Patients’ experiences of continuity in the care of type 2 diabetes: a focus group study in primary care

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ABSTRACT

Background
Continuity of care is fundamental to general practice and type 2 diabetes is a common chronic disease with major health and social impacts. Nevertheless, continuity, as experienced by patients with type 2 diabetes, remains a neglected area.

Aim
To explore perceptions and experiences of continuity of care in general practice from the perspectives of patients with type 2 diabetes, focusing on the advantages and disadvantages of different types of continuity.

Design of study
Focus groups with patients.

Setting
Seven practices with different organisational structures in Leeds, UK.

Method
Seventy-nine patients with type 2 diabetes were recruited. Focus group interviews were conducted with 79 patients with type 2 diabetes from seven practices in Leeds, UK.

Results
Patients experienced three different types of continuity: relational (or longitudinal) continuity, cross-boundary (or team) continuity, and continuity of information. Patients’ perceptions of continuity were influenced by several factors including a personal relationship between themselves and their healthcare professional, their own beliefs and behaviours, presence of diabetes, and the systems and structures of general practices. Patients identified the advantages and disadvantages of two types of continuity. Relational or longitudinal continuity was important in providing psychosocial care, but with a risk of misdiagnosis. The advantages of cross-boundary or team continuity were to provide physical care, whereas the main disadvantages were the absence of personal care and patient confusion.

Conclusion
Perceptions of continuity by patients with type 2 diabetes were influenced by several factors; they perceived several advantages and disadvantages associated with different types of continuity. Patients might expect certain healthcare benefits by following certain types of continuity.

Keywords
continuity of care; general practice; patients; type 2 diabetes mellitus.

INTRODUCTION

Type 2 diabetes is a major public health problem, associated with significant morbidity and mortality.1 The UK Prospective Diabetes Study (UKPDS) showed that intensive glycaemic control reduces the progression of diabetes-related complications.2 Five years after its completion, patients reported peace of mind because they felt that they could share their concerns with professionals who listened and developed trust with them over many years; most participants were keen to join another trial as long as clinical management was provided by the same health professional.3

Continuity has been regarded as a crucial component of quality of care.4,5 Experienced continuity is defined from the patient’s perspective as the coordinated and smooth progression of care.6 There are several aspects of experienced continuity; these are summarised in Box 1.

Over the past 20 years, diabetic care in the UK has moved from the traditional hospital-based system to joint care between the hospital and primary care, and this process is set to continue.10 The management of diabetes as a chronic disease requires support from a team comprising individuals from different disciplines and with different training.11 Patients may be given...
conflicting advice by different team members because the doctor or nurse does not have all the information needed for the consultation.12,13 Furthermore, the information in clinical records may be incomplete or incorrect,14 and problems may be compounded between care settings.14,15

Taking patients’ views into account is associated with greater perceived relational or longitudinal continuity,15 but there is a lack of research about when continuity would benefit patients. The aim of this study was to explore the perceptions and experiences of continuity from the perspective of patients with type 2 diabetes, focusing on the advantages and disadvantages of different types of continuity.

**METHOD**

**Sampling and recruitment of practices**

This study was undertaken in Leeds, UK. Maximum variation purposive sampling17 was employed to recruit seven practices from different demographic settings (two rural, five urban), of different list sizes — two small practices (<4000 patients), two medium-sized practices (4000–10000 patients), and three larger practices (>10000 patients) — and operating different appointment systems (one allocating patients to GPs’ personal lists).

**Sampling and recruitment of patients**

Patients with diabetes who were registered with the recruited practices were grouped according to their age in 10-year age bands (21–30, 31–40, 41–50, 51–60, 61–70, >71 years) and were sampled from each age group depending on the number represented in that age band (that is, more patients in an age group meant more were selected). As sampling patients from different ages is one criterion of maximum variation purposive sampling, we used 10-year age bands to ensure that the focus groups comprised patients of different ages.

Patients were sent a letter to inform them of the study and ask if they wanted to participate; reminders were sent after 2 weeks. If patients did not respond after a further 2 weeks, others with similar age and sex characteristics were sampled. This process was repeated until sufficient participants (n = 4–10) of males and females in approximately equal numbers had been recruited to each group. Patients’ expenses were reimbursed. In total 79 patients were recruited to 12 focus groups from seven different practices.

**Conducting focus groups**

Participant confidentiality was ensured and informed consent was obtained from participants before the focus groups were conducted. These groups were facilitated by the lead author and observed by another, who gave feedback to the lead author. Both facilitators were GPs and took care to ensure they did not compromise the groups’ responses or impose their own ideas upon them.

Focus groups were conducted in the practice where participants were registered. Four practices held one focus group each, one practice held two focus groups, and two practices each held three focus groups. Some practices held more focus groups than others because more patients had been recruited from there or because the practice had an organisational structure that could affect continuity and merit more investigation, for example, personal lists.

The topics covered by the focus groups included:

- definitions and experiences of continuity;
- factors promoting or inhibiting continuity; and
- advantages and disadvantages of continuity.

These were selected based mainly on important

<table>
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<tr>
<th>Box 1. Different aspects of experienced continuity (coordinated and smooth progression of care from the patient’s point of view).</th>
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| ![Relational or interpersonal continuity: an ongoing therapeutic relationship between a patient and one or more providers.](https://example.com)
| ![Longitudinal continuity: care from the same health professional or as few professionals as possible, consistent with other needs.](https://example.com)
| ![Cross-boundary or team continuity: effective communication between professionals and services, and with patients.](https://example.com)
| ![Informational continuity: excellent information transfer following the patient.](https://example.com)
| ![Management continuity: a consistent and coherent approach to the management of a health condition that is responsive to a patient’s changing needs.](https://example.com)
| ![Geographic or institutional continuity: relates to care that is given/received in person on one site (office, home or hospital).](https://example.com)
| ![Flexible continuity: services that are flexible and adjusted to the needs of the individual over time.](https://example.com)

*These two types of continuity were not found to be sufficiently distinct from each other and are often regarded as one type of continuity.*17,18

**How this fits in**

Type 2 diabetes is a major health problem with both short- and long-term complications and psychosocial impact. Continuity of care is fundamental to general practice, but how patients with type 2 diabetes define and experience continuity of care in general practice remains uncertain. This study showed that several factors were important influences on patients’ perception of each type of continuity, including interpersonal relationships within the context of patient–doctor relationships, their own beliefs and behaviours, and the organisation of general practice. The advantages and disadvantages varied with the type of continuity.

Relational or longitudinal continuity was important in providing psychosocial care, but was associated with the risk of misdiagnosis. Cross-boundary or team continuity was important in providing physical care, but it was associated with less personal care and greater potential for patient confusion.
points highlighted in the literature. An unstructured approach with open-ended questions was used to allow participants to answer from a variety of perspectives. Participants were encouraged to think about their own experiences to identify factors that sustain and inhibit continuity.

Data analysis

The framework approach, which has been widely used for qualitative analysis in primary care, was used to analyse focus group data. This involved five stages:

- Familiarisation with the data: listening to participants’ conversations and reactions, and reading transcripts of the focus groups to identify topics that participants found interesting or relevant.
- Creating a thematic framework: assigning the raw data into categories, including both predefined and emerging types of continuity (Box 1). These main themes were further divided into sub-themes that represented the breadth of experiences and attitudes among participants.
- Indexing: allotting codes to the main and sub-themes that emerged from analysis and applying these systematically to all the data.
- Charting: taking data from the original transcripts and rearranging them into the framework, and creating tables. The columns represented themes (for each theme across responders) and rows represented cases (for each responder across themes).
- Interpretation and analysis: pulling together charted data so that key characteristics of the original data were interpreted as a whole to offer new insights.

The data analysis was led by the lead author, validated and discussed by the co-authors. Emergent findings from the analysis were regularly discussed and refined as part of an ongoing iterative process, which prevented one researcher dominating the analysis and imposing their views on the results.

RESULTS

Patient characteristics

Of the 79 patients recruited, 45 (57.0%) patients were male and 34 (43.0%) female. Their ages ranged from 27–91 years (mean = 67.2 years, median = 68.0 years, standard deviation [SD] = 11.1). Apart from one patient from Pakistan with good spoken English, all patients were white British. Forty-seven (59.5%) had been registered with their practices for >20 years and the remaining 32 (40.5%) for <20 years. Forty-seven (59.5%) had had diabetes for at least 5 years, 26 (32.9%) for 6–20 years, and the remaining six (7.6%) for >20 years.

Findings from focus groups

Patients’ experiences of continuity (experienced continuity) matched three of types of continuity outlined in Box 1:

- relational (longitudinal) continuity;
- cross-boundary (team) continuity; and
- continuity of information.

No new definitions of continuity were identified from patients’ perspectives.

Relational (or longitudinal) continuity

Many patients with type 2 diabetes experienced relational continuity with a named GP or practice nurse with whom they consulted regularly. The availability of the named GP or practice nurse, even if only by telephone, was crucial for patients in allowing them to maintain relational continuity:

‘... you live and you breathe diabetes from the moment you are told you’re diabetic. And Sister [A] is just … you only have to pick up a phone and she’ll be there … that to me is continuity.’ (Patient 1, age 66 years, female, practice 3)

Patients commonly perceived continuity as relational where there was familiarity, trust and confidence in the relationship factors that acted to develop and maintain the continuity:

‘I would prefer to see just one doctor and I feel that I know him and he knows me …’ (Patient 5, age 62 years, female, practice 5)

‘I prefer to see one, because I still think there’s more continuity ... I think once you’ve got a doctor you can trust then hang on. I mean, why swap it for some unknown …’ (Patient 1, age 69 years, female, practice 4)

Relational continuity made patients more comfortable, and inspired confidence to address embarrassing problems:

‘... there’s something better about seeing your own GP; because you go in and you’re instantly at ease, because you know him, whereas you go in to a strange person, or somebody, and especially if it might be a little embarrassing problem, you think “Ooh, crikey,” you know. And you don’t quite know where to start. But you feel better when it’s your own doctor …’ (Patient 1, age 69 years, female, practice 4)

‘The thing is you see one GP; he gives you
However, some patients had bad experiences of relational continuity when the GP failed to diagnose their condition, perhaps because of overfamiliarity. As a result, some of these preferred to consult another GP, in order to get a new perspective. This only really happened, however, when there had been an opportunity to consult someone else:

‘I used to be under one doctor and he’d hardly give you anything. He [was] giving me paracetamols once and I [was] getting worse and they sent for this locum that came during the night. She was a young woman and she says “oh he wants to be in hospital straight away, he’s got pneumonia”. And he’d given me paracetamol. So I changed from him …’ (Patient 4, age 78 years, male, practice 3)

‘… I mean I had an [incident] here … I saw my doctor, and I’d been complaining about pains in me chest for about 2 year[s], anyway it wasn’t until I went to hospital and had tests up there, and I came down, back down to see my doctor and he said, “Oh I’m glad they’ve found something wrong with you” I thought, “well 2 year[s] I’ve been complaining”.’ (Patient 4, age 78 years, male, practice 5)

The structure of patients’ practices influenced the way they perceived continuity. In single-handed practices, or those operating personal lists, patients were usually unable to consult anyone but their registered GP:

‘Well, he’s … the only doctor in the practice … you’ve no other choice, put it that way.’ (Patient 4, age 75 years, male, practice 2)

‘… I mean here’s really well organised at this practice [practice uses a personal list], they don’t want you to be going to see anybody, any time. They like you to keep to your own, your GP.’ (Patient 5, age 71 years, female, practice 4)

Patients were also aware that being registered at a large group practice could sometimes cause difficulty in consulting a named GP, which could hinder the establishment of relational continuity:

‘… I mean until they started building this practice up, we’d about three doctors … but now you’ve got about at least six doctors here now, so they don’t know you …’ (Patient 3, age 69 years, female, practice 5)

The presence of diabetes was the factor that made patients with type 2 diabetes consult a GP-diabetes specialist. Many of these patients perceived continuity as being relational continuity with the GP-diabetes specialist:

‘But listening to all these people about continuity of care, I think that we should have a specialist, a guy that knows about diabetes that you need to go to get this care, and I think Dr [Y] has to some extent put himself in that way.’ (Patient 3, age 67 years, male, practice 4)

Some patients with type 2 diabetes valued consulting the GP-diabetes specialist whom they perceived as an expert, likely to benefit them more than if they consulted another GP in the practice. Also, as a result of continuity with the GP-diabetes specialist, they felt that he/she could detect signs of diabetic complications and start appropriate interventions earlier:

‘It’s good for the doctors if they become a specialist, like a diabetic specialist, because they see more of diabetic patients in the practice and so they get plenty of experience which, if you just went to a GP who saw everybody, they would only see one or two diabetics probably and they wouldn’t know as much about it.’
(Patient 6, age 76 years, female, practice 4)

‘I think if you see him [GP-diabetes specialist] regular you’ve less chance of complications, because I think he will pick up on them so early that, you know, they could treat them before they got to any terrible state.’ (Patient 4, age 63 years, male, practice 4)

As part of diabetes care, some patients attended the hospital regularly; thus, they had more experience of hospital care and recognised longitudinal or relational continuity provided by hospital doctors. Their main reasons for attending the hospital were to monitor the progress of their diabetes and to be reassured about their health:

‘The continuity that we were talking about, all right, I now go down to the clinic once a year, and as long as everything’s all right I’m quite happy.’ (Patient 3, age 72 years, male, practice 4)

Patients viewed their contact with hospital doctors as an important part of the management of their diabetes; newer treatments could be accessed and complications recognised earlier:

‘All I can say is that your ordinary GP can only have a limited experience on different things, and I would say that diabetes is one of them, you have to go to a specialist who knows the job.’ (Patient 3, age 91 years, male, practice 3)

‘There are occasions when you need a kick, and you need to have something different. Now, unless you are going to a consultant and who actually then says something different, then you’re gonna get the same treatment from the doctor that you’ve got here, and you’ll get the same pills and the same quantity of them and no changes … ’ (Patient 6, age 70 years, male, practice 1)

On the other hand, the majority of patients agreed that they could not receive their diabetes care from the same doctor on each visit to the hospital, due to regular turnover and rotation of staff; therefore, longitudinal continuity was absent. This frustrated them because they could receive different treatment and advice, which is confusing:

‘… at the infirmary … definitely the continuity of care just was not there … I didn’t see the same doctor in 3 years. I saw a different doctor every time … I got different types of advice … ’ (Patient 5, age 65 years, male, practice 1)

However, a few patients had a chance to consult the same doctor at the hospital (consultant or registrar) frequently, which they considered to be evidence of continuity:

‘Well, when I went to the infirmary I did have continuity, because I was seeing a lady registrar, and I used to see her every time I went, every 3 month[s], and I did have continuity with her … ’ (Patient 2, age 69 years, female, practice 1)

Cross-boundary or team continuity

Some patients preferred to receive care from a named GP; however, sometimes they consulted other GPs. Another group of patients preferred to receive care from any available GP at their practice and not necessarily always from the same GP. Also, some patients recognised that, when their condition was urgent or severe, immediate intervention became a priority, rather than waiting to consult a named GP:

‘As continuity I like to see the same doctor every time if possible, but obviously if an emergency arises I’ll see anybody, as I did this last weekend. I got an allergic reaction and my tongue swelled up on Saturday and I came to see the emergency doctor.’ (Patient 4, age 67 years, male, practice 4)

‘… I don’t have a problem with if I come in and see different GPs, you know, there’s no problem with seeing different people, provided I get cured of whatever it is I’ve got.’ (Patient 4, age 60 years, male, practice 1)

The system in some large group practices did not encourage patients to consult the same GP each time. This in turn made patients unconcerned about whom to consult. These patients became familiar with the idea of consulting any GP regarding all GPs who worked at the practice as equal:

‘I think it’s just to get another doctor’s name … I think what it is, they give you a doctor that goes on your prescriptions … but it doesn’t, necessarily mean that you’ve, that is your doctor alone … They share them out, don’t they? Share the patients out among them.’ (Patient 1, age 88 years, male, practice 5)

‘They’re all our GPs, we belong to a group practice, we don’t have one doctor, we have six doctors … ’ (Patient 4, age 58 years, male, practice 5)

Some patients identified doctors, particularly younger GPs or locums, who did not show a personal interest, and were more concerned with
providing physical rather than personal or psychosocial care:

‘… you’re seeing a different face, they’re doctoring you from notes you’re not getting that personal contact.’ (Patient 4, age 75 years, male, practice 2)

Also, patients considered that consulting more than one doctor could disorganise the treatment plan initiated by their named GP as they might receive different opinions from the various doctors, confusing them about whose advice to follow:

‘… if you’re working under two or three they all have slightly different opinions of everything and somewhere along the line if you’re seeing three or four GPs and they all have a little difference of opinion, somewhere along the line there will be a slip-up.’ (Patient 4, age 58 years, male, practice 6)

‘I think if you see too many people you get too many different variations on a theme, don’t you …’ (Patient 5, age 65 years, male, practice 1)

Some patients seemed only willing to consult specific GPs, being selective about whom they saw. Their choice needed to fulfil their expectations:

‘… I’m not really bothered who I see as long as I know they’re good at what they’re doing and you get good doctors like you get good electricians and bad electricians”.’ (Patient 2, age 57 years, male, practice 4)

Continuity of information

Patients also identified continuity of information. Medical records offering continuity of information enabled patients to consult any available GP at their practice. They believed that all the details of their medical, social and personal history were available in the records, to provide a holistic picture, even to an unfamiliar GP:

‘I would have preferred to have continued with my GP. I suppose that also it is not strictly necessary because now everything is in the computer. So, the computer helps a lot for this sort of continuity. Everybody knows what this patient is like.’ (Patient 1, age 59 years, male, practice 4)

‘I’m not really bothered about seeing one doctor. I’m just quite, as long, if I feel ill and I want to see somebody and I can get in, that’s fine, and if all my records are on the computer I’m quite happy to go that way.’ (Patient 7, age 49 years, female, practice 7)

Since patients could consult different healthcare professionals, they felt that their medical records should be available so that the GP-diabetes specialist, and indeed other team members, could be aware of their management:

‘… now continuity, as you said, is interaction between the doctor and the nurse … because now everything is in the computer.’ (Patient 1, age 59 years, male, practice 4)

Finally, patients recognised the importance of continuity of information as a form of communication that should take place between the hospital and their general practice, and the importance of two-way information sharing.

‘The one in charge of your health care in the system is your GP. So, even though you go to a specialist … he has to refer to your GP. So all the information must be fed to the GP”.’ (Patient 1, age 59 years, male, practice 4)

DISCUSSION

Summary of main findings

This study explores previously neglected areas of concern, perceptions and experiences of continuity of care in general practice from the perspective of patients with type 2 diabetes. The definitions of continuity emerging from this study were compared with the pre-existing definitions proposed in the literature. Patients identified several factors influencing the different types of continuity, including a personal relationship with the healthcare professional, their own beliefs and behaviours, the presence of diabetes and the system and structure of general practice. Patients also identified several advantages and disadvantages with two types of continuity. They perceived that relational continuity is important in providing psychosocial care, whereas it has the risk of misdiagnosis. The advantages of cross-boundary or team continuity were to physical aspects of care, but at the expense of personal aspects of care and the patient might be confused as a result of not knowing whom to follow.

Comparison with existing literature

This study showed that patients with type 2 diabetes hold diverse views about continuity that were influenced by their own experiences of a particular type of care. The predominant type of continuity identified was relational or longitudinal continuity, which is also found to be the most frequent type of continuity identified in the literature. Furthermore, patients with diabetes sometimes spent more of their time with the practice nurse and established relational continuity.
with the nurse. Sixty-four per cent of diabetes clinics in England and Wales are run by both GPs and practice nurses, and 34% by practice nurses alone.25 Thus, some patient relationships with practice nurses might be long; it is known that relational continuity increases as the duration of contact increases.23

A few patients identified relational continuity with the hospital specialist. However, in other countries, there is a greater chance of establishing relational continuity with hospital staff as patients can bypass GPs by self-referring to specialists in hospital.24 There is a movement in some European countries to compensate for the fragmented nature of specialised hospital care by promoting longitudinal continuity during a hospital stay.25 This might be expected to increase patients’ perceptions of relational continuity from hospital doctors. Also, patients with diabetes who attend the hospital frequently might develop a close relationship with a hospital doctor, constituting relational continuity. However, the majority felt a lack of relational continuity with hospital doctors compared with general practice. Staff turnover is an obstacle to providing longitudinal continuity in the hospital.26

When patients have a long-term condition such as diabetes, they invariably need to consult several healthcare professionals; hence, it was unsurprising that they identified relational continuity frequently. Relational continuity is highly valued for patients with chronic and psychological problems compared with acute or minor problems.21 Diabetes is a chronic condition with several physical and psychosocial complications; hence, relational continuity has been more appreciated by patients. Nonetheless, the concept of the personal doctor could be an added value in the perception of relational continuity, which can be achieved with relatively few contacts, particularly if satisfaction is high.27

Patients believed that relational continuity improved the relationship with the named professional.28,29 A doctor who knew the patient was more likely to identify appropriate therapies.28 Also, knowing the patient contributes to quality of care by ensuring that patients are treated as individuals; it is associated with increased knowledge which can inform decision-making and may be a factor that improves patient outcomes.29,30

The potential risk of familiarity leading to misdiagnosis is a new insight obtained from patients with type 2 diabetes in this study. It may occur in relational continuity because GPs might assume that they are already aware of everything significant and may not conduct more important investigations.31 Patients decide to change doctor or practice if they assess quality of care as poor.30 Misdiagnosis is one indicator of poor quality. Indeed, patients reported benefits of consulting an unfamiliar doctor, such as early detection of diabetes.35 However, many complained that unfamiliar doctors (often younger GPs or locums) did not show a personal interest, and were more likely to provide physical rather than psychosocial care. Loss of personal care may occur when consulting an unfamiliar doctor, as the length of contact is usually short.31

Patients in this study were greatly influenced in their views by organisational factors, especially practice size. Indeed, being registered in a large practice is usually no guarantee that the patient will see one GP consistently, as the practice’s systems may not promote longitudinal continuity.26 Recent organisational changes in UK general practice have encouraged a team rather than personal approach. GPs’ reduced availability has reduced patients’ access to their usual GP.37,38 A recent Canadian study of patients with type 2 diabetes identified several factors that affected continuity with their usual healthcare providers, including access to services, interaction with their usual or other doctors, communication between those healthcare providers, and the patient’s personal responsibility to manage diabetes.29 Although there were some similarities with our results, differences between the healthcare systems may limit the transferability of their findings to the UK.

**Strengths and limitations of the study**

Focus groups were used to collect data as they allowed participants to interact, and provided direct evidence about the similarities and differences of their experiences of continuity. However, group dynamics might have been different with patients from different practices in the same group, allowing for different experiences to be explored.

For purposes of maximum variation sampling, there was one participant from an ethnic minority group. But it was not an aim of the study to explore continuity from the perspectives of ethnic minority groups; therefore we made no specific attempt to over-recruit such patients.

Although an emphasis had been made to recruit patients from various age groups into focus groups, this proved somewhat problematic in that many people with type 2 diabetes are elderly; the mean age of our participants was 67 years. It was therefore difficult to make age comparisons within the dataset. Analysis of data for other variables of maximum variation, such as sex, and type of practices (single-handed, large group, operated personal list) were considered and findings have been presented if they were relevant.

**Implications for future research and clinical practice**

Healthcare providers should be aware of patients’ understanding of continuity of care. Integrating certain types of continuity within a practice system, such as enforcing a personal list, may create conflict. While
there are some advantages in consulting an unfamiliar doctor, patients’ priorities and requirements should be paramount. Moreover, patients may seek relational continuity in a practice where organisational factors prevent them from accessing their usual healthcare professional. This might get more difficult with implementation of the new GMS contract, the introduction of more walk-in centres and out-of-hours services. However, the continuing relationship between patients and their usual healthcare professionals should not be threatened. Indeed, patients may adapt to these changes by reshaping their perceptions of continuity; they may seek team rather than relational continuity. The treatment of type 2 diabetes requires the skills of a multidisciplinary team with the consequence that no one healthcare professional is solely responsible for the patient. Primary care trusts and practices should encourage longitudinal continuity for patients — this means ensuring that patients are able to access their chosen healthcare professional. This will maximise opportunities for the development of relational continuity.

Funding body
The Sultan Qaboos University (SQU) at the Sultanate of Oman funded Dr Alazraki as part of his postgraduate education in the UK

Ethics committee
The Leeds Teaching Hospitals-NHS Trust (CA01/127)

Competing interests
The authors have stated that there are none

Acknowledgements
We would like to thank all who were involved in this research, including patients, without whom this research would not have been completed; GPs for allowing their practices to take part; Hazel Blackburn for secretarial support. The views expressed in this paper are those of the authors and not SQU.

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