mrs L had had 14 consultations with 6 GPs and 2 practice nurses. The pattern of these consultations reflected the complex set of preferences she had described at interview: 3 consultations had been with Dr D, the female partner, for endometriosis, and 3 had been with Dr E, her 'own' GP, for the fibromyalgia which had prevented her from working for the previous 3 years and a further 6 had been with her 'own' and 4 other GPs for a range of 'acute' symptoms including a urinary tract infection, hay fever, acne and a sore mouth.

The considerations which shaped this pattern were elaborated further in the consultation record booklets that she completed. These indicated, for example, that she had initially tried to see her 'own' GP for her urine infection 'because I trust him' but had wanted a same-day appointment and so had seen another GP because her 'own' 'was booked up till Friday' (b17). They also showed that she had made an appointment for her husband to see 'our own GP because he knows

## **Continuity of care: the views of patients and carers**

our family circumstances really well' and had succeeded as she had made it well in advance 'for the day my husband was off work as he cannot take time off at present due to work pressure.'(bl6) By contrast, three consecutive booklets showed that, in seeking help for her son's sore throat and voice loss she had first asked for and seen her 'own' GP for a same-day appointment, then several days later rung NHS Direct who had advised her to see a pharmacist which she did before finally contacting her practice again. At this point she did not mind whom she consulted for a same-day appointment and saw the trainee GP with her own GP in attendance.

This group also included a number of other young parents who made an effort to maintain personal continuity with their GP for their own problems but who looked for quick access to any appropriate health care provider (including health visitors or nurses) for their young child. By contrast with Mrs L, the mother in the next example had initially emphasised quick access to care but had come to value personal continuity when she subsequently developed a long-term problem.

### **Strategic – case example 2**

*Ms M, was a woman in her mid-30s with an 18 month old child, who suffered from post-natal depression. When interviewed (before her baby was born) she had indicated a strong preference for quick access to health care and no concern for personal continuity. Indeed, she liked her practice, with 4 partners and a number of other part-time GPs, precisely because it offered her a range of doctors to choose from: 'You've got a good choice of male and female doctors, you don't have to see the same doctor. If you want to see another one you can, within the same practice.' As well as valuing the opportunity to get 'a second opinion', the large practice provided a more accessible service 'because it's, I'm flexible, the practice is flexible and the two work well together so it means I get the immediacy of the care. That's the thing, I'm not having to wait a week just to see a doctor.' She did not mind whom she saw except on occasion 'if I've particularly wanted a female doctor then I've specified, cos they don't actually ask, you know, when you ring.'* (p10)

*By the time the longitudinal study was carried out, she had had her baby and developed post-natal depression. In the context of this new long-term and very personal problem, her consultation record booklets conveyed a strong preference for her own GP when she consulted for herself but no preference for any particular GP when she consulted for her daughter. The contrasts presented by the 10 booklets she completed in a 6 month period were striking. Consultations for herself were almost entirely related to the post-natal depression where she was willing to wait a week (bl 3) 10 days (bl 5) or book well in advance (bl 7) to see her own GP 'because she'd been very supportive after the birth of my daughter and took time to listen' (bl 3) and because 'she knows my history and circumstances and I know I can trust her' (bl 5). Only towards the end of the study did she raise other considerations when making an appointment, notably a practitioner to*

## **Continuity of care: the views of patients and carers**

avoid: 'I wanted to consult the female practice therapist not the male therapist whom I'd seen about a year ago and who I found very unhelpful and lacking in understanding'.

By contrast, when she consulted for her daughter she did not mind which GP she saw but was concerned about when she saw them – either very quickly or at a time which did not disrupt other valued activities. Alternating with the consultations for herself noted above, she described a series of consultations in which she took her daughter for an MMR vaccination (bl 4), for an urgent appointment when her daughter developed 'a measles-like rash 5 weeks after MMR' (bl 6), for a check-up 'for reassurance' following an acute infection for two weeks (bl 8) and for another urgent appointment when her daughter was 'very ill'. In each case she was happy to see 'any GP' but wanted an appointment either 'as soon as possible' (for emergencies) or (for other problems) on Monday or Friday because her daughter was at nursery the other days (bl 4) or in the late afternoon so her daughter 'would have had a nap and so that she wouldn't miss nursery' (bl 8). She eventually saw a health visitor (bl 4), 3 different GPs (bl6, bl8, bl12) all of whom she praised. As she explained in relation to the last in the series of consultations, the practice has 'a number of urgent appointments available each day and I presume there's a rota for the doctors who see urgent patients, so you can't chose who to see. [but the GP I saw] has 3 children of her own . . . so I felt she had some understanding of my concerns and took them seriously.' (bl 12)

Over the course of the year, she consulted her own GP 7 times and the practice therapist 7 times all for herself but consulted many other GPs on many other occasions for her daughter.

A final example illustrates another aspect of the complexity in continuity of care, that of continuity across a family or household unit. This may be particularly important where one family member provides care for another (for example, for a partner with a disabling condition or for a young child).

### **Strategic – case example 2**

Mr N is a middle-aged married man with limiting long term illnesses (including Parkinson's Disease, arthritis and psoriasis) who lived with his wife who was his main carer. During the initial interview, Mr and Mrs N presented themselves as a unit, with Mrs N often answering questions on her husband's behalf and from his perspective. (He noted in one of his booklets that his PD meant he sometimes had difficulty speaking.) Over the course of the year, Mr N had 15 consultations with his practice, 6 with his 'own' GP, 3 with another GP, 5 with one practice nurse and 1 with another. In his booklets, he indicated that he did not mind whom he saw for his routine blood tests (though he always saw the same practice nurse) nor for the

## **Continuity of care: the views of patients and carers**

*emergency visit he made when he cut his finger badly nor when he deteriorated suddenly and needed the Rapid Response team. But he emphatically wanted to see his 'own' GP when he had problems following a change to his PD medication made by his consultant neurologist and when he arranged for his 'regular review'. The latter he wanted arranged in conjunction with his wife, so they could both be reviewed together. Thus, although he saw a number of different health care providers, his 'own' GP provided the continuing thread which held his care together and linked it with that of his main carer, his wife.*

### **4.3.4 A note on other health care providers**

For some patients, health care professionals other than GPs – for example, nurses, counsellors, physiotherapists, occupational therapists, podiatrists, pharmacists and others – were also important providers of primary health care. It was rare, however, for patients to regard these professionals in the same way they regarded GPs. This was in part because most patients saw a GP more often than any other type of health care provider and in part because it was their GP who had referred them to these other providers. Most patients, for example, regarded practice nurses as part of their GP's 'team', carrying out specific technical procedures under the GPs' direction and on his or her behalf, and consolidating rather than challenging their relationship with their GP. Seeing a practice nurse for a blood test, for example, was regarded almost as an extension of seeing the GP who had asked for the blood test to be done. In this context, individual practice nurses were generally regarded as more or less interchangeable. There were exceptions to this – for example, when a particular nurse was preferred as more skilled at certain procedures or for her sunnier personality – but they were rare. More commonly, patients assumed that the nurses they saw had the technical skills and expertise to do their job, and did not mind which of them they saw. This was also the case with regard to other health care providers such as pharmacists and podiatrists, whose knowledge and personality were also generally noted with approval.

One exception to this was Ms P, a middle aged single woman, not working because of a limiting long-term illness (schizophrenia). At interview, she said that when she needed to see a GP 'I ask for Dr R, because I think she is supposed to be my doctor, but I don't come very often. I only come if it's really necessary for me.'(p2) She valued the practice, however, because 'It works very well for me with the nurse, Caroline. Because she takes my blood pressure, she makes a blood test, she gives me my injection every month.' The importance of Caroline as her main primary care professional was reflected in her practice notes which showed that she had consulted 17 times over the previous year, 11 times with Caroline, 4 times with another nurse at the practice, and twice with a GP (not her own) for an eye infection.

## ***Continuity of care: the views of patients and carers***

She rarely saw a GP but had established and sustained personal continuity with a practice nurse and, like those who valued personal continuity with their GP, found great reassurance in this, saying 'Caroline will know if something goes wrong' (p15).

### **4.4 Conclusions**

In the longitudinal study we have looked in detail at the way a sub-sample of patients have used primary care services over the period of a year. This has involved pulling together the interviews described in the previous chapter, patients' own written comments on individual consultations and the notes provided by their practice for the preceding year. On this basis, we have developed a typology to describe how patients use services in relation to their preferences for personal continuity or other aspects of care. It is important to note that the typology is of patterns of use of primary care services (not types of people) and while we would expect the categories in the typology to endure, we would also expect that individuals would move between them as their circumstance change.

In the context of the typology, we can make a number of general observations about how patients use primary care services.

First, it is clear that there are considerable differences between patients in terms of their preferences with regard to personal continuity and other aspects of the consultation and that these are not always readily predictable. Older people, particularly women, generally preferred personal continuity of care and younger, healthy people generally preferred swift access to care but this was not always the case. Most people were consistent in their preferences, over time and in terms of views and behaviour, but some were not. Indeed, we observed examples of patients changing both their preferences and their behaviour over the course of the study. Most people had fairly clear and straight-forward preferences but some had very complex sets of preferences which shifted with each new consultation in relation to, for example, the nature of the problem, whether it was their own problem or that of someone for whom they cared and whether considerations other than health care were more important at the time.

Second, patients differ markedly in their ability to realise their preferences and how satisfied they are when they do. Some patients appeared to get what they wanted almost effortlessly, though this was generally the result of their long-term investment in their GP or of practice policies and the way they were implemented. Other patients got what they wanted but only by working very hard to do so. The efforts these patients made demonstrate how important it is to some patients that they see their 'own' GP and how imaginative and resourceful they could be in overcoming the obstacles that practices put in their way. It also appeared – and this is perhaps a counter-intuitive finding – that those who wanted quick access to a health care

## ***Continuity of care: the views of patients and carers***

provider generally found this easier than those who wanted personal continuity with their own GP who often had to make considerable efforts over a longer time to do so. Moreover, those patients with long-term illnesses who wanted quick access to care from any doctor, rather than preferring personal continuity with their own GP, were often dissatisfied with the care they received as a result.

In terms of testing and developing our model, the longitudinal study has given us insight into the ways aspects of practice organisation and culture constrain patients' experience and how patients adapt to these constraints by altering their preferences or acting to overcome them. One observation, which extends the initial model concerns the importance of the personalities and personal styles of those involved in providing primary care, and the personal relationships they form with the patients who use them. These often had a marked effect on whether or not patients were able to realise their preferences. Open access or 'advanced access' systems, for example, tended to favour swift access to a practice GP but could also support personal continuity if the receptionist recognised a patient as 'belonging' to a particular GP. Conversely, booking appointments in advance generally facilitated personal continuity but, when implemented bureaucratically, could prevent patients from seeing their 'own' GP in an acceptable time and so force them to see another GP. By contrast, GPs who were prepared to be flexible could demonstrate their personal commitment to patients by over-riding practice policy and meeting their requests for a consultation or home visit. Perhaps the key lesson from this is that the way patients experience their use of primary care services will depend on the complex interplay of structural factors – for example, practice size, number and times of surgeries, appointment systems – and individual agency – for example, patients own efforts to realise their preferences and the way individual receptionists, doctors, nurses and others interpret the policies they are responsible for putting into practice.

### ***4.5 Post script***

In bringing together material collected in different ways, at different times and from different sources, the longitudinal study has provided an insight into the differences in the ways patients and practices regard patients' use of primary care.

First, a number of patients, particularly women, included in their consultation record booklets consultations they booked for their partner and children. As they were not themselves the 'patient' in these consultations, they were not included in the records provided by their practice. As the patients who completed the booklets clearly thought of them as occasions when they were consulting the doctor, this raises the question of how one defines 'the patient' and how far consultations are about more complex sets of relationships.

## ***Continuity of care: the views of patients and carers***

Second, patients often included in their consultation record booklets consultations with health care providers who were not included in the records provided by their practices. These consultations were not with complementary or alternative practitioners but with a range of providers within the NHS such as NHS Direct, podiatrists and an allergy clinic. This raises the question of what patients perceive as primary care and how other primary care services relate to their GP practice.

Third, and perhaps most intriguingly, some patients presented a picture of their use of primary care services in their consultation record booklets, which was quite different from that presented by their practice in their practice notes. Some patients did not record consultations with GPs other than their 'own' or did not include consultations with providers within the practice other than the GPs. Other patients recorded every contact they had with their practice, including encounters with a receptionist to book an appointment or a telephone call to the practice to get the results of test they had had. This raises the question of how patients interpret the significance of contacts with individuals within the practice and how this might differ from what primary care providers themselves intend.



## Chapter 5 The conjoint study

### 5.1 Introduction

This chapter uses stated preference discrete choice experiments (SPDCE), often referred to as conjoint analysis, to investigate individuals' preferences for different characteristics of a visit to primary care for a range of different reasons. With this technique, the relevant attributes that influence individuals' preferences for a service are identified (Ryan, 2000). Relevant values, or levels, for these attributes are also identified. For example, a relevant attribute of a primary care consultation is the type of professional consulted. The relevant levels of this attribute could be seeing a GP or seeing a nurse. The respondent is then given a series of choices between different scenarios, in which the attributes are the same for each scenario but the levels are different. The respondent chooses one of these scenarios. SPDCE use these choices between different scenarios to estimate the strength of preferences for different attributes of a choice. This enables the researcher to test whether attributes are valued, as well as the relative importance attached to different attributes.

The technique has been widely used in the health care field. Recent examples include studies of women's and health care professionals' preferences for Down's syndrome screening (Bishop *et al*, 2004), women's preferences for intrapartum care (Hundley and Ryan, 2004), preferences for type of haemodialysis (Halpern *et al*, 2004), patients' preferences for acute pain treatment (Gan *et al*, 2004), patients' preferences for the characteristics of osteoarthritis treatments (Radcliffe *et al*, 2004), and preferred drug treatments for asthma (Johansson *et al*, 2004).

Some authors have also used the technique to investigate patient preferences relating to the use of primary care services and also the value of continuity of care in health care. Scott *et al* investigated parents' preferences for the characteristics of out of hours primary care for their children (Scott *et al*, 2003). The authors sampled parents of children who had received a home visit or visited an emergency centre or were registered with a GP. They found the most important aspect of care to be "whether the doctor seemed to listen", where the person was seen (home and A&E were both preferred to a primary care emergency centre), whether the respondent saw a GP from their own practice, and waiting time. Respondent preferences were affected by their characteristics (e.g. age, education, and age of children). Scott and Vick also examined characteristics of the doctor-patient relationship (Scott and Vick, 1998). They found that the most important characteristics of the patient consultation were being able to

## ***Continuity of care: the views of patients and carers***

talk to the doctor, patients' understanding of the doctor's explanation, waiting time for an appointment and the amount of information given to the patient. Similar results were obtained from 101 general practice attendees in Aberdeen (Scott and Vick, 1997). In both these studies patient characteristics were found to affect the values placed upon attributes of care.

Three hundred and one women at low obstetric risk were sampled about their preferences for intrapartum care (Hundley *et al*, 2001). These authors found that continuity of caregiver was one of the characteristics of care valued by respondents. For this sample it was also found that women in areas with the least continuity valued it less than those in other areas (Hundley and Ryan, 2004). In a study of the preferences of women for intrapartum care that included a sample of 118 women having a home birth and 139 women having a hospital birth, continuity of care was found to be significant in determining the preferences of both groups (Longworth *et al*, 2001).

Although we found evidence about the characteristics of some forms of primary care valued by patients, and also that continuity of care is valued in other services (e.g. maternity care), we found no studies that specifically examined continuity of care in accessing primary care services for routine health problems using a SPDCE framework. The aim of this component of our study was to use SPDCE to model the relative importance of different attributes of primary care to patients, under different hypothetical consulting conditions. In addition, we wished to assess whether the value placed on the attributes of primary care was influenced by patient and practice characteristics, as predicted in our model of continuity.

## **5.2 Methods**

### **5.2.1 Questionnaire development and piloting**

The development of a questionnaire for use in a SPDCE study involves: (i) identifying the attributes of primary care to be included in the questionnaire, and assigning levels to these attributes, and (ii) generating scenarios with varying combinations of levels of attributes. These are then presented as choices to patients, in order to obtain their preferences for the different scenarios.

#### ***(i) Attributes and levels***

The first stage of the process, which involves identifying attributes and assigning levels to these attributes, can be carried out in a range of different ways depending on the research question and the aim of the study. Where attributes are not predefined, qualitative work is recommended to identify attributes (e.g. Louviere *et al* 2000, Ryan 2000).

## ***Continuity of care: the views of patients and carers***

The qualitative interviews described in Chapters Three and Four were used as a basis for identifying the attributes of primary care to be included in the questionnaire. Analysis of the interviews resulted in a list of the attributes of primary care that patients and carers described as being important, which provided the basis for selecting the attributes to be included in the questionnaire.

In developing a questionnaire for use in a SPDCE, it is essential that attributes and levels are realistic and capable of being traded off against each other. We imposed an extra criterion on our selection of attributes and levels: the questionnaire would only include attributes that patients might reasonably be expected to have information about prior to the consultation; in other words, attributes that patients might consider when making decisions about which primary care provider to consult. We also wanted to reflect some of the features of currently available primary care services, particularly the available alternatives at GP surgeries and the alternatives such as walk-in centres.

Five members of the project team reviewed the list generated from the patient interviews (MB, SB, CT, DT, KW), using the criteria described above, and a preliminary list of 11 attributes was drawn up. Each attribute was assigned between 2 and 4 levels. The project team reviewed this list iteratively, until consensus was reached on the attributes and levels to be included in the first draft of the questionnaire for piloting. There was consensus on four attributes: relational continuity; informational continuity; type of health professional; access (how long you have to wait for a consultation). Opinion was split on two further attributes: convenience of the appointment time and number of minutes wait in the waiting room.

We tested the six possible attributes with a convenience sample of seven patients who each completed a SPDCE questionnaire including five attributes: the four attributes on which there was consensus plus one of the other attributes. Participants also took part in a short interview to ascertain their views on the attributes, and their understanding of the questionnaire. It was clear that several patients found the questionnaire difficult, and in the light of this, the number of attributes was reduced to four.

The four attributes and levels chosen for the study were relational continuity (operationalised as whether you see someone you know and trust or not); informational continuity (defined as whether the person you see has information about your full medical history or not); type of health professional (GP or nurse); and access (defined as how long you have to wait for a consultation in days). The access attribute had 4 levels, ranging from same day to 10 days (except for the minor acute vignette where levels ranged from 0 to 7 days as pilot interviews indicated that respondents found longer waits unrealistic in this context).

## ***Continuity of care: the views of patients and carers***

### ***(ii) Generating scenarios***

Given the number of attributes and levels, a full factorial design would have required 32 different scenarios ( $2 \times 2 \times 2 \times 4$ ). It would not have been feasible to present this number of scenarios to patients, and we did not need to compare all possible scenarios. Some may be clearly dominated by others, for example, where two scenarios are identical except for number of days wait. The number of scenarios was therefore reduced to eight, using a fractional factorial design. This uses a subset (or fraction) of a complete factorial design. It assumes that interactions between attributes are not significant.

The discrete choice approach involves offering respondents a series of pairwise choices between scenarios. In this study, one scenario was chosen to be constant across the pairs, and to be compared with each of the 7 remaining scenarios. Respondents were asked to indicate their preferred scenario from each of the seven pairings (see the questionnaire included in the Appendices).

### **5.2.2 Framing the choices**

There is evidence that patients' priorities for attributes of primary care vary depending on the reason for consulting (Kearley *et al* 2001, Schers *et al* 2002), and the interviews described in Chapters Three and Four provided further evidence for this. Vignettes describing different types of consulting problems were developed to frame the sets of choices. Initially, six different types of consulting problem were identified from analysis of the interviews: acute, low worry; acute, high worry; emotional, complex, requiring disclosure; ongoing condition, low worry; ongoing condition, high worry; embarrassing /awkward problem. Following input from the Patient Advisory Group and initial piloting three vignettes were chosen. These were the following:

- Imagine that, in your current state of health, you develop a minor problem (such as a minor rash, earache, or a sticky eye). You are pretty sure you know what it is, and you want some treatment for it.
- Imagine that, in your current state of health, you develop some new symptoms. You are not sure what these symptoms mean, or whether you should worry in case they might be serious. You want to consult someone to find out what the symptoms mean.
- Imagine that, in your current state of health, you are due for a routine check-up (such as an asthma or diabetes check, or a blood pressure check).

These three vignettes described (i) a case with new symptoms with low uncertainty ('minor acute'), (ii) new symptoms with high uncertainty, and (iii) routine monitoring. Health status is also likely to influence priorities, and so patients were asked to consider the

## ***Continuity of care: the views of patients and carers***

vignettes in the context of their current health status. The questionnaire included measures of health status, for example, EuroQol (EQ-5D) (Brookes 1996).

In order to reduce the burden on the respondents, each version of questionnaire included only two of the vignettes. Patients were asked to imagine that they were consulting for the type of problem described in the first vignette, and to make a series of seven choices between scenarios. They were then asked to imagine that they were consulting for the type of problem described in the second vignette and to make another series of seven choices. This meant that each respondent had to make a total of fourteen choices.

In addition to questions on health status, the questionnaire also collected socio-demographic data and information about patients' recent use of primary care, to allow the effects of these factors on preferences to be explored.

### **5.2.3 Pilot study**

A small pilot study was carried out to assess response patterns and patient understanding of the questionnaire, prior to the full study. Postal questionnaires were sent to a random sample of 50 patients from a single Leicestershire practice, with no reminders. The response rate for the postal survey was 24%. Questionnaires were also administered to a convenience sample of 16 patients (including members of the patient advisory group), and short interviews carried out to check patients' understanding of the questionnaire, and to help refine attribute levels, wording of the vignettes, and questionnaire layout. Analysis of the data from this pilot indicated that responses had theoretical validity, in that coefficients had the expected signs and had plausible magnitudes.

### **5.2.4 Econometric model**

The model used follows that used previously to investigate the value individuals place upon out of hours care (Scott *et al*, 2003). Individuals would be faced with a choice between two scenarios relating to a primary care contact. They would have different levels of preference for these two scenarios. They would prefer the option (e.g. scenario A or B) that yielded them the most satisfaction. However, this level of satisfaction is unobserved, all we know is whether a particular respondent chose A or B. The respondent would choose A if the difference between the level of satisfaction between the two scenarios was positive, i.e.  $A-B > 0$ .

We can think of this difference as:

$$= (\alpha + \beta X_i + \gamma C_n + \varepsilon_{in}) - (\alpha + \beta X_j + \gamma C_n + \varepsilon_{jn})$$

Where  $X_i$  and  $X_j$  are the value of the attributes in scenarios A and B,  $C_n$  describes the characteristics of the  $n^{\text{th}}$  person and  $\alpha$  is a constant

## ***Continuity of care: the views of patients and carers***

(intercept term),  $\beta$  is the value of the coefficients, and  $\varepsilon$  is the random error. We also assume that the value placed upon attributes depends upon personal characteristics  $C$  such that:

$$\beta = \theta + \gamma C_n$$

This means that the difference between scenarios becomes

$$(\alpha + \theta X_i + \gamma C_n X_i + \gamma C_n + \varepsilon_{in}) - (\alpha + \theta X_j + \gamma C_n X_j + \gamma C_n + \varepsilon_{jn})$$

For each vignette we obtain seven responses per person, and it cannot be assumed that the consequent errors are independent across these responses as there will be a 'person characteristic' that is influencing the results. We therefore need to include a random effects error term  $\mu$  into this equation. The difference now becomes

$$(\alpha + \theta X_i + \gamma C_n X_i + \gamma C_n + \varepsilon_{in} + \mu_n) - (\alpha + \theta X_j + \gamma C_n X_j + \gamma C_n + \varepsilon_{jn} + \mu_n)$$

And if we take differences for each pairwise choice  $k$  we get the following equation:

$$= \theta X_k + \gamma C_n X_k + \varepsilon_{kn}$$

As can be seen from this equation the terms common to both sides of the minus sign drop out leaving only the attributes of the choice and interaction terms formed by multiplying the attributes by individuals' characteristics. However, the inclusion of the intercept term  $\alpha$  and the random effects error term  $\mu$  can be used to check for misspecification due to unobservable attributes and interaction terms (Scott *et al*, 2003). Models were estimated using a random effects probit in the statistics package STATA 8 (STATA Corporation, Texas). Two types of model were estimated for each vignette. Firstly, we estimated models using only difference terms on the main attributes. We then estimated models using the main attribute difference terms and also interaction terms between attributes and person and practice characteristics. The characteristics used are given in Table 5.1. For each characteristic, four interaction terms were formed, one for each of the difference terms. For this model a large number of variables were included, many of which were not significant ( $p > 0.1$ ). To achieve a more parsimonious model all terms with a significance of greater than  $p = 0.5$  were removed from the model. Subsequently, the least significant variables were removed one at a time with the model re-run each time, this being continued until no variables had a  $p$  value of greater than 0.1. This formed a 'backwards stepwise' regression method.

## ***Continuity of care: the views of patients and carers***

Table 5.1. Variables used to construct interaction terms

<ul style="list-style-type: none"><li>•Dummy variable taking value 1 if respondent is female</li><li>•Respondents age</li><li>•Respondents age squared</li><li>•Dummy variable taking the value 1 if respondent was <u>not</u> white of English/Scottish/Welsh/Irish descent</li><li>•Dummy taking the value 1 if respondent is employed full, part or self employed</li><li>•Dummy taking value 1 if respondent is retired</li><li>•Dummy taking value one if educated beyond minimum school leaving age</li><li>•Dummy variable taking the value 1 if respondent has a degree</li><li>•EQ5D score</li><li>•EQ5D score squared*</li><li>•Dummy taking value one if health was good or better in last 12 months</li><li>•Dummy taking the value 1 if respondent has a long standing illness</li><li>•Dummy taking the value 1 if respondent has a limiting long standing illness</li><li>•Dummy taking the value 1 if the respondent has visited their GP on 3 or more occasions in the last year</li><li>•Dummy taking the value 1 if respondent visited a practice nurse in the last year</li><li>•Dummy taking the value 1 if respondent used NHS direct, NHS direct online, or a Walk in Centre in the last 12 months</li><li>•Dummy taking the value 1 if a respondent used any other services in the last year</li><li>•Dummy taking the value 1 if the respondent was registered in a Leicester based practice</li><li>•Dummy taking the value 1 if the respondents practice had a nurse practitioner</li><li>•Practice IMD deprivation score</li><li>•Practice list size</li></ul>
--

\*As EQ5D can take negative values the EQ5D was constrained to be >0 in order to generate consistent squared terms (3/666 values were affected by this).

### **5.2.4 Interpretation of the models**

All models had a binary dependent variable based on whether individuals chose scenario A (which was the same in each choice set) or the alternative scenario. The dependent variable took the value 1 if individuals chose A and 0 if they did not. The possible values of the

## ***Continuity of care: the views of patients and carers***

attribute difference variables are shown in Table 5.2. The sign of the coefficient on the variables in the model depends upon the way that variable is created, i.e. the value chosen for the levels of the attributes. For example, for seeing either a nurse or a GP we could have defined seeing a GP as 0 and seeing a nurse as 1, or vice versa. This will effect the sign on the coefficient. The way our models were set up meant that a negative coefficient on each of the variables would mean that individuals would prefer to see a GP, they would prefer seeing someone they knew and trusted, they would prefer someone with information about their full medical history, and they would prefer to be seen sooner rather than later.

**Table 5.2. Possible values of attribute levels and value of difference variable**

<b>Attribute for Scenario A</b>	<b>Value</b>	<b>Attribute for alternative scenario</b>	<b>Value</b>	<b>Value of difference variable</b>
You Consult a GP	0	You Consult a GP	0	0
	0	You Consult a nurse	1	-1
Who you do not know	1	Who you know and trust	0	1
	1	Who you do not know	1	0
Who has information about your full medical history	0	Who has information about your full medical history	0	0
	0	Who does not have information about your full medical history	1	-1
You wait 5 days for the consultation*	5 (4)	You are seen on the same day	0	5 (4)
	5 (4)	You wait 2 days for the consultation	2	3 (2)
	5 (4)	You wait 5 days for the consultation	5 (4)	0
	5 (4)	You wait 10 days for the consultation	10 (7)	-5 (-3)

\*Note: the values given in the table are for the new uncertain vignette and the routine check-up vignette. Values in brackets are for the minor acute vignette.

### **5.2.5 Full postal survey**

Patients were recruited from nine practices: six in Leicestershire (code numbers 03, 04, 06, 10, 12, 15) and three in London (code numbers 400, 600, 800; see Chapter Two for details of the practices from which patients were recruited for the SPDCE study).



## ***Continuity of care: the views of patients and carers***

In each practice, an age-stratified random sample of 160 patients was drawn from practice lists, including 40 patients from each of the following age groups: 18-29, 30-54, 55-74, and 75+. The three different vignettes should each cover these four age groups giving twelve groups in total. The sample size required for a SPDCE study is generally recommended to be not less than 50 respondents per group (Permain *et al* 1991) and the target for this study was at least 100 respondents per group. This would require 1200 responses, since each questionnaire gives responses to two vignettes and we required 600 completed questionnaires. Mailing 160 patients in nine practices would generate 1440 mailed questionnaires; giving around 600 returned questionnaires with response rates of over 40%. In view of the relatively complex nature of SPDCE questionnaires, this was felt to be an achievable response rate.

Questionnaires were posted to patients with a covering letter from the practice. This first mailing was followed by up to two reminders. The postal pilot indicated that the response to the questionnaire was likely to be relatively low; in a bid to improve response rates, all patients were invited take part in a prize draw for shopping vouchers by returning a prize draw card along with their completed questionnaire.

It was recognised that some patient groups would have difficulty completing a postal questionnaire. One key group are patients who do not have English as a first language, and preliminary analysis of data indicated that patients from ethnic minority groups were under-represented among responders. In order to ensure inclusion of this group of patients, personal interviewer administration of the questionnaires was arranged in two practices (pr05 and pr15, see Chapter Two for details of practices), with the help of two researchers with Asian language skills from the Department of Health Sciences at the University of Leicester.

## **5.3 Results**

### **5.3.1 Sample details**

We obtained 646 completed questionnaires out of a total valid number of mailed questionnaires of 1375; this gave a response rate of 47%. Response rates for Leicester were 48% (440/914) and 44% (204/461) for London<sup>1</sup>. In addition we obtained 20 responses by face-to-face interview giving a total sample size of 666. In total we had 457 people who answered the minor acute vignette, 431 people who answered the new uncertain vignette, and 444 people who answered the routine check up vignette.

### **5.3.2 Characteristics of the sample**

Descriptive statistics for the available sample are shown in Table 5.3 for the full data set (N=666). The majority of responders were female (61%), and the sample was predominantly white of English/Scottish/Welsh/Irish descent (87%). Seventy-three percent of the sample reported that their health in the last 12 months had been good or better and the mean EQ5D score was 0.81. The majority of responders were users of services in the last 12 months with 83% having seen a GP. Overall NHS Direct had been used by 8% of people. Table 5.3 also gives descriptive statistics for each of the three vignettes. These samples are overlapping as every respondent chose between scenarios for two different vignettes. The values for the three vignettes are generally similar. However, there are some minor differences between groups; for example, the minor acute vignette was answered by more middle-aged individuals in full time work and by fewer individuals aged over 65. The use of services by individuals in the three different vignette groups were similar, with no obvious large differences in usage.

---

<sup>1</sup> This calculation excludes 20 face-to-face interviews carried out in Leicester and two individuals for whom the location of practice was unknown.

## Continuity of care: the views of patients and carers

**Table 5. 3. Comparison of descriptive statistics by vignette**

Variable	Minor acute (N=457)	New Uncertain (N=431)	Check up (N=444)	Full data (N=666)
Sex (percentage female)	62%	60%	60%	61%
<b>Lifestyle typology</b>				
Young working person/student	11%	10%	12%	11%
Parent of young children	7%	6%	6%	7%
Middle age full time work	27%	25%	20%	24%
Carer	8%	8%	7%	8%
Over 65	36%	40%	44%	40%
Middle age/no full time work/no caring responsibility	12%	11%	11%	11%
Age (mean)	57	58	58	58
Is a carer?	30%	33%	32%	32%
<b>Ethnicity</b>				
PREFER NOT TO SAY	1.1%	1%	0%	0.9%
White English/Scottish/Welsh/Irish	87%	87%	86%	87%
White other	4.2%	4.3%	5.7%	4.7%
Indian	4.4%	4%	4.6%	4.3%
Pakistani	0.9%	1%	0.7%	0.8%
Bangladeshi	0.2%	0.2%		0.2%
Black Caribbean	0.2%	1%	0.5%	0.5%
Black African	0.7%	0%	0.5%	0.5%
Chinese	0.22%	0.24%		0.2%
Other	1.1%	1%	1.8%	1.4%
Work (full, part-time, or self employed)	48%	42%	38%	43%
Retired	42%	45%	48%	45%
Main provider?	53%	53%	54%	54%
Education after minimum school leaving age?	54%	53%	53%	53%
Degree?	34%	33%	34%	34%
Home owner	69%	71%	68%	70%
Car?	80%	77%	76%	78%
Health in last 12 months (good or better)	75%	73%	71%	73%
Long term illness in past 12 months	37%	37%	42%	39%
Limiting illness	24%	24%	26%	24%
Average EQ5D score	0.81	0.81	0.80	0.81
Consulted GP in last 12 months	82%	82%	83%	83%
Consulted practice or comm.. nurse in last 12 mo?	35%	39%	36%	36%
Consulted out of hours doctor in last 12 months?	7%	6%	7%	7%
Consulted at A&E in last 12 months	14%	12%	13%	13%
Consulted walk in centre in last 12 months	7%	7%	10%	8%
Consulted NHS direct in last 12 months	8%	8%	8%	8%
Consulted NHS direct online in last 12 months?	1%	1%	1%	1%
Consulted pharmacist in last 12 months?	22%	18%	20%	20%
Other service in last 12 months	16%	18%	17%	17%

### **5.3.3 Regression models using only difference terms**

The results of the models using only the difference terms are given in Tables 5.4-5.6. It is immediately apparent that the signs for all the coefficients on the difference terms are negative and highly significant. This indicates that individuals prefer to see a GP, they prefer to see someone they know, they prefer to see someone who has access to their notes, and they prefer to see someone sooner rather than later. The coefficient on wait is per day, i.e. the longer the wait, the more important this variable becomes.

The second point that is immediately apparent from Tables 5.4-5.6 is that the results differ depending upon the vignette used. To compare values across vignettes we can construct marginal rates of substitution (MRS) between the coefficient for the length of time needed to receive a consultation and the other attribute coefficients, these values are also given in Tables 5.4-5.6. This used a days wait as a common unit of value to quantify the value placed upon the other attributes. The more an attribute is valued then the longer an individual would be prepared to wait to receive a consultation with the desired level of this attribute. For the minor acute vignette an individual would be prepared to wait an extra 0.98 days to see a GP rather than a nurse, an extra 0.9 days to see someone they knew and an extra 1.63 days to see someone with access to their notes (i.e. 3.51 days to see a GP they knew and who had their notes than a nurse they did not know who did not have their notes). For the new uncertain vignette an individual would be prepared to wait an extra 3.54 days to see a GP, an extra 2.38 days to see someone they knew and an extra 3.92 days to see someone with access to their notes (i.e. 9.84 days to see a GP they know and who has access to their records). For the routine check-up an individual would be prepared to wait an extra 3.5 days to see a GP, 4.2 to see someone they knew, and 7.8 days to see someone with access to their notes (i.e. 15.5 days to see a GP they know who has access to their records). This implies that for a simple acute problem individuals are more concerned with access to care than continuity of care. For more complex or worrying problems and for routine check-ups for chronic conditions, individuals are more concerned with issues of continuity and also seeing a GP rather than a nurse. In addition individuals seem to place more weight on informational continuity rather than relationship continuity.

## ***Continuity of care: the views of patients and carers***

**Table 5.4. Results from regression model for minor acute vignette, difference terms only**

<b>Variable</b>	<b>Coefficient</b>	<b>Standard Error</b>	<b>p</b>	<b>MRS</b>
See GP or Nurse	-0.417	0.06	0	0.98
See person you know	-0.386	0.067	0	0.90
See person who has access to your notes	-0.697	0.063	0	1.63
Length of time in days you have to wait for consultation	-0.427	0.015	0	
Constant term	-0.134	0.074	0.071	
Number of respondents = 454, number of observations 3123 ; Log likelihood L = -1344.62				

**Table 5.5. Results from regression model for new uncertain vignette, difference terms only**

<b>Variables</b>	<b>Coefficient</b>	<b>Standard error</b>	<b>p</b>	<b>MRS</b>
See GP or Nurse	-0.812	0.066	0	3.55
See person you know	-0.544	0.063	0	2.38
See person who has access to your notes	-0.899	0.068	0	3.93
Length of time in days you have to wait for consultation	-0.229	0.01	0	
Constant	0.038	0.074	0.606	
Number of respondents = 431, number of observations 3017; Log likelihood L = 1519.68				

**Table 5.6. Results from regression model for routine check-up vignette, difference terms only**

<b>Variable</b>	<b>Coefficient</b>	<b>Standard error</b>	<b>p</b>	<b>MRS</b>
See GP or Nurse	-0.512	0.06	0	3.46
See person you know	-0.618	0.06	0	4.18
See person who has access to your notes	-1.149	0.062	0	7.76
Length of time in days you have to wait for consultation	-0.148	0.009	0	
Constant term	-0.021	0.069	0.766	
Number of respondents = 438, number of observations 3016; Log likelihood L = -1605.31				

### **5.3.4 Regression models using interaction terms with personal and practice characteristics**

The results of the minor acute model are given in Table 5.7. Where the sign on coefficients is negative it indicates that an individual with a particular characteristic values an attribute more, where signs are positive then they would value it less. The further from zero a coefficient is, the more important is that variable in determining preferences. However, care is needed with continuous variables (age, EQ5D, list size, IMD2004 deprivation score) as the value of a coefficient applies to each unit change of a variable. For who you saw, people in Leicestershire had stronger preferences for seeing a GP. People in practices with a nurse practitioner had weaker preferences for seeing a GP compared to a nurse. Age and age squared were both found to influence a person's preference for who they saw, with increasing age respondents generally had a higher preferences for seeing a GP. Relational continuity was found to be important. This attribute was more important for someone who had seen a nurse in the last year but less important for people who had used either NHS Direct or a walk-in centre. The coefficient on informational continuity was significant and highly negative indicating that individuals had a strong preference for someone with access to their notes. This effect increased with increasing deprivation scores. However, informational continuity was less important for female responders and for those who had used either NHS Direct or a walk-in centre in the last year. Access was the attribute with the highest number of significant interaction terms. It was found that having a degree, being in good health or better in the last 12-months, using other services (not GP, nurse, or NHS Direct/walk-in centre), and having a limiting long term illness all increased the value individuals placed on access. Those from a Leicestershire practice, who had used NHS Direct/walk-in centres in the last year, had used a GP three or more times in the last year, had visited a nurse in the last year, were older, or were from practices with higher IMD2004 deprivation scores would all have weaker preferences for access compared to other attributes.

## ***Continuity of care: the views of patients and carers***

**Table 5.7 Full model for minor acute vignette**

<b>Variable</b>	<b>Coefficient</b>	<b>Standard Error</b>	<b>p</b>
Who you see*age	-0.022	0.005	0.000
Who you see*age <sup>2</sup>	0.00014	0.000	0.029
Who you see*practice in Leicestershire	-0.115	0.031	0.000
Who you see*practice with nurse practitioner	0.353	0.108	0.001
See someone you know	-0.490	0.093	0.000
See someone you know*visited a nurse in the last year	-0.187	0.095	0.049
See someone you know*used NHS direct or walk in centre in the last year	0.299	0.155	0.054
See someone who has access to your notes	-0.763	0.119	0.000
See some who has access to your notes*used NHS direct or walk in centre in the last year	0.404	0.174	0.021
See someone who has access to your notes*IMD deprivation score	-0.012	0.004	0.002
See someone who has access to your notes*Female	0.191	0.101	0.057
How long you have to wait for a consultation	-0.389	0.060	0.000
How long you have to wait*age <sup>2</sup>	0.00002	0.000	0.009
How long you have to wait and has a degree	-0.245	0.033	0.000
How long you have to wait*good health or better in last 12 months	-0.133	0.035	0.000
How long you have to wait*has limiting long term illness	-0.092	0.041	0.025
How long you have to wait*used GP 3 or more times in last year	0.081	0.028	0.004
How long you have to wait*visited a nurse in the last year	0.066	0.028	0.019
How long you have to wait*used NHS direct or walk in centre in the last year	0.084	0.041	0.037
How long you have to wait*used any other services in last year	-0.107	0.029	0.000
How long you have to wait*practice in Leicestershire	0.305	0.107	0.004
How long you have to wait*IMD deprivation score	0.004	0.001	0.000
Constant	-0.107	0.084	0.200
Number of respondents = 402, number of observations 2766, Log likelihood L = -1054.86			

## ***Continuity of care: the views of patients and carers***

The model relating to the new uncertain vignette is given in Table 5.8. Women responders had weaker preferences for seeing a GP compared to a nurse, as did individuals who had seen a nurse in the last 12 months and those who were in Leicestershire practices. However, those who had higher EQ5D scores (better health) would have a stronger preference for seeing a GP, as would those with a long-term illness. The coefficient for the relational continuity attribute had a large negative value, indicating a strong preference for seeing someone who the respondent knew. If someone had seen a GP three or more times or had good health they would have weaker preferences for relational continuity. The coefficient on seeing someone with access to your notes was also strongly negative showing the importance of informational continuity. Again, individuals in good health or better in the last 12 months and those who had seen a GP three times or more had weaker preferences for informational continuity. For both forms of continuity frequent users of GPs and those in good health or better had weaker preferences for these factors and hence would value other aspects of the consultation relatively more. The difference term on access (how long you would have to wait for a consultation) was significant and negative indicating that individuals had a preference for shorter waiting times compared to longer ones. Those who were employed, and to a lesser extent those who were retired, had stronger preferences for reduced waiting times. This effect was also seen in those individuals who belonged to practices that had a nurse practitioner. There was also an increased preference for shorter waiting times in older individuals. Female respondents had lower preferences for short waiting times as indicated by a positive coefficient.



## ***Continuity of care: the views of patients and carers***

**Table 5.8. Full model with interaction terms – new uncertain vignette**

<b>Variable</b>	<b>Coefficient</b>	<b>Standard Error</b>	<b>p</b>
Who you see*female	0.183	0.109	0.094
Who you see*EQ5D	-0.814	0.158	0
Who you see*long term illness	-0.286	0.115	0.013
Who you see*used a practice nurse in last 12 months	0.266	0.108	0.013
Who you see*Leicester	0.288	0.106	0.007
See someone you know	-0.972	0.151	0.000
See someone you know*good or better health in last 12 months	0.314	0.132	0.017
See someone you know*used a GP 3 or more times in last year	0.292	0.108	0.007
See someone who has access to your notes	-1.409	0.161	0.000
See someone who has access to your notes*good or better health in last 12 months	0.463	0.14	0.001
See someone who has access to your notes*used a GP 3 or more times in last year	0.192	0.115	0.095
How long you have to wait for a consultation	-0.167	0.029	0.000
How long you have to wait*female	0.042	0.019	0.027
How long you have to wait*age	-0.008	0.002	0
How long you have to wait*employed full, part time or self-employed	-0.115	0.026	0
How long you have to wait*retired	-0.068	0.026	0.008
How long you have to wait*practice has nurse practitioner	-0.056	0.017	0.001
Constant	0.047	0.084	0.577
Number of respondents = 352, number of observations 2443, Log likelihood L = -1169.13			

The model for the routine check up vignette is given in Table 5.9. As can be seen, those who are non white (i.e. those not white English, Scottish, Welsh, Irish), people who are retired, those who have degrees, and frequent users of GP services would have stronger preferences for seeing a GP rather than a nurse. Individuals who have seen a nurse in the last year are not so concerned with seeing a GP. For relational continuity the coefficient for the difference term was significant and very strongly negative. However, individuals who were employed (full, part or self) had weaker preferences for relational continuity, as did individuals in practices with larger list sizes. For informational continuity the coefficient was again strongly negative, indicating strong preferences for this attribute. This would be

## ***Continuity of care: the views of patients and carers***

increased in those who had a degree. Preferences for informational continuity would be weakened for those who have seen other health care professionals (not GP, nurse, NHS Direct/walk-in centre), and someone who was not white (English, Scottish, Welsh, Irish). Individuals preferred shorter waits to longer ones. This effect would be increased in those with good health or better in the last month, in practices with a nurse practitioner and also practices in Leicestershire, if the individual had a limiting long standing illness, if the individual had seen any other health care professionals (not GP, nurse, NHS Direct/walk-in centre) in the last 12 months, or had used a GP three times or more in the last year. Individuals had weaker preferences for shorter waiting times if they had education post minimum school leaving age or if they were in practices with larger list sizes.

**Table 5.9. Full model with interaction terms – routine check-up vignette**

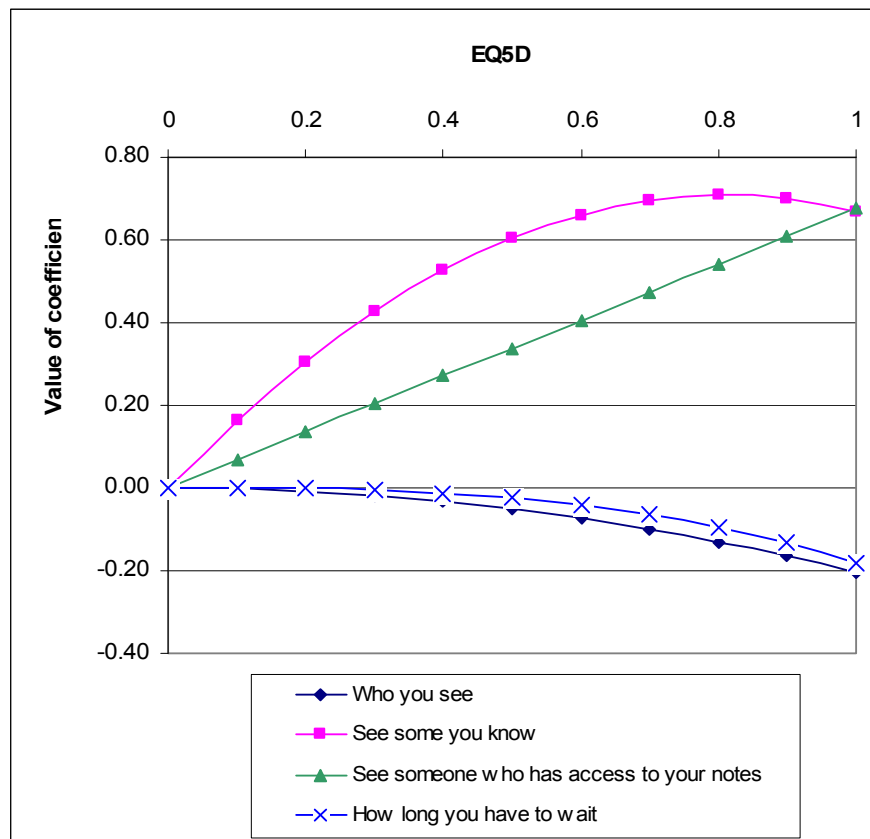
<b>Variable</b>	<b>Coefficient</b>	<b>Standard</b>	<b>p</b>
Who you see*ethnicity	-0.374	0.149	0.012
Who you see times*are retired	-0.321	0.098	0.001
Who you see*has degree	-0.280	0.107	0.009
Who you see*EQ5D2	-0.203	0.112	0.071
Who you see*use GP 3 or more times in last year	-0.241	0.101	0.016
Who you see*seen nurse in last year	0.220	0.103	0.033
See someone you know	-1.818	0.354	0.000
See someone you know*employed full part or self	0.176	0.098	0.071
See someone you know*EQ5D	1.743	0.830	0.036
See someone you know*EQ5D2	-1.075	0.606	0.076
See someone you know*list size	0.00004	0.000	0.001
See someone who has access to your notes	-1.839	0.285	0.000
See someone who has access to your notes*ethnicity	0.360	0.146	0.014
See someone who has access to your notes* has degree	-0.185	0.107	0.083
See someone who has access to your notes*EQ5d	0.677	0.320	0.035
See someone who has access to your notes*seen other health care	0.177	0.105	0.091
How long you have to wait for a consultation	-0.305	0.069	0.000
How long you have to wait*education post minimum age	0.034	0.017	0.048
How long you have to wait*EQ5D	0.513	0.156	0.001
How long you have to wait*EQ5D2	-0.355	0.113	0.002
How long you have to wait*good or better health in last 12 months	-0.060	0.023	0.008
How long you have to wait*limiting long standing illness	-0.049	0.024	0.043
How long you have to wait*use GP 3 or more times in last year	-0.029	0.018	0.095
How long you have to wait*seen other health care professionals in last year	-0.033	0.018	0.066
How long you have to wait*Leicestershire	-0.048	0.019	0.010
How long you have to wait*practice has nurse practitioner	-0.057	0.028	0.043
How long you have to wait*list size	0.00001	0.000	0.010
Constant	-0.001	0.077	0.991

Number of respondents = 354, number of observations 2437, Log likelihood L = -1243.30

## Continuity of care: the views of patients and carers

For the routine check-up vignette the EQ5D score seemed to be important in determining preferences with 6 out of the possible 8 variables being significant and hence included in the final model. This relationship is plotted in Figure 5.1. From this it can be seen that those who are healthy place less value on both relational and informational continuity and also value waiting time more. The more healthy individuals also have a small increased preference for seeing a GP rather than a nurse.

**Figure 5.1. Effect of health (EQ5D) on respondent preferences**



### **5.4 Discussion**

#### **5.4.1 Key findings**

A number of conclusions can be drawn from the SPDCE. Firstly, patients appeared to be willing to make tradeoffs between access (i.e. time needed to receive an appointment), and other aspects of the primary care consultation. This indicates that patients are aware of the clash between access and continuity of care and that they would be potentially prepared to wait longer for a consultation in order to receive increased continuity. The models also suggest that individuals in general would prefer to see a GP rather than a nurse. Secondly, the reason for the consultation is important in determining the amount of delay in access that individuals would be prepared to trade for increase continuity. This indicates that individuals have views on when they need continuity, i.e. for more serious or impactful conditions or where there are higher degrees of uncertainty surrounding the seriousness of the condition. Individuals also seem prepared to trade-off longer delays in consultation for routine check-ups for chronic conditions. Thirdly, these results indicate that individuals place high value on informational continuity. This may be because they would expect it and hence may be reluctant to accept scenarios where informational continuity was absent. Fourthly, individuals in poorer health are likely to value continuity more (for the new uncertain and minor acute vignettes).

For models using variables on the main attributes only, we found that all attribute terms were highly statistically significant and in the expected direction. This suggests the models had theoretical validity. When we constructed models that also included interaction terms, we found that individual and practice characteristics clearly had effects on the preferences of individuals for continuity of care and also whether individuals saw a GP or nurse. The findings, therefore, are broadly consistent with the model of continuity.

#### **5.4.2 Implications**

The results suggest that any policy changes likely to affect elements of continuity should take account of both the reasons for which different groups of people are consulting and the characteristics of these groups. Furthermore, we need to consider the ways that individuals may have made choices. Individuals seemed to give more weight to informational continuity as opposed to relational continuity. However, there are likely to be links between these variables since a familiar health professional will almost certainly have access to information even if they don't have the notes to hand. Therefore, it is possible that the best way of ensuring informational continuity may also be to ensure relational continuity. Certainly the results do not provide sufficient evidence to conclude that informational continuity can

## ***Continuity of care: the views of patients and carers***

substitute for relational continuity for most groups of patients. The findings of the SPDCE are, therefore, consistent with and serve to elaborate upon the findings of the qualitative studies. We consider the implications of all the component studies for policymakers, practices, health professionals and researchers in Chapter Seven of this report. The findings of the SPDCE tend to support our initial model of continuity in primary care (see Chapter Two), and highlight in particular that different people have different preferences, depending both on their personal characteristics and the services available to them.

### **5.4.3 Methodological issues**

A number of issues should be considered when evaluating this work. Clearly, our results indicate that the precise wording of the vignettes is very important. If the vignettes we used are broadly transferable to different types of primary care visits then so are our results. Equally, there could be important reasons for consulting that have not been covered by this work and this may limit generalisability. Also important in this work would be the decision on which attributes to include and the level of the attributes that are considered. We believe it is a strength of the present research that a group of studies employing different methods were used to address a common aim. For the SPDCE, this enabled us to draw on the results of a detailed qualitative study in framing our questionnaire. This maximised the likelihood of using appropriate attributes in the questionnaires.

Recognition of the nature of preferences is important for interpretation and use of the results of this type of study. In particular, the existence of lexicographic preferences will have implications for the strength of coefficients and policy implications arising from the work. For example, for the minor acute care vignette, some individuals may make choices that include picking the scenario that generates the shortest waiting period in each case. Our results indicate that individuals in the minor acute models would be prepared to wait for short additional periods in order to have increased continuity. But many individuals may not be prepared to trade-off any additional wait for increased continuity. The estimates of how much time individuals would wait for increased continuity would therefore be overestimated for all individuals with a strong preference for the shortest possible wait and underestimated for the rest of the respondents. However, this problem may be ameliorated by using models that include interaction terms; if groups with these lexicographic preferences tend to share characteristics (e.g. age, gender, employment status).

Overall, we achieved response rates of 47%. However, the response rate was not uniform across age groups and gender. This meant that our sample was under-representative of certain groups, particularly young responders and males. This may have influenced the results of the modelling as characteristics that were more relevant to younger responders may have been omitted from the model due to insufficient

## ***Continuity of care: the views of patients and carers***

statistical significance. Care needs to be taken in considering this factor when interpreting and applying the results.

In some SPDCE studies the researchers identify 'dominated' choices, i.e. those for which logical respondents would be expected to always choose one option over the other. Any respondents who give an inconsistent response to these questions are then removed from the analysis. This was not done in the present study. The findings of the qualitative study indicated that in some circumstances individuals' preferences could be unexpected but entirely explicable. For example, there may be individuals who would prefer to see a nurse rather than a GP, the underlying reason for their choice being entirely logical, and hence it would not be appropriate to exclude this individual's responses. Indeed, the variation in preferences between patient groups is an important finding of the study – a uniform policy on access and continuity in primary care would inevitably lead to failure to meet the preferences of some groups of patients.

Finally, we have not tied our results into the practicalities of providing primary care. Showing that relational and informational continuity are important is useful. This needs to be allied to strategies for changing the provision of primary care and available resources. For example, people may generally prefer to see a GP but there may not be enough GPs to meet this preference. Our results suggest many people are willing to 'trade-off' one attribute for another and hence may see a nurse if it involves more continuity or a shorter wait. Any implications of these results and potential policy changes would also need to take account of the costs of changing services. If two changes in the characteristics of primary care would be equally valued by certain groups of patients, and one would be less costly to implement, then that change would be the preferred one for these patients.

### **5.5 Conclusions**

The SPDCE study has shown how different patients place different values on attributes of primary care, and identified personal and health care system factors that influence these values. Patients do make trade-offs between attributes, but informational and relational continuity are important to many patients. These findings lend support to our model of continuity and point to the need to investigate the factors (personal, context, health care system) that influences peoples' preferences. These issues are investigated in the cross sectional survey.

## Chapter 6 The cross sectional survey

### **6.1 Introduction**

The qualitative and longitudinal components of the study have investigated aspects of continuity that are important to individuals, and the SPDCE component has addressed the trade-offs people are willing to make between aspects of continuity and other features of primary care. In this Chapter we report a cross sectional survey undertaken to identify the groups of patients for whom the different aspects of continuity are more or less important.

Very many surveys of patients' views of the care they have received have been undertaken in recent years. In the UK the new contract for GPs (NHS Confederation and BMA, 2003) includes a financial incentive to practices to undertake a patient survey each year; in addition a national programme of annual surveys of population samples to investigate views on primary health care has been introduced. The 2004 national primary care survey conducted by Picker Institute Europe at the request of the Healthcare Commission involved 850 patients aged over 16 in each PCT in England (Healthcare Commission, 2004). A total of 122,113 people responded, 49% of all those sent questionnaires. Although the questionnaire did not include any questions that specifically addressed aspects of continuity, 41% of those who reported having to wait longer than a day for an appointment said the main reason was that they wanted to see their choice of doctor.

Numerous studies of patient satisfaction with aspects of primary care have been undertaken, and the findings consistently indicate an association between being able to consult the same professional and satisfaction (Baker and Whitfield, 1992). In a substantial recent review of studies of patient satisfaction with health care, the factor that most consistently influenced satisfaction was the relationship with the provider, including information giving (Crow *et al*, 2002). However, information on factors that promote satisfaction does not adequately address the question on which aspects of care should take priority. This requires evidence about patients' preferences for different aspects of care, but fewer studies of patients' preferences have been undertaken. Nevertheless, in a systematic analysis of studies of patients' preferences with respect to primary care, Jung *et al* (2003) were able to identify 145 studies undertaken using either questionnaires or interviews of samples of patients attending a variety of services. The characteristics of patients were found to influence their preferences, younger patients generally placing greater emphasis on direct access to specialist care, quick referral and aggressive treatment than older patients. Older patients placed a greater emphasis on continuity, GP as opposed to specialist care, and having

## ***Continuity of care: the views of patients and carers***

the same doctor for all symptoms. Lower educated patients also placed greater emphasis on continuity. Patients with lower utilisation of services appeared to value self-referral whereas those with higher utilisation of services placed greater weight on continuity. Schers *et al* (2002) undertook a survey of 644 patients in the Netherlands on their views about continuity in primary care. They found that preferences for continuity varied according to the perceived seriousness of the health problem, although patient characteristics explained very little of the differences in views between patients.

However, despite the number of surveys undertaken in recent years, we have been unable to find a study based on a model that takes account of the different elements of continuity and investigates not only peoples' preferences or views but also the choices they make between different aspects of care, and the factors that influence those choices. The aims of the cross sectional survey reported here were:

1. to identify the context and circumstances in which various types of continuity of care are given greater or lesser weight in relation to other valued aspects of primary care (e.g. access, specialist knowledge, gender of provider, language of provider, trust in provider) and how this influences the way patients use the range of primary care services available to them
2. to determine the proportions of people in different groups who hold particular views about the importance of continuity.

## **6.2 Methods**

### **6.2.1 The survey questionnaire**

A questionnaire was designed taking account of the findings of the qualitative study and the provisional model. The first version of the questionnaire consisted of 15 pages, and since the response rate to this questionnaire proved to be relatively low, the layout was revised and a number of questions removed. The second version was four pages long, all the questions in this version having been included in the first version. All analyses are based on the questions included in the second (and therefore also the first, version of the questionnaire). Both versions are included in the Appendices, but the short version is described here.

Most questions were focused on the respondent's most recent consultation with a primary health care service. We wished to obtain information about what people actually did rather than merely about their general preferences in order to be able to investigate the choices they made in different circumstances. The majority of questions offered closed response options, and covered the following topics.



## ***Continuity of care: the views of patients and carers***

### ***(a) Background information***

We included questions on age, sex, ethnic group (using the categories of the 2001 Census), employment and educational level. Further questions asked respondents whether they needed someone to translate or interpret when they attended for health care, whether they were a carer or received help from a carer, who they lived with, whether they lived in owned or rented accommodation, and whether they had access to a car. We also included standard questions (Blaxter, 1990; Blaxter *et al*, 2001) to assess social support and social integration, one of which asks whether the respondent feels part of the area they live in and the other that asks whether they have seen or contacted friends or family in the last two weeks.

### ***(b) Use of primary health care services***

Questions sought information about: the length of time the respondent had been registered with their current practice, the services they had used in the past year (GP, nurse, out of hours, accident and emergency department, NHS walk-in centre, NHS Direct, NHS Direct Online, pharmacist for advice, or other services), who their most recent consultation had been for (self or someone else), which service had been consulted on that occasion, and the reason for that consultation (a new or recent problem, a long term condition, psychological or emotional problem, health promotion or prevention, or a problem not directly to do with health).

### ***(c) Health status***

To assess respondents' level of health, the questionnaire included a question on self-reported health in the past 12 months (five response options, excellent to poor), and another on presence of long-term illness or disability. We also included EQ5D, a standardised instrument for the measurement of health outcomes (EuroQuol Group, 2004). It provides a single index value for health status, and consists of five questions, each with a three-choice option response. The mean score for UK populations ranges from 0.94 among males and females aged 20-29 to 0.74 (males) and 0.69 (females) at aged 80 and over (a lower score indicating less good health).

### ***(d) Important aspects of primary health care***

Respondents were asked to indicate the degree of importance they attached to different aspects of primary health care with respect to their last consultation. The aspects concerned were:

- *access* - being able to make an appointment in advance,
- *professional expertise* - choosing a particular type of professional (for example, a nurse or a doctor),
- *relational continuity* - choosing a particular person, consulting someone known and trusted
- *length of consultation* - consulting someone with time to listen

## ***Continuity of care: the views of patients and carers***

- *informational continuity* – consulting someone with information about the patient's medical history in notes or a computer
- *longitudinal continuity* – consulting someone who personally knows the patient and the medical condition
- *gender* – consulting someone of the same sex
- *ethnic group* – consulting someone of the same ethnic group or culture.

For each of these questions, the respondent was asked to indicate their importance using a four-point option format, extremely important to not important. In addition, for each question the respondent was asked whether at their consultation they had received that aspect of care, with a yes / no response option. The questionnaire also included a question asking respondents when they wanted their consultation, and when the consultation actually took place.

### **6.2.2 Administration procedure**

Practices were asked to draw a random sample of 50 - 250 patients aged 18-80 according to practice size, randomisation being undertaken by requesting the practices' computer systems to generate a random list. The questionnaires were posted to patients together with a covering letter signed by a doctor at the practice, plus a reply paid envelope for return to the research teams either in Leicester or London. An acknowledgement letter or reminder was posted two weeks later, a second reminder being sent after a further two weeks if necessary. Practices also retained a paper copy of the list of patients including sex and age or year of birth.

We assumed that age group would be a key factor in explaining views and choices on continuity of care, and therefore aimed to obtain age-stratified samples from each practice using age groups of: 18-29, 30-54, 55-74, 75/+ years. Sample size was calculated to ensure that, within each age group, 95% confidence intervals for the proportion of respondents giving a particular response to a closed question would have a maximum width of 10% (+/- 5%). This required 400 respondents from each age stratum, and allowing for a 60% response rate gave a total sample size of 3335.

### **6.2.3 The practice and localities**

Information about the practices taking part in the study and the localities in which they were situated is presented in Chapter Two. In the cross sectional survey, nine London practices and 13 Leicestershire practices took part, plus the walk-in centre in Loughborough (Table 6.1).

## ***Continuity of care: the views of patients and carers***

**Table 6.1. Practices included in the cross sectional survey**

<b>Practice code</b>	<b>Leicester (1) or London (2)</b>	<b>Practice list size</b>	<b>Training or non-training</b>	<b>IMD 2004</b>
800	2	1500	Yes	4.35
400	2	3770	No	4.35
700	2	3200	No	23.29
500	2	5500	Yes	20.03
300	2	6500	No	14.11
900	2	8000	No	15.50
100	2	7000	Yes	38.94
600	2	7500	Yes	32.84
200	2	7300	No	33.28
3	1	9850	Yes	18.92
4	1	5400	No	4.79
6	1	13000	Yes	8.16
10	1	9800	Yes	44.78
12	1	13000	Yes	30.32
15	1	1300	Yes	29.98
1	1	9800	Yes	56.55
2	1	10353	Yes	21.55
5	1	1764	No	15.60
8	1	4000	Yes	23.63
13	1	1800	No	5.87
16	1	33000	Yes	19.96
Walk-in	1	-	-	44.78

We used the IMD2004 score for the locality of the practice as the indicator of deprivation (Office of the Deputy Prime Minister, 2003). IMD2004 uses a model of multiple deprivation in which a range of indicators is combined to produce a score. The scores relate to localities defined as 'lower layer super output areas' which include around 1,500 people. A total of 37 indicators are incorporated into IMD2004, most relating to 2001, including the 2001 Census. The domains covered are: income deprivation, employment deprivation, health deprivation and disability, education skills and training deprivation, barriers to housing and services, living environment deprivation and crime. A high score indicates greater deprivation. The mean IMD score for all lower layer super output areas in England is 21.67, range 0.59-86.36. The median is 17.02, the 25<sup>th</sup> centile being 9.62 and the 75<sup>th</sup> centile 30.02. The 10<sup>th</sup> centile is 5.74, and the 90<sup>th</sup> 45.23 (the 95<sup>th</sup> centile is 53.90).

## ***Continuity of care: the views of patients and carers***

### **6.2.4 Analyses**

The initial step in the analysis was the calculation of descriptive statistics, using SPSS v 10. From this initial analysis, we selected those variables that appeared to explain differences between respondents in whether they received aspects of primary care that they regarded as important. These potential explanatory variables were initially included in multinomial multi-level regression models using Mlwin (Rasbash *et al*, 2004), but this approach was replaced by single level multinomial logistic regression using SAS v 8.2 (Stokes *et al*, 2000).

## **6.3 Results**

### **6.3.1 The respondents**

Questionnaires were sent to a total of 3091 people, and 1437 were returned completed, a total response of 46.5%. The response rate was discussed with the SDO. Since the total number of responses was close to the target number and adequate numbers were included in each life stage category, it was agreed to complete the analysis rather than repeat the survey.

574 (40.1%) respondents were male and 837 (58.5%) female (20, 1.4%, did not indicate their sex). Of those sent questionnaires, 48.5% were male and 51.5% female, the response rate from males being lower than females. Response rates were below 30% in the 18-29 year age group, but above 50% in the other age groups. The mean age of respondents was 53 (SD 18.7) years, the youngest respondent being 18 years of age and the oldest 93 (Table 6.2). The numbers of respondents in each life stage category are shown in Table 6.3.

---

**Table 6.2. Numbers (%) of respondents in different age groups**

---

<b>Age</b>	<b>sex</b>		<b>Total</b>
	<b>male</b>	<b>female</b>	
18-29	46 (28.6)	115 (71.4)	161
30-54	191 (36.7)	329 (63.3)	520
55-74	180 (42.0)	249 (58.0)	429
75 and above	128 (51.4)	121 (48.6)	249

---

## Continuity of care: the views of patients and carers

**Table 6.3. Numbers of respondents according to life-stage categories**

	Sex		Total
	male	female	
Selected	46 (32.6)	95 (67.4)	141
2	10 (9.3)	97 (90.7)	107
3	209 (53.7)	180 (46.3)	389
4	22 (24.2)	69 (75.8)	91
5	218 (47.3)	243 (52.7)	461
6	50 (30.7)	113 (69.3)	163
	555	797	1352

**Table 6.4. Numbers (%) of respondents and years registered with current GP**

0-12 months	1-5 years	5-10 years	More than 10 years	Not sure	total
72 (5.1)	215 (15.2)	213 (15.1)	894 (63.2)	20 (1.4)	1414

Table 6.4 shows the period respondents had been registered with their current GP. The median number of consultations in the past year was 3.0, range 25<sup>th</sup> centile 2.0 and 75<sup>th</sup> centile 6.0. The most commonly consulted health professional was the GP (Table 6.5), the next most common being a nurse.

**Table 6.5. Numbers (%) of respondents consulting different providers in the previous 12 months. The %s add up to more than 100% since many respondents consulted more than one type of provider**

GP	Nurse	Out of hours service	Accident & emergency	Walk-in centre	NHS Direct	Pharmacist
1266 (88.5)	660 (46.1)	108 (7.5)	240 (16.8)	157 (11.0)	207 (14.5)	327 (22.9)

## ***Continuity of care: the views of patients and carers***

1218 (87.9%) respondents reported that their last consultation was for themselves, 168 (12.1%) reported consulting for someone else. For 1252 (89.0%), the most recent consultation was with a general practitioner, for 33 (2.3%) it was a phone call with a general practitioner, 37 (2.6%) a home visit by a general practitioner or nurse, 64 (4.5%) attendance at a walk-in centre, 2 (0.1%) a call to NHS Direct, and 19 (1.4%) another service. The reasons given for the most recent consultation are shown in Table 6.6.

**Table 6.6. Reason for the most recent consultation.**

	<b>%</b>	
new problem	504	39.7
routine check for long term problem	415	32.7
non-routine, long term problem	69	5.4
psychological problem	16	1.3
health promotion	36	2.8
non-health problem	4	.3
something else	69	5.4
new problem plus another problem	118	9.3
long term problem plus another (not new)	40	3.1
Total	1271	100.0

When asked whether they would choose to see the same person again, 1090 (78.4%) would, 151 (10.9%) said that the person they had seen would not be their first choice, 25 (1.8%) said they would prefer not to consult that person again, and 124 (8.9%) said that the question did not apply. When asked whether they had been given the help, treatment or advice they needed, 1167 (83.8%) reported that they had been, 199 (14.3) to some extent only, and 27 (1.9%) that they had not. Most were satisfied with their consultation (Table 6.7), although 10.6% were either neither dissatisfied or satisfied, or not satisfied.

**Table 6.7. Responses to the question: Overall, were you satisfied with how things went?**

	<b>n</b>	<b>%</b>
very satisfied	861	61.7
quite satisfied	387	27.7
neither satisfied nor dissatisfied	111	8.0
quite dissatisfied	23	1.6
very dissatisfied	14	1.0
Total	1396	100.0

## ***Continuity of care: the views of patients and carers***

The mean EQ5D score was 0.818 (standard deviation 0.244). 28.6% reported that their health had been fair or poor over the past 12 months, and those in these categories had a lower EQ5D score and were more likely to report having a long-term illness, health problem or disability (Table 6.8). 598 (43.4%) reported having a long-term illness, health problem or disability, of whom 344 (57.5%) reported that their condition imposed some limitations on their work or activities.

**Table 6.8. Responses to the question: Over the past 12 months, how would you say your health has been?**

	<b>n</b>	<b>%</b>	<b>Mean EQ5D score</b>	<b>% with a long term condition</b>
Excellent	187	13.3	0.975	11.9
Very good	387	27.5	0.926	21.8
Good	432	30.7	0.848	42.8
Fair	309	21.9	0.652	74.9
Poor	94	6.7	0.422	94.6
Total	1409	100.0		

319 (22.6%) lived alone. 878 (61.1%) lived with a partner or husband or wife, 131 (9.6%) with children aged 0-4 years, 138 (9.1%) with children 5-10 years old, and 202 (14.1%) with young people 11-18 years. 106 (7.4%) lived with parents, parents in law or step parents, and 122 (8.5%) lived with other family or friends. 24 (1.7%) needed someone to translate or interpret when they attend their GP practice. 340 (24.7%) had a role as a carer, either of a family member, friend or neighbour, and 231 (17.3%) received help from a family member, friend or neighbour because of ill health or disability.

Although the majority of respondents were white English, Scottish or Welsh, 4.1% were South Asian, 1.6% Afro-Caribbean, 8.0% other white groups, and 4.3% other ethnic groups (Table 6.9). 49.2% were in employment (Table 6.10).

## ***Continuity of care: the views of patients and carers***

**Table 6.9. Ethnic group of respondents**

	<b>n</b>	<b>%</b>
white English, Scottish,	1131	82.0
white other	110	8.0
Indian	46	3.3
Pakistani	5	.4
Bangladeshi	5	.4
Black Caribbean	13	.9
Black African	10	.7
Chinese	12	.9
other	47	3.4
Total	1380	100.0

**Table 6.10. Current work status**

	<b>n</b>	<b>%</b>
full time	424	29.8
part time	160	11.2
self employed	116	8.2
unemployed	36	2.5
retired	483	33.9
unable work due to ill	73	5.1
home/family	73	5.1
student	35	2.5
other	23	1.6
Total	1423	100.0

730 (54.4%) were the main provider in the household. 782 (57.2%) had continued in education after the minimum age, and 533 (37.1%) had a degree or equivalent professional qualification.

**Table 6.11. Respondents' housing**

	<b>n</b>	<b>%</b>
self owned	933	67.1
private rent	93	6.7
HA rent	86	6.2
council rent	170	12.2
residential	17	1.2
other	91	6.5
Total	1390	100.0



## ***Continuity of care: the views of patients and carers***

The housing of respondents is outlined in Table 6.11. 1068 (78.0%) people lived in households with a car. 20.2% either were uncertain or did not feel part of the area they lived in (Table 6.12), and 25.2% had seen or been in touch with family or friends on two or fewer occasions in the previous two weeks (Table 6.13).

---

**Table 6.12. Responses to the question: How much do you agree that you feel part of the area you live in?**

	<b>n</b>	<b>%</b>
strongly agree	287	20.6
agree	823	59.1
uncertain	199	14.3
disagree	59	4.2
strongly	24	1.7
Total	1392	100.0

---

**Table 6.13. Responses to the question: How often in the last 2 weeks have you seen friends or family members you do not live with, or contacted them by phone, letter, email?**

	<b>n</b>	<b>%</b>
not at all	36	2.5
1 or 2	323	22.7
3-6	416	29.2
>6	649	45.6
Total	1424	100.0

## ***Continuity of care: the views of patients and carers***

### **6.3.2 The practices**

Nine practices were in London and 12 plus a walk-in centre in Leicestershire. The mean list size of the practices was 10,488, SD 7508, range 1764-33000. 13 practices were training and 11 reported having a personal list system. The mean number of full-time partners per practice was 5.6 (SD 4.1, range 1-18), part-time partners 1.5 (SD 1.2, range 0-4), and other non-partner general practitioners mean 1.8 (SD 1.6, range 0-5). One practice had an open appointment system, 12 a mix of same day and advanced booked appointments, 4 advanced access with some pre-booking, and three same day appointments only. The mean percentage of appointments with nurses was 25.8% (SD 11.2%, range 10-40%). Two practices rated the value of personal continuity as 2, nine as 3, seven as 4 and three as 5, on a scale of 1 (not important at all) to 5 (extremely important). Practices' responses to the culture questions are shown in Table 6.14.

**Table 6.14. Practices' attitudes towards aspects of continuity**

	<b>1 (not important)</b>	<b>2</b>	<b>3</b>	<b>4 (good)</b>
Information continuity	2	3	6	10
Sharing information within the practice team	0	2	9	10
Professionals' sense of belonging to a group	2	2	7	9
Cohesive practice style	1	4	7	8

Four practices were in localities with no other local services, 9 with some local services and 8 and the walk-in centre in areas with many alternative local services. Five practices described themselves as being inner-city, 13 and the walk-in centre as urban, and three as rural.

### **6.2.3 Aspects of continuity and patients' choices**

The questionnaire included one question asking when patients wanted to consult someone and when they did actually consult, and nine questions about their preferences for aspects of continuity or other features of care and whether their preferences were met. Between 53.7% and 82.4% of respondents had their preferences for the day of the consultation met (Table 6.15). Patients' preferences were most likely to be met if they wanted to consult on the same day, or if they preferred to wait for more than 10 days. Patients who wanted to be

## ***Continuity of care: the views of patients and carers***

seen within a few days, although not the same day, were more likely to find that their preferences could not be met. However, failure to meet patients' preferences does not always indicate that the patient had to wait longer than preferred for the consultation, for example among those who wished to have a consultation in four days time, more were seen within four days than were seen in more than four days.

**Table 6.15. Preferences for day of consultation and whether the preference was met**

<b>When the consultation was wanted</b>	<b>When the consultation actually occurred</b>						<b>Total</b>
	same day	2 days	4 days	week	10 days	>10 days	
same day	472 (82.4)	63 (11.0)	23 (4.0)	10 (1.7)	5 (0.9)		573
2 days	32 (8.7)	262 (71.0)	39 (10.6)	22 (6.0)	8 (2.2)	6 (1.6)	369
4 days	10 (9.3)	19 (17.6)	58 (53.7)	15 (13.9)	3 (2.8)	3 (2.8)	108
1week	6 (3.5)	18 (10.4)	25 (14.5)	108 (62.4)	9 (5.2)	7 (4.0)	173
10 days	2 (5.0)	2 (5.0)	3 (7.5)	4 (10.0)	24 (60.0)	5 (12.5)	40
>10 days	2 (7.7)			1 (3.8)	3 (11.5)	20 (76.9)	26
	524 (40.7)	364 (28.2)	148 (11.5)	160 (12.4)	52 (4.0)	41 (3.2)	1289

The questions about preferences for aspects of continuity or other features of care had two elements, the first asking the respondent how important they regarded that feature of care (categorised as extremely important, important, slightly important or not important), and the second whether their preference had been met (categorised as yes or no). For analysis, the categories for importance were collapsed into two groups (extremely important and important, and slightly important and not important), and combined with the second element to produce three categories of response: (a) the aspect of care was not important; (b) the aspect of care was important and was experienced; (c) the aspect of care was important but was not experienced. The findings are shown in Table 6.16. The large majority of patients did not regard seeing a professional of the same sex or ethnic group as important. In contrast, large majorities regarded seeing someone with time to listen and someone with information on their history (informational continuity) as important. Around two thirds of respondents regarded seeing a particular person or seeing someone they knew and trusted (relational continuity) as important, and around three quarters regarded being able to book in advance (access),

## ***Continuity of care: the views of patients and carers***

choosing the type of professional (professional expertise), or someone who knows them personally (longitudinal continuity) as important. Most patients tended to experience the aspects of care they regarded as important, although more than 10% did not experience either booking in advance, seeing a particular person, seeing someone they know personally or someone with information on their history despite regarding these aspects of care as important.

**Table 6.16. Importance attached to features of care and whether these features were experienced.**

	<b>Not important</b>	<b>Important and experienced</b>	<b>Important but not experienced</b>	<b>Total</b>
<b>Booking in advance</b>	308 (25.8)	720 (60.3)	166 (13.9)	1194
<b>Choosing type of professional</b>	258 (21.3)	925 (76.3)	29 (2.4)	1212
<b>A particular person</b>	421 (34.8)	620 (51.3)	168 (13.9)	1209
<b>Someone known and trusted</b>	457 (37.4)	661 (54.0)	105 (8.6)	1223
<b>Someone with time to listen</b>	118 (9.5)	1072 (86.0)	57 (4.6)	1247
<b>Information on history</b>	167 (13.0)	986 (76.5)	136 (10.6)	1289
<b>Someone knows patient personally</b>	297 (24.7)	752 (62.5)	154 (12.8)	1203
<b>Someone of own sex</b>	1029 (87.4)	124 (10.5)	24 (2.0)	1177
<b>Own ethnic group or culture</b>	1056 (92.9)	66 (5.8)	15 (1.3)	1137

### **6.2.4 Modelling**

In order to investigate the influence of elements of the model of continuity on respondents' experiences of and choices relating to continuity, we undertook logistic regression modelling with the issues in Table 6.16 as the dependent variables. Tables 6.17-6.25 present the data for the explanatory variables investigated in the models. In these Tables, the variables have been grouped according to their relationship to the four levels of the provisional model of continuity (see Chapter Two). The type of professional seen was coded as either GP or other (around 50% of whom were nurses), ethnic group as either white or non-white, and level of isolation as either high or low. A variable practice culture was created by combining the four practice attitude statements (see Table 6.14). In view of the difficulties of modelling a categorical variable with 6 levels, life-stage was represented in the models by principal constituent variables (age, work status, sex, carer or not). As a prelude to more formal modelling, and in order to identify the most important predictor variables, and basic significance tests are presented below. These candidate predictor variables were later entered into stepwise logistic regression models.

## ***Continuity of care: the views of patients and carers***

**Table 6.17. The explanatory variables related to whether the respondent was able to book their last consultation in advance, n (%). \*Chi square for categorical and ANOVA for continuous variables.**

	<b>Not important</b>	<b>Important and experienced</b>	<b>Important and not experienced</b>	<b>P*</b>
<b>Circumstances</b>				
Consultation was for:				
- self	241 (23.5)	637 (62.1)	148 (14.4)	.000
- someone else	64 (43.8)	67 (45.9)	15 (10.3)	
Reason for consulting:				
- new problem	163 (30.7)	296 (55.7)	72 (13.6)	.006
- routine	89 (20.4)	283 (64.8)	65 (14.9)	
- other	27 (23.1)	75 (64.1)	15 (12.8)	
<b>Professional seen</b>				
GP	234 (22.0)	674 (63.3)	156 (14.7)	.000
other	74 (56.9)	46 (35.4)	10 (7.7)	
<b>The respondent</b>				
Mean age	49.2	53.2	55.5	.001
Sex: male	13 (25.9)	275 (58.0)	76 (16.0)	.248
female	183 (25.8)	435 (61.4)	90 (12.7)	
Work:				
In work	154 (25.2)	381 (62.4)	76 (12.4)	.014
retired	82 (23.4)	223 (60.3)	64 (17.3)	
Not in work	68 (33.5)	111 (54.7)	24 (11.8)	
Ethnic group:				
white	272 (26.2)	620 (59.7)	147 (14.1)	.515
Non-white	36 (23.2)	100 (64.5)	19 (12.3)	
Mean EQ5D	.8365	.8135	.8171	.409
Level of isolation				
High	24 (21.1)	73 (64.0)	17 (14.9)	
Low	271 (25.9)	633 (60.5)	143 (13.7)	
<b>The practice</b>				
List size	9579	11179	10779	.011
Appointment system:				
open	50 (96.2)	2 (3.8)		.000
Same day & advanced access	170 (21.9)	497 (64.1)	108 (13.9)	
	56 (23.7)	140 (59.3)	40 (16.9)	
Mean IMD2004	21.4	24.6	25.6	.001
<b>The setting</b>				
Locality:				
city	74 (21.4)	223 (64.9)	48 (13.9)	.014
urban	169 (25.6)	402 (61.0)	88 (13.4)	
rural	63 (33.9)	93 (50.0)	30 (16.1)	
Leicester/London:				
Leicester	198 (27.2)	429 (58.9)	101 (13.9)	.367
London	110 (23.6)	291 (62.4)	65 (13.9)	

## ***Continuity of care: the views of patients and carers***

**Table 6.18. The explanatory variables related to whether the respondent saw their chosen type of professional at their last consultation, n (%). \*Chi square for categorical and ANOVA for continuous variables**

	<b>Not important</b>	<b>Important and experienced</b>	<b>Important and not experienced</b>	<b>p*</b>
<b>Circumstances</b>				
Consultation was for:				
self	216 (20.8)	800 (76.9)	24 (2.3)	.707
Reason for consulting:				
New problem	33 (21.9)	(113 (74.8)	5 (3.3)	
Routine	120 (21.4)	428 (76.3)	13 (2.3)	.016
	78 (17.6)	352 (79.5)	13 (2.9)	
	34 (32.7)	67 (64.4)	2 (2.9)	
<b>Professional</b>				
<b>GP</b>	210 (19.6)	833 (77.9)	27 (2.5)	.000
<b>Other</b>	48 (33.8)	92 (64.8)	2 (1.4)	
The respondent				
Mean age	50.4	52.3	41.1	.002
Sex: male	112 (23.4)	359 (74.9)	8 (1.7)	.152
female	143 (19.8)	558 (77.3)	21 (2.9)	
Work:				
In work	131 (20.3)	500 (77.4)	15 (2.3)	.016
retired	81 (22.9)	269 (76.2)	3 (0.8)	
Not in work	45 (21.8)	150 (72.8)	11 (5.3)	
Ethnic group:				
white	228 (21.6)	806 (76.3)	23 (2.2)	.379
Non-white	30 (19.4)	119 (76.8)	6 (3.9)	
Mean EQ5D	.8503	.8212	.8462	.218
Level of isolation				
High	23 (19.2)	93 (77.5)	4 (3.3)	.711
Low	227 (21.3)	813 (76.3)	25 (2.3)	
The practice				
List size	11371	10332	13175	.034
Appointment system:				
open	14 (21.2)	52 (78.8)		.732
Same day &	157 (20.1)	605 (77.5)	19 (2.4)	
Mean IMD2004	46 (19.7)	183 (78.5)	4 (1.7)	
	24.6	22.9	21.3	.155
The setting				
Locality:				
city	72 (21.8)	251 (75.8)	8 (2.4)	.263
urban	137 (20.0)	528 (77.1)	20 (2.9)	
rural	47 (24.6)	143 (74.9)	1 (0.5)	
Leicester/London:				
Leicester	179 (25.2)	521 (73.3)	11 (1.5)	.000
London	79 (15.8)	404 (80.6)	18 (3.6)	

## ***Continuity of care: the views of patients and carers***

**Table 6.19. The explanatory variables related to whether the respondent saw the particular person they preferred at their last consultation, n (%). \*Chi square for categorical and ANOVA for continuous variables**

	<b>Not important</b>	<b>Important and experienced</b>	<b>Important and not experienced</b>	<b>P*</b>
<b>Circumstances</b>				
Consultation was for:				
self	353 (33.9)	548 (52.6)	140 (13.4)	.019
Someone else	60 (41.7)	58 (40.3)	26 (18.1)	
Reason for consulting:				
New problem	223 (40.8)	243 (44.5)	80 (14.7)	.000
Routine	119 (26.9)	262 (59.3)	61 (13.8)	
Other	45 (41.3)	53 (48.6)	11 (10.1)	
<b>Professional seen</b>				
GP	369 (34.1)	576 (53.2)	137 (12.7)	.000
Other	52 (40.9)	44 (34.6)	31 (24.4)	
The respondent				
Mean age	43.4	55.6	51.1	.000
Sex: male	181 (37.6)	242 (50.2)	59 (12.2)	.140
female	233 (32.7)	372 (52.2)	108 (15.1)	
Work:				
In work	257 (41.7)	285 (46.2)	75 (12.2)	.000
retired	100 (26.9)	226 (60.8)	46 (12.4)	
Not in work	60 (28.4)	106 (50.2)	45 (21.3)	
Ethnic group:				
white	379 (36.1)	522 (49.8)	148 (14.1)	.021
Non-white	42 (26.3)	98 (61.3)	20 (12.5)	
Mean EQ5D	.8856	.7809	.8010	.000
Level of isolation				
High	35 (30.4)	63 (54.8)	17 (14.8)	.563
Low	376 (35.4)	545 (51.3)	141 (13.3)	
The practice				
List size	10494	10987	9786	.168
Appointment system:				
open	36 (57.1)	1 (1.6)	26 (41.3)	.000
Same day & advanced access	276 (35.2)	416 (53.1)	92 (11.7)	
Pre-booking allowed	63 (26.8)	135 (57.4)	37 (15.7)	.000
Mean IMD2004	22.4	25.3	21.4	
The setting				
Locality:				
city	125 (35.9)	184 (52.9)	39 (11.2)	.201
urban	221 (33.2)	349 (52.4)	96 (14.4)	
rural	71 (37.2)	87 (45.5)	33 (17.3)	
Leicester/London:				
Leicester	249 (33.9)	380 (51.7)	106 (14.4)	.632
London	172 (36.3)	240 (50.6)	62 (13.1)	



## ***Continuity of care: the views of patients and carers***

**Table 6.20. The explanatory variables related to whether the respondent saw someone they knew and trusted at their last consultation, n (%).  
\*Chi square for categorical and ANOVA for continuous variables**

	<b>Not important</b>	<b>Important and experienced</b>	<b>Important and not experienced</b>	<b>P*</b>
<b>Circumstances</b>				
Consultation was for:				
self	387 (36.6)	582 (55.1)	88 (8.7)	0.024
Someone else	62 (44.6%)	60 (43.2)	17 (12.2)	
Reason for consulting:				
New problem	240 (43.9)	245 (44.8)	62 (11.3)	0.000
Routine	129 (28.7)	294 (65.5)	26 (5.8)	
Other	50 (46.7)	44 (41.1)	13 (12.1)	
<b>Professional seen</b>				
GP	402 (36.9)	595 (54.7)	91 (8.4)	.412
other	55 (40.7)	66 (48.9)	14 (10.4)	
The respondent				
Mean age	48.4	57.0	46.0	.000
Sex: male	197 (41.3)	247 (51.8)	33 (6.9)	.029
female	253 (34.6)	406 (55.5)	72 (9.8)	
Work:				
In work	280 (45.7)	269 (43.9)	64 (10.4)	.000
retired	107 (27.2)	271 (68.8)	16 (4.1)	
Not in work	11 (31.7)	117 (56.3)	25 (12.0)	
Ethnic group:				
white	410 (38.6)	572 (53.8)	81 (7.6)	.002
Non-white	47 (29.4)	89 (55.6)	24 (15.0)	
Mean EQ5D	.8868	.7727	.8573	.000
Level of isolation				
High	38 (32.0)	62 (53.4)	16 (13.8)	.094
Low	409 (38.0)	580 (53.9)	87 (8.1)	
The practice				
List size	10,552	10396	11097	.663
Appointment system:				
open	38 (46.3)	43 (52.4)	1 (1.2)	.001
Same day & advanced access	299 (37.8)	411 (52.0)	81 (10.2)	
Pre-booking allowed	70 (30.6)	146 (63.8)	13 (5.7)	
Mean IMD2004	22.6	23.6	24.9	.225
The setting				
Locality:				
city	135 (38.9)	181 (52.2)	31 (8.9)	0.000
urban	238 (36.1)	350 (53.0)	72 (10.9)	
rural	80 (37.9)	129 (61.1)	2 (0.9)	
Leicester/London:				
Leicester	274 (36.6)	427 (57.0)	48 (6.4)	.001
London	183 (38.6)	234 (49.4)	57 (12.0)	

## ***Continuity of care: the views of patients and carers***

**Table 6. 21. The explanatory variables related to whether the respondent saw someone with time to listen at their last consultation, n (%). \*Chi square for categorical and ANOVA for continuous variables.**

	<b>Not important</b>	<b>Important and experienced</b>	<b>Important and not experienced</b>	<b>P*</b>
<b>Circumstances</b>				
Consultation was for:				
self	101 (9.4)	931 (86.4)	45 (4.2)	.099
Someone else	13 (8.8)	122 (83.0)	12 (8.2)	
Reason for consulting:				
New problem	61 (10.9)	474 (84.3)	27 (4.8)	.006
Routine	30 (6.6)	408 (89.5)	18 (3.9)	
	15 (14.9)	77 (76.2)	9 (8.9)	
<b>Professional seen</b>				
GP	102 (9.2)	961 (86.3)	50 (4.5)	.526
Other	16 (11.9)	111 (82.8)	7 (5.2)	
The respondent				
Mean age	49.5	54.0	41.5	.000
Sex: male	51 (10.5)	412 (85.1)	21 (4.3)	.492
female	64 (8.5)	650 (86.8)	35 (4.7)	
Work:				
In work	66 (10.5)	529 (84.1)	34 (5.4)	.118
retired	33 (8.0)	366 (89.3)	11 (2.7)	
Not in work	19 (9.5)	170 (84.6)	12 (6.0)	
Ethnic group:				
white	106 (9.8)	941 (87.0)	35 (3.2)	.000
Non-white	12 (7.3)	131 (79.4)	22 (13.3)	
Mean EQ5D	.8858	.8184	.8059	0.18
Level of isolation				
High	11 (10.0)	89 (80.9)	10 (9.1)	.069
Low	104 (9.4)	952 (86.3)	47 (4.3)	
The practice				
List size	10997	10330	12322	.112
Appointment system:				
open	6 (7.7)	72 (92.3)		.041
Same day &		691 (86.9)	30 (3.8)	
	20 (8.1)	208 (84.6)	18 (7.3)	
Mean IMD2004	23.9	23.6	19.4	.068
The setting				
Locality:				
city	43 (12.3)	294 (84.0)	13 (3.7)	.000
urban	67 (9.9)	566 (84.0)	41 (6.1)	
rural	8 (3.7)	208 (95.4)	2 (0.9)	
Leicester/London:				
Leicester	70 (9.2)	669 (87.7)	24 (3.1)	.008
London	48 (9.9)	403 (83.3)	33 (6.8)	

## ***Continuity of care: the views of patients and carers***

**Table 6.22. The explanatory variables related to whether the respondent saw someone with information on their history at their last consultation n (%). \*Chi square for categorical and ANOVA for continuous variables**

	<b>Not important</b>	<b>Important and experienced</b>	<b>Important and not experienced</b>	<b>P*</b>
<b>Circumstances</b>				
Consultation was for:				
self	127 (11.5)	868 (78.3)	114 (10.3)	.000
Someone else	36 (23.4)	96 (62.3)	11 (14.3)	
Reason for consulting:				
New problem	111 (19.5)	389 (68.2)	70 (12.3)	.000
Routine	24 (5.0)	413 (85.7)	45 (9.3)	
	18 (16.4)	79 (71.8)	13 (11.8)	
<b>Professional seen</b>				
GP	125 (10.9)	913 (79.3)	114 (9.9)	.000
Other	42 (30.7)	73 (53.3)	22 (16.1)	
The respondent				
Mean age	46.5	55.2	44.6	.000
Sex: male	74 (14.6)	385 (75.9)	48 (9.5)	.190
female	89 (11.6)	590 (76.9)	88 (11.5)	
Work:				
In work	108 (16.6)	465 (71.6)	76 (11.7)	.000
retired	33 (8.0)	358 (86.3)	24 (5.8)	
Not in work	26 (12.0)	157 (72.4)	34 (15.7)	
Ethnic group:				
white	150 (13.4)	865 (77.2)	106 (9.5)	.003
Non-white	17 (10.1)	121 (72.0)	30 (17.9)	
Mean EQ5D	.8634	.8100	.8610	.005
Level of isolation				
High	16 (13.3)	81 (67.5)	23 (19.2)	.004
Low	149 (13.1)	878 (77.3)	109 (9.6)	
The practice				
List size	10904	10176	12248	.009
Appointment system:				
open		78 (97.5)	2 (2.5)	.000
Same day &	26 (10.3)	631 (76.1)	82 (9.9)	
Mean IMD2004	25.6	199 (78.7)	28 (11.1)	.069
		23.1	22.6	
The setting				
Locality:				
city	58 (15.9)	278 (76.2)	29 (7.9)	.000
urban	98 (14.0)	502 (71.7)	100 (14.3)	
rural	10 (4.6)	204 (93.2)	5 (2.3)	
Leicester/London:				
Leicester	89 (11.3)	632 (80.1)	68 (8.6)	.001
London	78 (15.6)	354 (70.8)	68 (13.6)	

## ***Continuity of care: the views of patients and carers***

**Table 6.23. The explanatory variables related to whether the respondent saw someone with information and who knew them personally at their last consultation n (%). \*Chi square for categorical and ANOVA for continuous variables**

	<b>Not important</b>	<b>Important and experienced</b>	<b>Important and not experienced</b>	<b>P*</b>
Circumstances				
Consultation was for:				
self	234 (22.5)	672 (64.7)	132 (12.7)	.000
Someone else	59 (41.8)	63 (44.7)	19 (13.5)	
Reason for consulting:				
New problem	179 (34.5)	261 (50.3)	79 (15.2)	.000
Routine	66 (14.1)	349 (74.4)	54 (11.5)	
Other	31 (32.6)	52 (54.7)	12 (12.6)	
<b>Professional seen</b>				
GP	247 (23.0)	686 (64.0)	139 (13.0)	.001
other	50 (38.2)	66 (50.4)	15 (11.5)	
The respondent				
Mean age	45.2	58.8	47.1	.000
Sex: male	117 (24.4)	299 (62.4)	63 (13.2)	.974
female	174 (24.5)	445 (62.8)	90 (12.7)	
Work:				
In work	205 (34.4)	293 (49.2)	98 (16.4)	.000
retired	48 (11.8)	331 (81.5)	27 (6.7)	
Not in work	43 (22.3)	121 (62.7)	29 (15.0)	
Ethnic group:				
white	267 (25.5)	658 (62.8)	122 (11.7)	.005
Non-white	30 (19.2)	94 (60.3)	32 (20.5)	
Mean EQ5D	.8960	.7788	.8252	.000
Level of isolation				
High	28 (24.3)	65 (56.5)	22 (19.1)	.122
Low	265 (25.1)	660 (62.5)	131 (12.4)	
The practice				
List size	11260	10148	10065	.084
Appointment system:				
open	11 (13.9)	66 (83.5)	2 (2.5)	.000
Same day & advanced access	39 (16.4)	446 (58.0)	116 (15.1)	
Pre-booking allowed	23.8	23.1	24.1	.569
Mean IMD2004				
The setting				
Locality:				
city	91 (26.7)	196 (57.5)	54 (15.8)	.000
urban	163 (25.3)	389 (60.3)	93 (14.4)	
rural	40 (18.8)	167 (78.4)	6 (2.8)	
Leicester/London:				
Leicester	173 (23.6)	485 (66.2)	75 (10.2)	.001
London	124 (26.4)	267 (56.8)	79 (16.8)	

## ***Continuity of care: the views of patients and carers***

**Table 6.24 The explanatory variables related to whether the respondent saw someone of the same sex at their last consultation n (%). \*Chi square for categorical and ANOVA for continuous variables**

	<b>Not important</b>	<b>Important and experienced</b>	<b>Important and not</b>	<b>P*</b>
Circumstances				
Consultation was for:				
self	884 (87.4)	107 (10.6)	20 (2.0)	.826
Reason for consulting:				
New problem	126 (86.9)	15 (10.3)	4 (2.8)	
Routine	461 (88.1)	50 (9.6)	12 (2.3)	.450
<b>Professional</b>				
<b>GP</b>	373 (85.0)	57 (13.0)	9 (2.1)	
<b>other</b>	87 (89.7)	8 (8.2)	2 (2.1)	
The respondent				
Mean age	908 (87.1)	113 (10.8)	22 (2.1)	.565
Sex: male	121 (90.3)	11 (8.2)	2 (1.5)	
female	53.5	53.2	48.8	.499
Work:				
In work	439 (90.1)	44 (9.0)	4 (0.8)	.011
retired	577 (85.2)	80 (11.8)	20 (3.0)	
Not in work	520 (88.9)	53 (9.1)	12 (2.1)	.273
Ethnic group:				
white	343 (87.1)	46 (11.7)	5 (1.3)	
Non-white	161 (84.3)	24 (12.6)	6 (3.1)	
Mean EQ5D	921 (89.1)	97 (9.4)	16 (1.5)	.000
Level of isolation	108 (75.5)	27 (18.9)	8 (5.6)	
High	.8167	.8198	.8780	.489
Low	100 (88.5)	8 (7.1)	5 (4.4)	.095
The practice				
List size	902 (87.2)	113 (10.9)	19 (1.8)	
Appointment system:	10220	11992	11366	.039
open	67 (94.4)	4 (5.6)		.396
Same day &	647 (87.2)	77 (10.4)	18 (2.4)	
Mean IMD2004	217 (88.9)	23 (9.4)	4 (1.6)	
The setting	23.0	24.4	25.1	.397
Locality:				
city	275 (85.1)	41 (12.7)	7 (2.2)	.078
urban	565 (87.1)	68 (10.5)	16 (2.5)	
rural	186 (93.0)	13 (6.5)	1 (0.5)	
Leicester/London:				
Leicester	628 (88.0)	76 (10.6)	10 (1.4)	.157
London	401 (86.6)	48 (10.4)	14 (3.0)	

## Continuity of care: the views of patients and carers

**Table 6.25. The explanatory variables related to whether the respondent saw someone of the same ethnic group at their last consultation, n (%). \*Chi square for categorical and ANOVA for continuous variables**

	Not important	Important and experienced	Important and not experienced	P*
Circumstances				
Consultation was for:				
self	906 (92.4)	62 (6.3)	13 (1.3)	.265
Someone else	134 (95.7)	4 (2.9)	2 (1.4)	
Reason for consulting:				
New problem	488 (93.5)	27 (5.2)	7 (1.3)	.210
Routine	396 (91.2)	31 (7.1)	7 (1.6)	
Other	89 (97.8)	1 (1.1)	1 (1.1)	
<i>Professional seen</i>				
GP	945 (92.6)	61 (6.0)	15 (1.5)	.315
Other	111 (95.7)	5 (4.3)		
The respondent				
Mean age	51.2	63.4	51.6	.000
Sex: male	422 (92.3)	29 (6.3)	6 (1.3)	.796
female	623 (93.3)	36 (5.4)	9 (1.3)	
Work:				
In work	585 (96.1)	18 (3.0)	6 (1.0)	.000
retired	297 (87.6)	37 (10.9)	5 (1.5)	
Not in work	170 (92.9)	9 (4.9)	4 (2.2)	
Ethnic group:				
white	925 (93.2)	59 (5.9)	9 (0.9)	.005
Non-white	131 (91.0)	7 (4.9)	6 (4.2)	
Mean EQ5D	.8329	.7361	.8188	.007
Level of isolation				
High	93 (94.9)	4 (4.1)	1 (1.0)	.753
Low	941 (92.9)	59 (5.8)	13 (1.3)	
The practice				
List size	10494	10300	11558	.842
Appointment system:				
open	56 (87.5)	8 (12.5)		.141
Same day & advanced access		40 (5.5)	9 (1.2)	
Pre-booking allowed	209 (93.3)	11 (4.9)	4 (1.8)	.491
Mean IMD2004	22.9	24.8	24.2	
The setting				
Locality:				
city	301 (94.4)	14 (4.4)	4 (1.3)	.018
urban	591 (93.4)	32 (5.1)	10 (1.6)	
rural	160 (88.4)	20 (11.0)	1 (0.6)	
Leicester/London:				
Leicester	616 (92.4)	43 (6.4)	8 (1.2)	.504
London	440 (93.6)	23 (4.9)	7 (1.5)	

## ***Continuity of care: the views of patients and carers***

Nine individual datasets were created, one for each dependent variable. A multi-level modelling approach was attempted initially, with the aim being to model patients within GP practices (a 2-level model). However, due to the distribution of values for the dependent variable categories within practices, the models in most cases did not converge, producing negative definite matrices, and since further attempts to reconstruct positive definite matrices were not successful, the multi-level approach was abandoned and single level multinomial logistic regressions carried out. In those cases in which multi-level modelling was possible, the findings were little different from single-level models.

Although the multinomial logistic regressions give a global view of the impact of specific predictor variables on each of the nine dependent variables, we have decided not to present these results. Instead, we report here only results for single-level logistic regressions for the individual pair-wise comparisons between the three response categories, as these are of greater interest. For each dependent variable, three sets of logistic regressions were carried out, comparing the attribute being rated as (a) important and experienced vs important and not experienced, (b) not important vs important and experienced, (c) not important vs important but not experienced. The method used was forward stepwise regression, using Proc Logistic in SAS (version 8.2). The aim was to obtain a set of significant predictors for each pair-wise comparison. All analyses were main effects only models since the main aim was to find the best set of individual predictor variables in each case. Each of the 9 Tables below gives the results for a single dependent variable.

## ***Continuity of care: the views of patients and carers***

**Table 6.26. Logistic regression models for being able to book in advance at the last consultation (all results below are significant at the .05 level)**

	Odds ratio	95% confidence limits	
<b><i>(a) Important and were able to book in advance vs important and not able to</i></b>			
Attained degree level education vs had not	0.640	0.428	0.958
<b><i>(b) Important and were able to book in advance vs this not important</i></b>			
Increasing age (per year)	1.023	1.006	1.040
Whether a GP in a practice was consulted rather than another professional	15.988	8.000	31.952
The reason for the consultation was a routine problem rather than a new problem	1.659	1.089	2.526
In work rather than not in work but not retired	2.358	1.481	3.754
Same day appointment system vs pre-booking allowed	0.010	0.001	0.078
<b><i>(c) Important but not able to book in advance vs this not important</i></b>			
Age	1.025	1.011	1.039
Whether a GP in a practice was consulted rather than another professional	7.183	2.905	17.763
IMD2004	1.021	1.003	1.038

Table 6.26 shows the findings in relation to being able to book in advance (representing the attribute access). For the first comparison (a), the only variable explaining whether patients who wished to book in advance were able to or not able to was whether they had reached degree level in education (those with a degree being less likely to have been able to book in advance than respondents who did not have a degree). Variables explaining comparison (b) whether respondents wished to and were able to book in advance rather than did not regard booking in advance as important were increasing age, consulting a GP in a practice rather than another professional, consulting for a routine problem rather than a new problem, being in work rather than not in work, and attending a practice which allowed pre-booking of appointments rather than a same day appointment system. Variables



## ***Continuity of care: the views of patients and carers***

explaining comparison (c) whether respondents wished to book in advance but were unable to rather than not regarding booking in advance as important were consulting a GP in a practice rather than another professional, and increasing IMD2004 score (i.e. increasing deprivation).

**Table 6.27. Logistic regression models for being able to consult the preferred type of professional at the last consultation (all results below are significant at the .05 level)**

	<b>Odds ratio</b>	<b>95% confidence limits</b>	
<b>(a) Important to see a particular type of professional and did vs important but did not</b>			
Age (per additional year)	1.052	1.011	1.095
Practice list size (per additional patient)	0.99993	0.99989	0.99998
In work rather than not in work	3.251	1.278	8.273
Is a carer vs not a carer	0.278	0.108	0.714
<b>(b) The type of professional was not important vs important to see a particular type of professional and did</b>			
Male sex	1.495	1.062	2.105
Whether a GP in a practice was consulted rather than another professional	0.535	0.313	0.916
Consulting with a new problem rather than other problems	0.471	0.272	0.815
Consulting with a routine problem rather than other problems	0.420	0.238	0.741
Has a degree	0.544	0.383	0.773
<b>(c) Important to see a particular type of professional and did not vs not important</b>			
In Leicestershire rather than London	4.502	1.096	18.492
Practice list size (per additional patient)	0.99990	0.99984	0.99997
Respondent has a degree	0.188	0.057	0.616
In work vs not in work and not retired	7.524	2.149	26.344
Retired vs not in work	11.051	1.234	98.969
Being a carer	0.241	0.080	0.725

With respect to the dependent variable 'seeing the preferred type of professional', the variables explaining comparison (a) whether the

## ***Continuity of care: the views of patients and carers***

respondent who preferred to see a particular type of professional did rather than did not see that professional at the last consultation were increasing age, decreasing practice list size, being in work rather than not in work, and not being a carer (Table 6.27). Variables explaining comparison (b) whether the respondent regarded seeing a particular type of professional as not important rather than regarding this as important and did they did actually see their preferred type of professional were being male rather than female (males more likely to regard this as not important), consulting another professional rather than a GP in a practice, having another type of problem rather than a new or routine problem, and not having a degree (people without a degree were less likely to regard this as important). Variables explaining comparison (c) whether the respondent did not see the preferred type of professional at the last consultation or this not being important were living in Leicestershire rather than London, decreasing practice list size, being in work or retired versus not in work, and not being a carer.

## ***Continuity of care: the views of patients and carers***

**Table 6.28. Logistic regression models for being able to consult the preferred person at the last consultation (all results below are significant at the .05 level)**

	<b>Odds ratio</b>	<b>95% confidence limits</b>	
<b>(a) Important to see a particular person and did vs important but did not</b>			
Whether a GP in a practice was consulted rather than another professional	9.974	4.733	21.063
In work vs not in work and not retired	1.978	1.147	3.411
Retired vs not in work	2.941	1.514	5.711
Same day appointment system vs pre-booking allowed	0.021	0.003	0.173
Open appointments vs same day appointment system	78.332	9.832	624.071
<b>(b) Seeing a particular person was not important vs important and did see that person</b>			
Age (per additional year)	0.983	0.973	0.993
Sex (male vs female)	1.680	1.201	2.349
EQ5D	4.381	1.862	10.307
Whether a GP in a practice was consulted rather than another professional	0.286	0.136	0.603
IMD2004	0.983	0.970	0.997
Consulting for a new problem vs other problems	1.246	0.723	2.146
Consulting with a routine problem vs a new problem	0.467	0.328	0.666
White ethnic group vs other	2.041	1.174	3.546
Same day appointment system vs pre-booking allowed	40.542	5.141	319.689
Open vs same day appointment system	0.032	0.004	0.249
<b>(c) Seeing a particular person was not important vs important but did not see that person</b>			
EQ5D	7.674	2.449	24.047
Whether a GP in a practice was consulted rather than another professional	2.345	1.273	4.321
In work vs not in work (not retired)	2.508	1.438	4.373
Retired vs not in work	3.417	1.636	7.135

Variables that explained comparison (a) whether respondents who wished to consult a particular person did rather than did not were

## ***Continuity of care: the views of patients and carers***

whether the consultation was with a GP in a practice rather than another professional, whether they were in work or retired rather than not in work, and whether the practice appointment system allowed for pre-booking or open access rather than same day appointments only (Table 6.28). Variables explaining comparison (b) whether seeing a particular person was not important rather than important and experienced were younger age (younger people were more likely to regard seeing a particular person as not important), sex (males more likely to regard seeing a particular person as not important), increasing EQ5D score (i.e. better health), whether a GP in a practice was consulted (people consulting GP in a practice were more likely to regard seeing a particular person as important and to experience this), increasing IMD2004 score (lower score associated with regarding seeing a particular person as not important), consulting for a new problem than a routine one, being white rather than another ethnic group, attending a practice with same day appointments rather than pre-booking, or with open access rather than same day appointments. Variables that explained comparison (c) whether seeing a particular person was regarded as not important rather than important but this person was not consulted were higher EQ5D score, whether the person consulted was a GP in a practice rather than another professional, and whether the respondent was in work or retired rather than not in work.

## ***Continuity of care: the views of patients and carers***

**Table 6.29. Logistic regression models for being able to consult a known and trusted professional (all results below are significant at the .05 level)**

	<b>Odds ratio</b>	<b>95% confidence limits</b>	
<b>(a) Seeing a professional known and trusted was important and was seen vs important but not seen</b>			
Leicestershire vs London	1.711	1.028	2.846
Age (per additional year)	1.030	1.013	1.047
Consulting for a routine problem rather than other problems	4.151	1.717	10.036
Consulting for a routine problem rather than a new problem	2.709	1.507	4.870
White vs not white ethnic group	2.185	1.126	4.242
<b>(b) Seeing a professional known and trusted was important and experienced vs not important</b>			
Age	1.024	1.009	1.038
Sex	0.621	0.451	0.856
EQ5D	0.201	0.085	0.473
IMD2004	1.014	1.002	1.027
Consulting with a routine problem vs other problems	2.509	1.410	4.465
Consulting with a routine problem vs a new problem	2.225	1.598	3.096
In work vs not in work and not retired	0.581	0.373	0.906
Retired vs not in work	0.436	0.224	0.848
<b>(c) Seeing a professional known and trusted was important but not experienced vs not important</b>			
Male sex	0.473	0.271	0.824
White vs non white ethnic group	0.307	0.156	0.605

Variables explaining comparison (a) whether respondents who regarded seeing someone they knew and trusted as important and did or did not see such a person were whether they lived in Leicestershire or London (people in Leicestershire were more likely to have been able to consult someone they knew and trusted), increasing age, consulting with a routine problem rather than a new problem or other problems, and being white rather than non-white (Table 6.29). Variables explaining comparison (b) whether seeing someone who was known and trusted was regarded as important and was experienced rather than not important were increasing age, being female, lower EQ5D

## ***Continuity of care: the views of patients and carers***

score (i.e. worse health), higher IMD2004 score (i.e. higher deprivation), consulting with a routine rather than new or other problem, and not being in work rather than in work or retired. Variables explaining comparison (c) whether seeing someone who was known and trusted was regarded as important but was not experienced rather than not important were female sex and being non-white rather than white.

**Table 6.30. Logistic regression models for being able to consult someone with time to listen (all results below are significant at the .05 level)**

	<b>Odds ratio</b>	<b>95% confidence limits</b>	
<b>(a) Seeing someone with time to listen was important and happened vs important but did not happen</b>			
Leicestershire vs London	3.825	1.690	8.658
Age	1.051	1.025	1.078
Practice list size	0.99992	0.99987	0.99996
Level of social isolation	0.403	0.163	0.997
White vs non-white ethnic group	4.140	1.938	8.842
<b>(b) Seeing someone with time to listen was not important vs important and happened</b>			
sex	1.643	1.026	2.629
EQ5D	6.705	1.553	28.945
Consulting with routine problem vs other problems	0.362	0.164	0.892
<b>(c) Seeing someone with time to listen was not important vs important and did not happen</b>			
White vs non-white ethnic group	9.625	2.883	32.136

Variables that explained comparison (a) whether respondents who regarded seeing someone with time to listen at their last consultation and did rather than did not experience this were the location (increased likelihood of seeing someone with time to listen in Leicestershire rather than London), increasing age, decreasing practice list size, lack of social isolation, and being white rather than non-white (Table 6.30). Variables explaining comparison (b) whether respondents regarded seeing someone with time to listen as not important, or important and experienced were sex, increasing EQ5D score (i.e. better health), and consulting with routine rather than other problems. Variables explaining comparison (c) whether respondents regarded seeing someone with time to listen as not

## ***Continuity of care: the views of patients and carers***

important rather than important but not experienced at the last consultation were being white rather than non-white (non-white respondents were more likely to regard seeing someone with time to listen as important but not experienced).

**Table 6.31. Logistic regression models for being able to consult someone with information on the respondent's clinical history (all results below are significant at the .05 level)**

	<b>Odds ratio</b>	<b>95% confidence limits</b>	
<b>(a) Respondent regarded seeing person with information as important and did vs important but did not</b>			
Leicestershire vs London	2.599	1.556	4.342
Age increasing (per additional year)	1.028	1.010	1.046
Practice list size	0.99994	0.99991	0.9997
Whether a GP in a practice was consulted rather than another professional	3.996	1.953	8.178
Level of social isolation	0.457	0.247	0.847
White vs non-white ethnic group	1.876	1.030	3.417
<b>(b) Respondent regarded seeing person with information as important and did vs not important</b>			
Leicestershire vs London	1.981	1.232	3.183
Age	0.966	0.955	0.977
Practice list size	0.9997	0.99994	0.99999
Whether a GP in a practice was consulted rather than another professional	5.798	3.169	10.609
Consulting for routine problems vs other reasons	2.637	1.153	6.028
Consulting for routine problems vs new problems	4.203	2.371	7.450
<b>(c) Respondent regarded seeing person with information as important but did not vs not important</b>			
Consulting for routine problems vs other reasons	2.889	1.021	8.176
Consulting for routine problems vs new problems	3.143	1.581	6.249

## ***Continuity of care: the views of patients and carers***

Variables that explained comparison (a) whether respondents who regarded seeing someone with information about the medical history as important and did rather than did not experience this were living in Leicestershire rather than London, increasing age, decreasing practice list size, seeing a GP in a practice, lower social isolation, and being white rather than non-white (Table 6.31). Variables that explained comparison (b) whether respondents regarded seeing someone with information as important and did rather than not important were living in Leicestershire rather than London, decreasing age, decreasing practice list size, whether a GP in a practice was consulted, and whether the problem was for a routine problem rather than either a new or other problem. Variables that explained comparison (c) whether respondents regarded seeing someone with information as important but did not rather than not important were consulting with a routine problem rather than a new or other problem.

**Table 6.32. Logistic regression models for being able to consult someone the respondent knew personally and with information on their history (all results below are significant at the .05 level).**

	<b>Odds ratio</b>	<b>95% confidence limits</b>	
<b>(a) Regarded seeing known person with information as important and did vs important but did not</b>			
age	1.028	1.010	1.046
Level of social isolation	0.528	0.281	0.995
In work vs not in work and not retired	0.524	0.293	0.936
<b>(b) Regarded seeing someone known and with information as not important vs important and did happen</b>			
Age	0.996	0.955	0.977
EQ5D	6.197	2.223	17.270
Whether a GP in a practice was consulted rather than another professional	0.305	0.164	0.565
Consulting for routine problems vs new problems	0.351	0.237	0.519
Open appointment system vs same day appointments	2.590	1.144	5.865
<b>(c) Regarded seeing someone known and with information as not important vs important but did not happen</b>			
EQ5D	5.548	1.739	17.701
Consultation about self rather than another person	0.495	0.249	0.985
White vs non-white ethnic group	2.937	1.445	5.969



## ***Continuity of care: the views of patients and carers***

Variables that explained comparison (a) whether respondents regarded seeing someone they knew personally with information as important and did rather than did not experience this were increasing age, a low level of social isolation, and being in work rather than not in work (Table 6.32). Variables that explained comparison (b) whether respondents regarded seeing someone they knew with information as not important rather than as important and experienced this were decreasing age (younger people more likely to regard seeing a known person with information as not important), increasing EQ5D score, seeing another professional rather than a GP in a practice, consulting for a new rather than routine problem, and attending a practice with an open rather than same day appointment system. Variables that explained comparison (c) whether respondents regarded seeing someone they knew with information as not important rather than as important but not experienced were increasing EQ5D score, consulting about someone else rather than themselves, and being white rather than non-white.

**Table 6.33. Logistic regression models for being able to consult someone of the same sex (all results below are significant at the .05 level).**

	<b>Odds ratio</b>	<b>95% confidence limits</b>	
<b>(a) Regarded seeing someone of the same sex as important and did vs important but did not</b>			
Level of social isolation	0.193	0.051	0.723
<b>(b) Regarded seeing someone of the same sex as not important vs important and did</b>			
Practice list size	0.99996	0.99994	0.99999
White vs non-white ethnic group	2.768	1.525	5.024
<b>(c) Regarded seeing someone of the same sex as not important vs important but did not</b>			
sex	5.558	1.254	24.637
Level of social isolation	0.325	0.107	0.982
White vs non-white ethnic group	6.603	2.407	18.115

The only variable that explained comparison (a) whether respondents regarded seeing someone of the same sex as themselves and did rather than did not was level of social isolation, people who were socially isolated being less likely to see someone of the preferred sex (Table 6.33). Variables explaining comparison (b) whether respondents who regarded seeing someone of the same sex as not important rather than as important and experienced were increasing

## ***Continuity of care: the views of patients and carers***

practice list size and white ethnic group. Variables explaining comparison (c) whether respondents who regarded seeing someone of the same sex as important but did not rather than not important were sex (males more likely to regard seeing someone of the same sex as not important), level of social isolation (greater degree of social isolation associated with regarding seeing someone of the same sex as important but not experienced), and ethnic group, whites being more likely to regard seeing someone of the same sex as not important.

**Table 6.34. Logistic regression models for being able to consult someone of the same ethnic group (all results below are significant at the .05 level). \*see text below**

	<b>Odds ratio</b>	<b>95%confidence limits</b>	
<b>(a) Regarded seeing someone of the same ethnic group as important and did vs important but did not</b>			
White vs non-white ethnic group*	8.571	1.573	46.713
<b>(b) Regarded seeing someone of the same ethnic group as important and did vs not important</b>			
Age (per additional year)*	1.046	1.027	1.066
<b>(c) Regarded seeing someone of the same ethnic group as important but did not vs not important</b>			
White vs non-white ethnic group	0.234	0.067	0.814

The only variable explaining comparison (a) whether respondents who regarded seeing someone of the same ethnic group as important did or did not see someone of the same ethnic group was ethnic group, whites being more likely to see someone of their own ethnic group (Table 6.34). Ethnic group was also the only variable explaining comparison (b) whether respondents regarded seeing someone of the same ethnic group as important and did rather than regarding this as not important, and age was the only variable explaining comparison (c), whether respondents regarded seeing someone of the same ethnic group as important but did not or they regarded this as not important.

All logistic regression models were appropriately assessed for Goodness of Fit, and found to be satisfactory other than two of the models evaluating preferences and experience of seeing a professional of the same ethnic group, comparing not experiencing this versus not preferring this, and not experiencing this versus experienced this. For these 2 models, the results must be treated with caution, since some of the Goodness of Fit tests suggested poorly fitting models, and in each case the predictive power of the model was poor as evaluated by the percent concordant statistic, which was around 33% for both

## ***Continuity of care: the views of patients and carers***

models. The main reason for the poor fit of these models is sparse data. Exact Logistic Regression models were subsequently fitted to these 2 datasets, and the results were still significant.

### ***6.3 Discussion***

#### **6.3.1 Weaknesses and strengths of the study**

The response rate was disappointing. It was similar to the response rate of 49% for the 2004 national patient survey, which varied from 22% to 64% between primary care trusts (Healthcare Commission, 2004). In the national survey, the lowest response rate was from males in the age group 16-35 years (24%). The low response rate in people in the younger age group is likely to be partly explained by a relatively high proportion no longer being resident at the recorded address. They have a greater likelihood of moving home, and delay enrolling with a new general practice until a health problem arises. The response rates to the national survey tend to suggest that people are becoming less willing to complete postal surveys. The response to the 2003 primary care survey was 49% (Healthcare Commission, 2003), in 2002 it was 55% (Department of Health, 2002) and in 1998 it was 61% (Department of Health). It is possible to achieve higher response rates in selected patient groups, for example by administration of questionnaires directly to people attending a service, but the response rate achieved in our study appears typical of the current level of response to postal surveys through general practice patient registers. Caution is needed in interpreting the findings in relation to the younger age group, but our survey achieved satisfactory diversity with respect to the life stage categories, and also ethnicity. In the 2004 national survey, 5% of respondents were non-white (Healthcare Commission, 2004), but in our study the proportion was 10%, reflecting the diversity of the populations in the selected study areas.

Our survey did not involve a national random sample, and the direct extrapolation of the findings to the national population would be inappropriate. However, the study has achieved reasonable respondent diversity and was undertaken in two different locations and therefore the findings can be used to provide guidance to practices and PCTs on the likely views of their patients.

The survey followed an extended series of studies, including a substantial qualitative study and a longitudinal study, and consequently was able to draw on a detailed appreciation of the issues of importance to patients and carers. Furthermore, continuity was classified into relational and informational elements, and contrasted with other key attributes of primary health care. The questionnaire was not confined to an exploration of preferences, but by referring to

## ***Continuity of care: the views of patients and carers***

the most recent consultation was able to relate expressed preferences to what was experienced in the context of the immediate circumstances and the organisation of services. To our knowledge, this study is more securely grounded on evidence of patients' and carers' views and a theory of continuity than any previous survey of continuity in primary care.

### **6.3.2 Findings**

In this component of the study, we sought to determine the proportions of people in different groups holding particular views about the importance of continuity, and the context and circumstances in which various types of continuity are given greater or lesser weight in relation to other aspects of care (although the latter was also investigated in the SPDCE). The vast majority of patients want to consult someone who has time to listen and who has information about their clinical history (informational continuity), and most (but not all) experienced these attributes of care at their last consultation. Around two thirds of respondents regarded seeing someone they knew and trusted (relational continuity) as important, and most (but not all) of these experienced this attribute of care. Three quarters regarded booking in advance, choosing the type of professional and consulting someone they know as important, and most experienced these attributes. Most patients regarded seeing someone of the same sex or ethnic group as important, but seeing someone of the same sex was more important for women and seeing someone of the same ethnic group was more important for people in non-white ethnic groups. It appears, therefore, that most patients are able to negotiate a type of service that meets their preferences. Nevertheless, some patients do not succeed in negotiating their preferred type of service, and information on the characteristics of patients and service factors associated such failure is needed to enable providers to design services appropriately.

The survey investigated the extent to which variables in the four levels of the model (which includes the context and circumstances) explained patients' preferences and choices with respect to eight attributes of primary health care, three of which were relational continuity, informational continuity and longitudinal continuity. Variables in each level of the model helped to explain preferences and choices for relational continuity: *context* - the wider environment (whether Leicestershire or London), the immediate environment (the appointment system), the characteristics of the patient (age, health status, sex, employment status, ethnicity, IMD2004) and *circumstances* - type of health problem. Older people, people with worse health, females, and people consulting with non-acute problems were more likely to prefer relational continuity. People consulting a GP in a practice, people in Leicestershire rather than London, people in work or retired, older people, those consulting for routine rather than acute problems, and those attending practices with appointment

## ***Continuity of care: the views of patients and carers***

systems that allowed pre-booking were more likely to have their preferences met.

Levels of the model explaining informational continuity included the wider environment (Leicestershire or London), the immediate environment (practice size), characteristics of the patient (age, level of social isolation, ethnicity), and the circumstances (whether a GP in a practice or another professional was consulted, type of health problem). Levels of the model explaining longitudinal continuity included the immediate environment (appointment system), the characteristics of the patient (age, health status, level of social isolation, ethnicity, employment) and the circumstances (whether the consultation was about the individual or someone else, whether a GP in a practice was consulted or another professional, and type of health problem).

Variables related to the four levels of the model also explained preferences and choices for other attributes of care. Access was operationalised as being able to book in advance. We hypothesised that people with acute problems would wish to be seen quickly, but those with continuing problems would prefer to book in advance in order to see a particular professional. People who preferred to book in advance were older, had a routine problem, and were in work, and variables influencing whether they were able to book in advance were the practice appointment system, a higher educational level and increasing deprivation. Variables related to the model also explained the choice of professional expertise (the particular type of professional to consult), and consulting someone with time to listen. Only variables relating to patient characteristics explained preferences and choices for consulting someone of the same ethnic group (ethnicity, age), and only variables relating to the immediate environment (practice list size) and patient characteristics (level of social isolation, sex, ethnicity) explained preferences and choices for consulting someone of the same sex.

The findings support the findings of the qualitative and longitudinal studies in highlighting the role of the patient in contributing to their experience of primary care, in particular the level of continuity they obtain. Patients with new, minor problems tend to put speedy access before relational continuity in importance, and often also before informational continuity. Patients with long-term or more complex problems place greater weight on informational and relational continuity, the other attributes of the service giving way to the preference for an established relationship. The immediate environment influences the extent to which these preferences are met. Practice appointment systems which permit appointments to be booked in advance make relational continuity easier to achieve, and smaller practices also appear to have an effect in facilitating relational and longitudinal continuity. The wider environment also influences the likelihood of patients' preferences being met. Patients in London were less likely to have their preferences for aspects of continuity met than

## ***Continuity of care: the views of patients and carers***

those in Leicestershire. The explanation for this finding is unclear. There was no evidence that use of walk-in centres, NHS Direct or other alternative services explained this finding – indeed, these additional services did not appear to have any impact on patients' preferences and choices for continuity. This is consistent with the finding that walk-in centres do not have a significant impact on workload in nearby general practices (Chalder *et al*, 2003). We did not find evidence that the introduction of these services had led to fragmentation of care. It is probable that the features of the local health care service have a role in explaining the differences between Leicestershire and London, for example the greater diversity and complexity of services in London may make the achievement of continuity more difficult. The study does not provide evidence about the impact of substitution of GPs by nurses or other health professionals (Chapman *et al*, 2004). Most respondents appeared to regard a consultation with a GP as the norm (Table 6.18) and this is what they experienced.

Some patients find it particularly difficult to obtain care of the preferred attributes. Such patients may be less successful negotiators of their care. People who are not in work, or in a non-white ethnic group, or who have a degree of social isolation tend to have greater difficulty in obtaining what they want. This is an important finding. There is some US evidence on the views of non-white ethnic groups on their primary health care, Cooper-Patrick *et al* (1999) showing that African Americans rated their consultations as significantly less participatory than whites. This finding is supported by other US studies (Doescher *et al*, 2000). The way in which practices and local health services operate appears to discriminate against these disadvantaged groups. Service providers need to pay attention to the needs of these groups and take steps to help them obtain the primary health care they prefer. Such steps should involve minimising the complexity of service design and operating flexible appointment systems that include the option of booking appointments in advance. Training reception or triage staff in awareness of and sensitivity to the needs of people who have difficulty in negotiating their preferences for care may also have a role to play.

## Chapter 7 Discussion, conclusions and recommendations

### **7.1 Introduction**

In this Chapter we outline the main findings, consider the strengths and weaknesses of the component studies, consider how the findings have advanced knowledge and understanding of the place of continuity in the provision of primary health care, and discuss the implications for the health service and for further research.

### **7.2 Main findings**

#### **7.2.1 Views of patients and carers about continuity in primary care.**

We began this study after continuity of care had been highlighted as a priority area of interest by the SDO. Their scoping exercise had concluded that there was a lack of research about how patients and carers perceived and experienced it. This multi method study focused on the primary care setting in two parts of England, Leicestershire and West London. Our principal findings were:-

##### **1. Patients are well aware of the clash between relational continuity and quick access in primary care.**

As we perhaps expected, patients value all three aspects of continuity of care described by Haggerty *et al* (2003), that is relational (also called interpersonal), managerial, and informational. In common with professionals they often tended to take the term continuity to mean relational continuity although they recognised other aspects when prompted and sometimes volunteered these. Quite early in our study we found that patients were volunteering concerns, unprompted, about their increasing difficulty in seeing the doctor of their choice. We followed up these qualitative findings in later phases of the study. The longitudinal diary study (Chapter Four) showed how patients might sometimes give quick access higher priority than seeing a person they knew, but then they could be disappointed with that interaction.

##### **2. Patients and carers have clear views on when they need relational continuity.**

They want it for more serious and more impactful problems. They are much less concerned when they perceive themselves as fit and their problems do not seriously impact on their lives. This is most clearly illustrated in the SPDCE (Chapter Five) and backed up by the larger number of responses to our questionnaire survey (Chapter Six). By exercising choice according to the circumstances, patients are co-producers of experienced continuity.

## ***Continuity of care: the views of patients and carers***

### **3. Patients do not confine their view of continuity to primary care.**

They see no reason why the NHS should not join up in any way or aspect that their health problems require. This was particularly evident in some of the interviews with more seriously ill patients whose care required but did not always get good *cross-boundary continuity*. Patients expect GPs to know exactly what has happened to them in hospital and have the results of tests (Chapter Three).

### **4. These days, patients expect good *informational continuity*.**

At interview and in survey responses they told us how they expected their primary care professionals to have their records available and their resulting frustration if this does not happen. In the SPDCE and cross sectional survey, great importance was given by respondents to the professional having information on the patient's medical history.

### **5. Patients also value *relational continuity*.**

We used the words 'seeing a person you know and trust' to describe the positive therapeutic relationship which is the key feature of *relational* continuity. Patients particularly value relational continuity of care if they are in poorer health or for problems with great impact on their lives (Chapters Five and Six).

### **6. Continuity of care, both *informational* and *relational*, becomes generally more important as patients get older, become more ill and feel more vulnerable.**

The SPDCE (Chapter Five) showed that patients gave high priority to the availability of records and were prepared to wait for such an appointment. They would wait a shorter time to see someone they knew and trusted, even with new and unexplained symptoms. However, our scenarios did not include any situations where the patient had already felt threatened and vulnerable and symptoms suggesting deterioration were appearing.

### **7. Some patients are more successful than others in obtaining care with the attributes they prefer.**

The groups who are disadvantaged in this include those from non-white ethnic groups, the socially isolated, and those not in work. It is possible that patients in these groups are less effective in negotiating for their care, although the structure and organisations of services may also present more barriers for them to overcome. Our longitudinal study showed how even motivated patients could be frustrated in their attempts to get relational continuity.

### **8. There are differences between locations (London and Leicestershire) in the extent to which patients' preferences are met.**

Patients in London were less likely than those in Leicestershire to experience relational continuity, informational continuity or



## ***Continuity of care: the views of patients and carers***

longitudinal continuity<sup>2</sup> even when they preferred these attributes of care.

### ***7.3 Strengths and weaknesses***

#### **7.3.1 Strengths**

- This is the largest primary care study of its kind to focus on the views of patients and carers as opposed to doctors and nurses.
- Our multi-method approach has helped us go further than previously in unravelling the complexity of continuity as it is experienced by patients and the nature of the persistent commitment and negotiation that is needed to make personal continuity happen. We were able to get both depth and triangulation as well as a taste of 'choice in action' through the SPDCE.
- We were able to study a variety of settings in two areas in order to cope with previous suggestions that London might be different (which proved to be the case). While taking in a range of practices, we concentrated on larger practices in urban settings including substantial cultural minorities, whereas the folklore of relational continuity in primary care has often come from smaller practices in stable rural or semi-rural communities.
- Survey response rates were creditable considering the nature of the questionnaires and the reluctance of practices to get fully involved at this time of major practice upheaval (for example, the introduction of the new GMS contract simultaneously with new research governance processes).
- We included a longitudinal element. This is exceptional in the continuity literature.
- The input from our patient group was vital to the design of later study phases. This was voiced directly by our patient representative member of the study team.
- We recruited participants through a number of sources so as to include those who were not registered with a GP or did not look to general practice as their preferred site for primary care.

---

<sup>2</sup> Longitudinal continuity means merely that the patient's clinical contacts are mainly with the same clinician (or clinical team), without there necessarily being any therapeutic relationship (Saultz 2003). Some longitudinal continuity is necessary for good relational continuity but it need not be 100%.

## ***Continuity of care: the views of patients and carers***

### **7.3.2 Weaknesses**

That said, we were disappointed by participation rates, particularly by the response rate for our cross sectional survey. We therefore lacked the views of patients who might be getting poorer continuity, notably younger patients. Nevertheless, despite this qualification, the cross sectional survey did identify the problems faced by some relatively more vulnerable sub-groups of the population, including non-white ethnic groups and people who are socially isolated. Tables 7.1-4 present information about the participants in the qualitative, DCE and cross sectional studies. The study samples were similar to the national population in terms of ethnicity, and reasonably similar in terms of age, but were less representative in terms of gender (a greater proportion of participants were female) and occupation (a greater proportion of participants were retired). Some caution is therefore needed in generalising from the findings to all people resident in England and Wales. The multi-method nature of the study does to some extent provide reassurance since the principal findings are consistent between component studies, but it is possible that the preferences and choices of a younger, working population are not fully represented in our findings.

---

**Table 7.1 Ethnicity of the study participants in comparison with England and Wales.**

<b>Ethnic group</b>	<b>England &amp; Wales (%)*</b>	<b>Qualitative study (%)</b>	<b>DCE (%)</b>	<b>Cross sectional survey (%)</b>
White	91.3	79.5	91.8	90.0
South Asian	3.9	7.7	5.4	4.1
Black	2.2	5.1	1.1	2.3
Other	2.6	7.7	1.7	3.6

\*National Statistics (2005)

## ***Continuity of care: the views of patients and carers***

**Table 7.2. Gender of respondents compared to the population of England and Wales**

	<b>England &amp; Wales*</b>	<b>Qualitative study</b>	<b>DCE</b>	<b>Cross sectional survey</b>
% males	48.7	38.5	39.0	40.1
% females	51.3	61.5	61.0	58.5

\*National Statistics (2005)

**Table 3. Age group of participants compared to the population of England and Wales.**

	<b>England &amp; Wales (%)*</b>	<b>Qualitative study (%)</b>	<b>DCE (%)</b>	<b>Cross sectional survey (%)</b>
		11-17: 5.1		
18-29	16.8	18-29: 11.4	12.2	11.2
30-54	47.7	30-59: 39.7	25.2	36.2
55-74	25.3	60-79: 39.7	34.8	29.9
75 & above	10.1	80/+: 3.8	27.8	17.3

\*National Statistics (2005)

**Table 4. Employment and retirement among participants and in England and Wales.**

	<b>England &amp; Wales* (%)</b>	<b>Qualitative study</b>	<b>DCE</b>	<b>Cross sectional survey</b>
In work	60.6	34.6	43.0	49.2
Retired	13.6	-	45.0	33.9

\*National Statistics (2005)

- It was our impression that patients from cultural and ethnic minorities were less likely to respond to invitations to take part in interviews. Nevertheless, the proportion of people from ethnic minority groups in the study samples exceeded the proportion in the national population (Table 7.1) Since we have identified that people in non-white ethnic groups have different preferences for aspects of primary health care services and that their preferences are less likely to be met than people in white ethnic groups, future studies are required devoted specifically to ethnic minority groups.
- Delays with LREC and research governance procedures handicapped our conduct of the diary study and particularly the

## ***Continuity of care: the views of patients and carers***

two questionnaire studies. Every pilot test and every minor change to a questionnaire involved ethics committee and research governance review and approval, a process that added four to five months to the project schedule. This meant that the questionnaires had to be mailed in the summer holiday period which must have adversely affected response rates. There was no time left to wait for the favourable autumn period and in any case there was little enough time for considered analysis.

- The selection and consent procedures for the longitudinal diary study (Chapter Four) could have led to the recruitment of a disproportionate number of patients who regarded their practice particularly positively.

### **We mitigated these problems by:**

- Our researchers being persistent and working overtime on many occasions to meet deadlines.
- Using other available monies to hire extra researchers and administrative support over the final six months of the study.
- Being a well established multi-centre team with trust and good communications
- Opportunistic flexibility as the context of our work evolved, particularly around advanced access and the new GP contract, where practices could sometimes be persuaded that participation would give them both new understanding of their appointment booking systems and their patients' preferences as well as recognition by their local Primary care trust.
- Recruiting patients who were critical of their practice and dissatisfied with their care to the longitudinal diary study, as well as patients who rarely consulted and patients who looked outside general practice for their primary care services. The findings were thus novel and revealing.

## **7.4 How this study has advanced our knowledge and understanding**

The study has provided better understanding of:

- **When and how emphasis on quick access clashes with seeing the practitioner of choice.**

This study amplifies recent work by Schers *et al* in the Netherlands (2002) and Kearley in Oxfordshire (2001). Patients clearly adjust their priority for seeing a trusted practitioner according to the availability of appointments and the nature of their problem. Interestingly in our discrete choice experiment patients gave relational continuity highest priority in the scenario of a routine check up, whereas Kearley found that this was the one area where patients and doctors disagreed, with the Oxfordshire patients reporting less need to see their usual doctor for a hypertension or contraceptive check. This may be a methodological issue relating to the wording of questions, with lower perceived impact of the ongoing problems in Kearley's study. However, this project also offers support for the contentions of Bower *et al* (2001) that patients want *both* quick access *and* relational continuity – *where appropriate* – i.e. when the problem justifies it in their view.

The implication of this is that practices need to communicate better with patients about how they operate and how they may best be used. There seems to be great scope for less formal modern methods of communication using phone, text messages and email (see Mechanic D 2001<sup>3</sup>). Equally patients need assistance in communicating their needs. As the choice of primary care services widens it may no longer be good enough to have a culture where the patient does not expect to discuss the nature of their problem with the person (receptionist) with whom they are negotiating for access. They need help with choosing which service mode and/or practitioner who will suit them best. Currently practices handle this by using expensive experienced professionals (doctors and nurses) for so-called 'triage'. In future all practices may need to invest in receptionists specifically trained, skilled and empowered for this task. These staff will need to be highly skilled if they are to adequately assist disadvantaged patients obtain the care they prefer.

- **How patients value personal care and want to see it implemented in the modern NHS alongside good informational continuity**

We found strong support for *relational continuity* – with patients very willing to give it less priority for minor problems. The survey (Chapter

---

3 Mechanic D. How should hamsters run? Some observations about sufficient patient time in primary care. *BMJ* 2001;323:266-268

## ***Continuity of care: the views of patients and carers***

Six) suggested that patients in some practices may have had to prioritise personal continuity less because it is just not an option for them. But those who experience it want to see it continue. Patients give even higher priority to *informational continuity* and clearly will not tolerate an NHS which lacks a proper communication of records between appropriate professional team members and across institutional boundaries.

For more serious problems and for older and less independent patients, our respondents generally did not see informational continuity as replacing relational continuity as is so often assumed. Rather they see informational continuity as a basic right or constituent of care, and relational continuity as a highly desirable aspect of care.

- **The ways in which patients cope with access systems in primary care**

The longitudinal diary study has given us a unique and original account of what is involved for patients in getting and retaining relational continuity. This proves to require commitment, persistence, tact and social skill for repeated negotiations with receptionists. The lesson is that less fortunate patients need help from the NHS. Primary Care Organisations (Trusts and practices) need to invest in training staff to be sensitive to the needs of patients who may be either socially or culturally disadvantaged or too distressed by their problems to negotiate the relational continuity that they might particularly benefit from. Perhaps the NHS can learn from the successful patients.

We also found that the inflexible operation of advanced access systems created difficulties for some patients who wished to book in advance to see a particular professional. Work we have already published (Windridge *et al*, 2004) has contributed to informing a review of policy, and health authorities and PCTs have been instructed to request practices to halt the embargoing of appointment slots beyond the 48-hour access target.

- **The vital roles played by all members of primary care teams particularly nurses as practitioners and receptionists as mediators of access**

Generally patients differentiated less between doctors and nurses than we expected. It seems that, where suitable nurses and nurse practitioners are available, they have potential for bearing a greater share of the work of delivering clinical primary care. We did not specifically examine the ways in which patients most valued interaction with nurses – whether for primary assessment of undifferentiated problems or ongoing management and support of established diagnoses. This will need more detailed study in future. In particular, most practices still have relatively few nurses and so the problems of the loss of personal continuity in practices with large complements of GPs have yet to be faced. Some practices still do not book appointments with individual named nurses. Receptionists were

## ***Continuity of care: the views of patients and carers***

very salient in the diary study and their role was constantly being questioned in relation to access and appointments in the other studies. More work on how to develop and refine receptionist roles for better patient service is urgently needed.

*Overall* our findings are consistent with the work of Bower *et al* (2001) suggesting that patients indeed want *both* quick access *and* relational continuity, rather than one or the other. But fitter patients with minor problems would be happy with quick access to a less well-known practitioner. Relational continuity needs to be a higher priority for both practices and primary care trusts. Practitioners need incentives and also education about how to maximise relational continuity of care in their own contexts. Primary care trusts need to be more aware that their performance may be judged by their ability to help their professionals give care which is satisfyingly personal for patients and carers.

### ***7.5 The findings and development of the model of continuity***

#### ***Experienced continuity as an outcome***

Experienced continuity as described in the scoping report is an *outcome* - the patient's experience of care as continuous and joined up. The other dimensions of continuity (relational, informational, management) are *processes* that produce this outcome for the patient. A feeling of continuity is based on the sum of experiences over time. The experience of continuity becomes more important, and needs more work to maintain, as there are more 'things' to continue over time (treatments, emotions, stories, and so forth).

One or more processes might need to happen to produce this experience of continuity. Relational continuity is one way of producing continuity (this can ensure continuity of management, information, and care - in particular this is the only way in which continuity of 'personal knowledge' about the patient can happen), so in some ways relational continuity is the highest level - the most complete and efficient way to produce a feeling of continuity. However, even though relational continuity might be the best process to produce the experience of continuity, it may not always be desirable, for example, it may mean the patient having to wait longer for appointments, or even have negative consequences such as missed diagnoses - e.g. we interviewed a carer whose husband's lung cancer was diagnosed by their 'non usual' GP. Relational continuity may not always be possible or necessary. Patients can feel that their care is continuing when information is passed between health professionals, or health professionals work together to co-ordinate treatment or management. We are not, therefore recommending that relational continuity be imposed, merely that it be facilitated rather than handicapped. In a recent review Saultz proposes interpersonal (i.e. relational) continuity

## ***Continuity of care: the views of patients and carers***

as the highest of three hierarchical levels (Saultz 2003). The lowest level is informational continuity, with longitudinal continuity, that is repeated contacts with one individual or team as an intermediate level. This hierarchical scheme does not fit the UK context well but our findings are compatible with a view that relational continuity is a 'higher order' aspect of continuity, while the need for continuity of information is seen as a basic need by patients and professionals.

The model (see Chapter Two) does not fully address the relationships between the different varieties of continuity. In order to understand how to provide the sort of continuity needed (to inform policy, PCTs, practices), guidance is needed on what makes the processes that produce a feeling of continuity happen - who is responsible for continuity?

Continuity is produced by the system/organisations, by individual practitioners, and by the patient (e.g. the way they use the system). In defining what continuity is we need to look at what the system does, what the patient does, and the interaction between the two - any of these can make or break continuity. By clarifying these issues we are in a better position to find out how to provide continuity.

Relational continuity is jointly produced, as described in the model: the system (e.g. appointment system - particularly to what extent it sets up a tradeoff between personal continuity and quick access, personal list system), the individual provider (whether they ask the patient to come back and see them again, how often they are available), and the patient (the importance they place on personal continuity and their willingness to trade-off against quick access, the strategies they use to access the system, their resources). Indeed, a key finding of the study is the role that patients play in negotiating with providers to obtain care that meets their preferences. There is a problem, however, if a patient with a need for relational continuity is confronted by barriers at any of these levels (e.g. an appointment system that makes personal continuity difficult). The problem is particularly severe if the patient is not an effective negotiator or is disadvantaged, for example because of their social circumstances or ethnic group. Such barriers may not be apparent on casual review of a practice's access system. It is necessary to seek patients' actual experiences.

In contrast, continuity of information is mainly produced by: the system (information recording and transfer) and the individual provider (through getting to know the patient, or familiarising themselves with the notes), although the patient has some responsibility (e.g. providing relevant information). Sometimes the informational continuity that should have been provided by the system or individual providers breaks down. Patients can sometimes compensate for example, by retelling their story, but this can undermine their confidence in the service and is inefficient. This is also problematic if the patient is unable to take responsibility for continuity



## ***Continuity of care: the views of patients and carers***

of their information (for example, if they have difficulties in communication).

Continuity of management is the responsibility of: the system (policies, protocols, organisation of services), and individual practitioners (making management plans, communicating with other practitioners). (We accept that there is a trend for greater involvement of patients in the management of some conditions, but this process is not yet well developed and was not evident in our studies). When continuity of management/treatment breaks down, it is difficult for patients to correct the problem - many of the negative or distressing stories recounted by patients in our studies concerned their attempts to compensate for breakdowns in management continuity (see for example the story reported in Low, 2004, in the Appendices).

It is important to note that relational continuity can help to bridge the gaps in information or management continuity caused by failures in the system. In this way, relational continuity therefore has a central role in the care of people with complex problems.

### ***7.6 Implications***

#### ***7.6.1 The service***

Primary health care services continue to develop in order to meet the need for health care as efficiently and effectively as possible. Our findings indicate that continuity will remain an important attribute of care. In reviewing the future options for the provision of health care, the Wanless Report (Wanless, 2002) recognised the importance to many patients of continuity in primary care, but acknowledged that maintaining continuity in the increasingly fragmented and complex health service of the future will be a key challenge.

The Department of Health is currently conducting a consultation exercise in preparation for the publication of a white paper on services provided in the community by the NHS and social care (Department of Health, 2005). One of the three questions being asked in the consultation is: 'how, when and where do you want to get help when you need you need it?'. Whilst the content of the forthcoming white paper cannot be predicted, it is clear, therefore, that access and continuity are among the issues the white paper will consider. The proposals it will contain are likely to be informed by the findings of the annual patient surveys of patient experience of primary care. The recently published 2005 survey (Healthcare Commission, 2005) has served to highlight the importance of access and continuity. Seventy-four per cent of respondents reported being seen within the 48 hour national target. Thirty-eight per cent reported delaying an appointment in order to consult a doctor of their choice, and 70% reported that their practice allowed them to book appointments more than three days in advance.

## ***Continuity of care: the views of patients and carers***

Our findings throw additional light on the significance of relational continuity and have implications for policymakers and those who deliver primary care services.

### **7.6.2 Policymakers**

Policymakers, including those charged with preparing the white paper, should consider whether new policies will serve to make the provision of relational continuity to those patients who want this feature of care more or less difficult. Our findings indicate that some patients do have difficulty in obtaining relational continuity when they want it, particularly people who are poorly equipped to challenge providers or understand the operation of increasingly complex service structures. Policymakers should consider encouraging providers to recognise the needs of such patients and ensure that they can respond with flexibility and understanding. This means encouraging systems where patients are specifically invited to express their preference for whom they see and then taking steps to make this possible. There is a need for further research on how to do this (see implications for research below). Policymakers should also recognise that informational continuity is a necessary attribute of primary care but is not a substitute for relational continuity.

In encouraging relational continuity for those patients who want it, policymakers should ensure that it is taken into account in performance monitoring. For example, the annual national primary care patient survey should be modified to include questions on relational and informational continuity. Consideration should also be given to the inclusion of a question on cross-boundary/interface continuity. In order to encourage practices to operate appointment systems that facilitate relational continuity, the Quality and Outcomes Framework (QOF) should be amended, for example by rewarding practices that allow patients to book appointments in advance (to enable patients to negotiate absence from work, or arrange care of a dependent family member, or arrange transport etc). The period that should be open to advanced bookings will vary depending how many appointment slots are filled and the preferences of the patient. Some of the patients we interviewed booked their appointments a month in advance to make sure they saw their doctor of choice and had plenty of time to make their arrangements to attend.

The new white paper may give encouragement to the decline in numbers of small practices and their replacement by large groupings or big units sometimes referred to a 'super-surgeries'. As the same time, GPs may receive encouragement to specialise in discrete fields of care, with some becoming designated as GPs with special interests. These policy developments must be introduced in a form that does not impair the ability of those patients who want relational to obtain it. This means that relational continuity is an issue that all practices, and not merely small ones, should be expected to offer. Large groupings or big units must be required to operate systems that allow for

## ***Continuity of care: the views of patients and carers***

relational continuity, and to demonstrate that patients who want relational continuity are receiving it. The appointment systems of GPs with special interests, who only work part-time as normal GPs, should make provision for relational continuity by, for example, making a greater proportion of their appointments bookable more than a week in advance rather than bookable only on the same day, and encouraging receptionists to respond flexibly to patient requests to see their chosen doctor. The explanation for the difference experience of patients in London and Leicestershire is uncertain. Health services in London are more various and potentially more complex than those in Leicestershire, but patients in the two settings may have different perspectives. This issue would justify further research.

### **7.6.3 PCTs**

PCTs in England are currently undergoing re-structuring, with commissioning being transferred to practices. Nevertheless, they have a role to play in facilitating the provision of relational continuity to those patients who want it. They need to give priority to relational continuity in managing practice performance, balancing access targets with an equally valued priority for relational continuity. In their management of out-of-hours services and walk-in centres, attention should be given to local policies on the appropriate transfer of information to the patient's general practitioner. In designing new services at the interface with secondary care, simplicity of service structure from the patient's perspective should be a key goal, and evaluations of new services should give careful attention to the experience of patients and carers. In areas in which a high proportion of the population belong to minority ethnic groups, PCTs need to make sure that practices are operating appointment systems that take the account of the particular needs of local people. PCTs should also support professional development and other training activities that enable practices to learn how to provide relational continuity.

### **7.6.4 Practices**

There are also implications for practices. In addition to improving relational continuity, efforts by practices to improve informational and managerial continuity of care are also needed. Part of this lies in improved information technology, through shared records and direct booking systems. But part lies through staff training and retaining the personal touch and judgement at all levels. The flexibility and understanding needed to respond to patients who request relational continuity depends on the attitudes of practice staff and the policies they are asked to follow. Therefore, practices themselves need to consider how much they should prioritise relational continuity and how to implement their agreed decision, bearing in mind the needs of less assertive patients. This needs team work, staff awareness and training. An important improvement is to inform their patients more

## ***Continuity of care: the views of patients and carers***

effectively on how they operate their appointment systems, and invite patients to bring their particular needs to the attention of receptionists. Wider availability of information of this type would enable patients to make more informed choices about which practice to attend. It should be made easy for patients to express their choice of professional, and they should be encouraged to access this person or people at all times. Satisfaction measures used by practices should include assessment of access to relational continuity.

Particular attention must be given by practices to those patients who find it difficult to negotiate for the attributes of care they prefer. This may involve the identification of such patients in much the same way as chronic diseases are coded in practice IT systems. By identifying and highlighting patients who have difficulty negotiating for the care they prefer, practices will be in a better position to reduce the disadvantages these patients otherwise have to cope with.

### **7.6.5 Professionals**

Some primary care professionals may believe that the importance of relational continuity has declined, since people tend to move home more frequently and expect quick access to care. Professionals, therefore, do not need to make any effort to offer relational continuity.

The findings of this study challenge this viewpoint. It is certainly true that many patients do not seek relational continuity, but those with worrying or complex problems do. Professionals need to be aware that patients have different needs, and that they must accommodate to these needs. The concept of relational continuity should be included in the training of primary care professionals, attention being given to the different roles of relational, informational and management continuity, and the preferences of patients for different types of continuity at different times in their lives. Professional bodies also have a role to play. Bodies that provide assessment schemes (for example, the Royal College of General Practitioners Fellowship by Assessment or Quality Practice Award schemes) should include review of the provision of relational continuity.

### **7.6.7 Research**

(a) More research is required on how patients achieve relational continuity and on the barriers and enablers to this. Studies would include:

- Longer and larger diary studies, perhaps concentrating on people with a major problem such as diabetes or depression.
- A follow-up study of 1-2 years of a sample of patients newly registering with a practice. Patients could be recruited at registration and selected if they seem to have ongoing problems of sufficient impact to justify prioritised relational continuity of care

## ***Continuity of care: the views of patients and carers***

(for example by receptionists referring to a priority list when negotiating access to the most appropriate practitioner).

(b) Is relational continuity worth more to the NHS than currently realised? What are the costs of discontinuity/anonymity in terms of waste, duplication and dissatisfaction?

- studies within practices about the use of resources in relation to the number of different practitioners seen alongside assessment of clinical outcomes.

(c) How can we help practices improve relational continuity?

- studies of staff behaviour – especially receptionists
- exploration of different ways of empowering those patients who have difficulty in negotiating the care they prefer; example methods may include computerised self-booking systems, patient advocacy systems, and receptionist and/or patient training
- intervention studies of how to give higher priority to relational continuity, including educational instruments and feedback and reward systems.

(d) Putting these facets together the goal should be the phased development of a research programme culminating in a major trial of a well worked out intervention to improve relational continuity with qualitative parallel study of mechanisms and outcomes which include costs, clinical endpoints, and patient and staff morale and satisfaction.

### ***7.8 Conclusion***

We have found much good practice and a wide variety of patient views. Informational continuity is valued by all and continued efforts to improve this, including the use of shared electronic patient records, are fully justified. But for many patients, improved informational continuity is seen in addition to rather than as a substitute for appropriate relational continuity. Patients are finding that relational continuity is sometimes difficult to achieve, especially in the context of single-minded prioritising of access. The DH is aware of this to some extent, and recently proposed guidance to PCTs that they should specify a minimum of three days availability of advance booking could be some help if implemented sensitively.

But proper valuing and encouragement of relational continuity needs a combination of better understanding of the symbiosis between access and continuity and imaginative ways of ascertaining and then meeting patients' preferences.

## Chapter 8 References

### Chapter 1

Airey C, Bruster S, Erens B, Lilly S, Pickering K, Pitson L. 1999. *National Survey of NHS Patients*. General practice 1998. London: NHS Executive (<http://193.32.28.83/public/nhssurvey.htm>).

Baker R, Mainous AG III, Gray DP, Love MM. 2003. Exploration of the relationship between continuity, trust in regular doctors and patient satisfaction with consultations with family doctors. *Scan J Prim Health Care* 21:27-32.

Baker R, Streatfield J. 1995. What type of general practice do patients prefer? *Br J Gen Pract* 45:654-9.

De Maeseneer JM, De Prins L, Gosset C, Heyerick J. 2003. Provider continuity in family medicine: does it make a difference for total health care costs? *Annals of Family Medicine* 1:144-8.

Freeman G, Shepperd S, Robinson I, Ehrich K, Richards S, Pittman P, Sand H. 2000. *Report of a Scoping Exercise for the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO)*.

Gulliford M, Morgan M, Hughes D, Beech R, Figeroa-Munoz J, Gibson B, Hudson M, Arumugam C, Connell P, Mohiddin A, Sedgwick J. 2001. *Report of a Scoping Exercise for the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO)*.

Haggerty JL, Reid RJ, Freeman GK, Starfield BH, Adair CE, McKendry R. 2003. Continuity of care: a multidisciplinary review. *BMJ* 327:1219-21.

Harrison A, Dixon J, New B, Judge K. 1997. Funding the NHS. Can the NHS cope in the future? *BMJ* 314:139-42.

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

Howie JGR, Heaney DJ, Maxwell M, Walker JJ, Freeman GJ, Rai H. 1999. Quality at general practice consultations: cross sectional survey. *BMJ* 319:738-43.

Kinnersley P, Anderson E, Parry K *et al*. 2000. Randomised controlled trial of nurse practitioner versus general practitioner care for patients requesting 'same day' consultations in primary care. *BMJ* 320:1043-8

Koopman R, Gill J, Mainous AG III, Baker R, Gilbert G. 2003. Continuity of care and recognition of diabetes, hypertension, and hypercholesterolemia. *Archives of Internal Medicine* 163:1357-61

## ***Continuity of care: the views of patients and carers***

Lomas J, Fulop N, Gagnon D, Allen P. 2003. *On Being a Good Listener: Setting Priorities for Applied Health Services Research*. Millbank Quarterly, 81(3):

Mainous AG, Baker R, Love MM, Gray DP, Gill JM. 2001. Continuity of care and trust in one's physician: evidence from primary care in the United States and the United Kingdom. *Fam Med* 33:22-7.

Mainous AG III, Koopman RJ, Gill JM, Baker R, Pearson WS. 2004. The relationship between continuity of care and diabetes control: Evidence from the National Health and Nutrition Examination Survey III. *American Journal of Public Health* 94:66-70.

Meerabeau L. 1998. Consumerism and health care: the example of fertility treatment. *Journal of Advanced Nursing* 27:721-9.

McKinley RK, Fraser RC Baker RH, Riley RD. 2004. The relationship between measures of patient satisfaction and enablement and professional assessments of consultation competence. *Medical Teacher* 3:223-8

NHS Service Delivery and Organisation National R&D Programme 2000. *National Listening Exercise: Report of the Findings*. <http://www.sdo.lshtm.ac.uk/pdf/listeningexercisereport.pdf>

Nutting PA, Goodwin MA, Flocke SA, Zyzanski SJ, Stange KC. 2003. Continuity of primary care: to whom does it matter and when? *Annals of Family Medicine* 1:149-55.

Preston C, Cheater F, Baker R, Hearnshaw H. 1999. Left in limbo: patients' views on care across the primary/secondary interface. *Quality in Health Care* 8:16-21.

Raddish M, Horn SD, Sharkey PD. 1999. Continuity of care: is it cost effective? *Am J Manag Care* 6:727-34.

RCGP. 1996. *The Nature of General Medical Practice. Report from practice 27*. London: Royal College of General Practitioners.

Saultz JW. 2003. Defining and measuring interpersonal continuity of care. *Ann Fam Med* 1:134-43.

Saultz JW, Albedaiwi W. 2004. Interpersonal continuity of care and patient satisfaction: a critical review. *Ann Fam Med* 2:445-451.

Schers HJ, Webster S, van den Hoogen HJM, Avery A, Grol RPTM, van den Bosch WJHM. 2002. Continuity of care in general practice: a survey of patients' views. *Br J Gen Pract* 52:459-62.

Tarrant C, Windridge K, Bolton M, Baker R, Freeman G. 2003. Qualitative study of the meaning of personal care in general practice. *BMJ* 326:1310

Venning P, Durie A, Roland M, Roberts C, Leese B. 2000. Randomised controlled trial comparing cost effectiveness of general practitioners and nurse practitioners in primary care. *BMJ* 320:1048-53.

## ***Continuity of care: the views of patients and carers***

### **Chapter 2**

Bryan S, Buxton M, Sheldon R, Grant A. 1998. Magnetic resonance imaging for the investigation of knee injuries: an investigation of preferences. *Health Economics* 7:595-603

Bryan S, Gold L, Sheldon R, Buxton M. 2000. Preference measurement using conjoint methods: an empirical investigation of reliability. *Health Economics* 9:385-95.

Kralewski J, Dowd BE, Kaissi A, Curoe A. 2004. Measuring the culture of medical group practices. Personal communication

Ryan M, Farrar S. 2000. Using conjoint analysis to elicit preferences for health care. *BMJ* 320:1530-3.

### **Chapter 3**

Balint M. 1957. *The doctor, his patient, and the illness*, Pitman, Tunbridge Wells.

Bryman A. 2001. *Social Research Methods*, Oxford University Press, Oxford.

Lockenhoff CE, Carstensen LL. 2004. Socioemotional selectivity theory, aging, and health: The increasingly delicate balance between regulating emotions and making tough choices. *Journal of Personality* 72 :1395-1424.

Low J. 2004. Continuity of care from the patient's point of view: context, process and relation. *Family Medicine* 36:61-4.

Mano H. 1992. Judgements under distress: Assessing the role of unpleasantness and arousal in judgement formation. *Org. Behav. Human. Dec. Process*, 52, 216-245.

Stokes T, Dixon-Woods M, Windridge KC, McKinley RK. 2003. Patients' accounts of being removed from their general practitioner's list: qualitative study. *BMJ*. 326(7402): 1316.

### **Chapter 4**

Ritchie J, Lewis J (eds). 2003. *Qualitative Research Practice: A guide for social science students and researchers*. London: Sage

### **Chapter 5**

Bishop AJ, Marteau TM, Armstrong D, Chitty LS, Longworth L, Buxton MJ, Berlin C. 2004. Women and health care professionals' preferences for Down's Syndrome screening tests: a conjoint analysis study. *BJOG* 111;775-9

Brookes R. 1996. EuroQual: The current state of play. *Health Policy* 37:53-72.



## ***Continuity of care: the views of patients and carers***

Hundley V, Ryan M. 2004. Are women's expectations and preferences for intrapartum care affected by the model of care on offer? *BJOG* 111;550-60.

Hundley V, Ryan M, Graham W. 2001. Assessing women's preferences for intrapartum care. *Birth* 28(4) 254-263.

Halpern SD, Berns JS, Israni AK. 2004. Willingness of patients to switch from conventional to daily hemodialysis: looking before we leap. *American Journal of Medicine* 116;606-12.

Gan TJ, Lubarsky DA, Flood EM, Thanh T, Mauskopf J, Mayne T, Chen C. 2004. Patient preferences for acute pain treatment. *British Journal of Anaesthesia* 92;681-8.

Johansson G, Stallberg B, Tornling G, Andersson S, Karlsson GS, Falt K, Berggren F. 2004. Asthma treatment preference study: a conjoint analysis of preferred drug treatments. *Chest* 125;916-23.

Kearley K, Freeman, GK, Heath A. 2001. An exploration of the value of the personal doctor-patient relationship in general practice. *Br J Gen Pract* 51(470);712-718.

Longworth L, Ratcliffe J, Boulton M. 2001. Investigating women's preferences for intrapartum care: home versus hospital births. *Health and Social Care in the Community* 9(6), 404-413.

Louvier JJ, Hensher DA, Swait JD. 2000. *Stated choice methods – analysis and application*. Cambridge: Cambridge University Press.

Permain D, Swanson J, Kroes E, Bradley M. 1991. *Stated Preference Techniques: A guide to practice*. Hague Consulting Group, The Hague.

Ratcliffe J, Buxton M, McGarry T, Sheldon R, Chancellor J. 2004. Patients' preferences for characteristics associated with treatments for osteoarthritis. *Rheumatology* 43;337-45

Ryan M, Farrar S. 2000. Using conjoint analysis to elicit preferences for health care. *BMJ* 320:1530-1533.

Schers H, Webster S, van den Hoogen H, Avery A, Grol R, van den Bosch W. 2002. Continuity of care in general practice: a survey of patients' views. *Br J Gen Pract* 52(479):459-462.

Scott A, Watson, MS, Ross S. Eliciting preferences of the community for out of hours care provided by general practitioners: a stated preference discrete choice experiment. *Social Science and Medicine* 56. 2003. 803-14.

Vick S, Scott A. 1998. Agency in health care. Examining patients' preferences for attributes of the doctor-patient relationship. *Journal of Health Economics*. 17;587-605.

## ***Continuity of care: the views of patients and carers***

### **Chapter 6**

- Baker R, Whitfield M. 1992. Measuring patient satisfaction: a test of construct validity. *Quality in Health Care* 1:104-9.
- Blaxter M. 1990. *Health and Lifestyles*. London: Routledge
- Blaxter M, Poland F, Curran M. 2001. Measuring Social Capital: *Qualitative Study of how older people relate social capital to health. Final Report to the Health Development Agency*. London
- Chalder M, Sharp D, Moore L, Salisbury C. 2003. Impact of NHS walk-in centres on the workload of other healthcare providers: a time series analysis. *BMJ* 326:532.
- Chapman JL, Zechel A, Carter YH, Abbott S. 2004. Systematic review of recent innovations in service provision to improve access to primary care. *Br J Gen Pract* 54:374-81.
- Crow R, Gage H, Hampson S, Hart J, Kimber A, Storey L *et al*. 2002. The measurement of satisfaction with healthcare: implications for practice from a systematic review. *Health Technol Assess* 6:(32).
- Department of Health. 2002. *The 2002 NHS Patient Survey*. [www.dh.gov.uk/assetRoot/o4/02/40/50/04024050.pdf](http://www.dh.gov.uk/assetRoot/o4/02/40/50/04024050.pdf)
- Department of Health 1998. *The 1998 NHS Patient Survey*. [www.dh.gov.uk/assetRoot/04/03/59/99/04035999.pdf](http://www.dh.gov.uk/assetRoot/04/03/59/99/04035999.pdf)
- Doescher MP, Saver BG, Franks P, Fiscella K. 2000. Racial and ethnic disparities in perceptions of physician style and trust. *Arch Fam Med* 9:1156-63.
- EuroQol Group. 2004. What is EQ5D? <http://www.euroqol.org/index.htm> (accessed 11 February 2005).
- Healthcare Commission. 2003. *Primary Care Trust Patient Survey 2003*. [www.chai.org.uk/assetRoot/04/00/46/20/04004610.pdf](http://www.chai.org.uk/assetRoot/04/00/46/20/04004610.pdf)
- Healthcare Commission. 2004. *Patient survey report 2004 – primary care*. London: Healthcare Commission.
- Jung HP, Baerveldt C, Olesen F, Grol R, Wensing M. 2003. Patient characteristics as predictors of primary health care preferences: a systematic literature analysis. *Health Expectations* 6:160-81.
- NHS Confederation and BMA. 2003. *New GMS Contract 2003*. London: General Practitioners Committee and NHS Confederation, 2003
- Office of the Deputy Prime Minister. 2003. *The English Indices of Deprivation, 2004*. London: The Queen's Printer and Controller of Her Majesty's Stationery Office.
- Rashbash J, Steele F, Browne W, Prosser B. 2004. *A User's Guide to Mlwin, version 2*. London Centre for Multilevel Modelling, University of London.

## ***Continuity of care: the views of patients and carers***

Schers H, Webster S, van den Hoogen H, Avery A, Grol R, van den Bosch W. 2002. Continuity of care in general practice: a survey of patients' views. *Br J Gen Pract* 52:459-62.

Stokes ME, Davis CS, Koch GG. 2000. *Categorical Data Analysis using the SAS System*. SAS Institute Inc: Cary, North Carolina.

### **Chapter 7**

Bower P, Gask L, May C, Mead N. 2001. Domains of consultation research in general practice. *Patient Education and Counselling* 45:3-11.

Department of Health. 2005. About your health, your care, your say. Survey of patients 2005. Primary Care Trust.  
[http://www.dh.gov.uk/NewsHome/YourHealthYourCareYourSay/YourSayArticle/fs/en?CONTENT\\_ID=4118922&chk=XaM1VB](http://www.dh.gov.uk/NewsHome/YourHealthYourCareYourSay/YourSayArticle/fs/en?CONTENT_ID=4118922&chk=XaM1VB)

Haggerty JL, Reid RJ, Freeman GK, Starfield BH, Adair CE, McKendry R. 2003. Continuity of care: a multidisciplinary review. *BMJ* 327:1219-21.

Healthcare Commission. 2005.  
<http://www.healthcarecommission.org.uk/assetRoot/04/01/93/73/04019373.pdf>

Kearley KE, Freeman GK, Heath A. 2001. An exploration of the value of the personal doctor-patient relationship in general practice. *Br J Gen Pract* 51:712-8.

Low J. 2004. Continuity of care from the patient's point of view: context, process and relation. *Family Medicine* 36:61-4.

Office of National Statistics. 2005. 2001 Census.  
<http://www.statistics.gov.uk/census2001/census2001.asp>

Saultz JW. Defining and Measuring Interpersonal Continuity of Care *Ann. Fam. Med*, 2003;1:134-143.

Schers H, Webster S, van den Hoogen H, Avery A, Grol R, van den Bosch W. 2002. Continuity of care in general practice: a survey of patients' views. *Br J Gen Pract* 52:459-62.

Wanless D. 2002. *Securing our Future: Taking a Long Term View. Final Report*. London: HM Treasury ([http://www.hm-treasury.gov.uk/consultations\\_and\\_legislation/wanless/consult\\_wanless\\_final.cfm](http://www.hm-treasury.gov.uk/consultations_and_legislation/wanless/consult_wanless_final.cfm))

Windridge K, Tarrant C, Freeman G, Baker R, Boulton M, Low J. 2004. Problems with a 'target' approach to access in primary care: a qualitative study. *Br J Gen Pract* 54:316-3.

## Appendices

1. Consultation record booklet used in the longitudinal study.
2. Version of the patients' choices questionnaire used in the SPDCE.
3. Long version of the cross sectional survey questionnaire.
4. Short version of the cross sectional survey questionnaire.
5. Two articles reporting aspects of the findings – not published here for copyright reasons.

## **Disclaimer**

This report presents independent research commissioned by the National Institute for Health Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, the NIHR SDO programme or the Department of Health. The views and opinions expressed by the interviewees in this publication are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, the NIHR SDO programme or the Department of Health

## **Addendum**

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

The management of the Service Delivery and Organisation (SDO) programme has now transferred to the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton. Prior to April 2009, NETSCC had no involvement in the commissioning or production of this document and therefore we may not be able to comment on the background or technical detail of this document. Should you have any queries please contact [sdo@southampton.ac.uk](mailto:sdo@southampton.ac.uk).

Addendum:

This report was amended on 29<sup>th</sup> September 2011 to update the correct copyright statement and/or correct the publication date. The content of the report has not been changed.