# Patients' perceptions and experiences of transitions in diabetes care: a longitudinal qualitative study

Julia Lawton BA PhD,\* David Rankin MA MPhil,† Elizabeth Peel BA PhD‡ and Margaret Douglas MB ChB MSc MRCGP MFPHM§

\*Senior Research Fellow, †Research Associate, The University of Edinburgh, UK, ‡Senior Lecturer, Psychology, School of Life and Health Sciences, Aston University, Birmingham, UK and §Public Health Consultant, Lothian NHS Board, Edinburgh, UK

# Correspondence

Dr Julia Lawton Centre for Population Health Sciences Community Health Sciences The University of Edinburgh Medical School Teviot Place Edinburgh EH8 9AG UK E-mail: j.lawton@ed.ac.uk

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## Abstract

**Objective** To examine patients' perceptions and experiences over time of the devolvement of diabetes care/reviews from secondary to primary health-care settings.

**Design** Repeat in-depth interviews with 20 patients over 4 years.

**Participants and setting** Twenty type 2 diabetes patients recruited from primary- and secondary-care settings across Lothian, Scotland.

**Results** Patients' views about their current diabetes care were informed by their previous service contact. The devolvement of diabetes care/reviews to general practice was presented as a 'mixed blessing'. Patients gained reassurance from their perception that receiving practice-based care/reviews signified that their diabetes was well-controlled. However, they also expressed resentment that, by achieving good control, they received what they saw as inferior care and/or less-frequent reviews to others with poorer control. While patients tended to regard GPs as having adequate expertise to conduct their practice-based reviews, they were more ambivalent about nurses taking on this role. Opportunities to receive holistic care in general practice were not always realized due to patients seeing health-care professionals for diabetes management to whom they would not normally present for other health issues.

**Conclusions** It is important to educate patients about their care pathways, and to reassure them that frequency of reviews depends more on clinical need than location of care and that similar care guidelines are followed in hospital clinics and general practice. A patients' history of service contact may need to be taken into account in future studies of service satisfaction.

## Introduction

Health service reforms have been taking place both nationally and internationally to provide 'services that are convenient and closer to home', by shifting the balance of care from hospital to community settings.<sup>1</sup> As part of these reforms, the routine care and review of many patients with type 2 diabetes mellitus (T2DM) has moved from hospital outpatient clinics to GP surgeries.<sup>2,3</sup> Hospital-based care is now increasingly restricted to those on insulin, who have diabetic complications or whose diabetes control is poor. To achieve this shift in service provision in the UK, diabetes clinics have been introduced in general practices, led by GPs and/or practice nurses with special expertise and training in diabetes. The nature of this diabetes care has also been influenced by the new contract for GPs introduced in 2004. This includes the Quality and Outcomes Framework (QOF), which gives financial incentives for the achievement of standards of process and quality in care. Diabetes is one of the areas for which QOF standards have been set.<sup>4</sup>

An economic agenda and pressures on specialist services arising from T2DM's increasing prevalence have driven these broader changes in diabetes services provision.<sup>5</sup> However, it has also been suggested that patients will themselves benefit from the devolvement of their diabetes care to general practice. Presumed benefits include practice-based services being local and convenient to access,<sup>1,6,7</sup> and patients experiencing more holistic and better 'relational continuity'<sup>8</sup> of care, by virtue of receiving their diabetes and other medical care in the same setting and from health professionals with greater familiarity of their social context.<sup>6</sup>

What has been absent from, or assumed in, the above discussions are patients' own views. When research has drawn upon patients' perspectives, it has tended to focus upon their general satisfaction with diabetes services and/or their understandings of what constitutes 'continuity' in diabetes care.<sup>8-11</sup> Patients' experiences of, and views about, transitions in their diabetes care have received considerably less attention, despite the major changes in service provision described above. Notable exceptions are Murphy et al.<sup>12</sup> who interviewed patients before and after the introduction of a structured diabetes service in general practice, and Smith et al.13 who investigated patients' views about the introduction of a shared care service for diabetes.

In 2002/03, we conducted an interview study with patients newly diagnosed with T2DM,

based in the Lothian region of Scotland. This study was timed to coincide with the early phases of the devolvement of routine diabetes care and diabetic reviews to general practice within this location.<sup>14–17</sup> Patients were interviewed at baseline, 6 and 12 months, enabling their changing contact with diabetes services to be captured and examined in-depth.

Following diagnosis, the majority were referred to a hospital outpatient clinic where they received a care package comprising group education classes, a variety of clinical tests/examinations and a consultation with a diabetes consultant. By the end of the first year, many were discharged, or about to be discharged, to general practice, where on-going diabetes care and reviews were to be provided in a GP/nurse led clinic. When patients continued to attend hospital clinics, this was normally because their general practice had not yet set up a diabetes clinic.<sup>15</sup>

Like Murphy *et al.*,<sup>12</sup> we found general patient support for the relocation of diabetes care/reviews to general practice, primarily because general practices are local and convenient to travel to. While respondents attached importance to seeing consultants, whom they perceived as diabetes experts,<sup>16</sup> many could see potential advantages to receiving specialist diabetes care from primary-care professionals, such as nurses. This is because these professionals were perceived as being particularly approachable and able to give clear information and advice about diabetes and its management.<sup>14</sup>

Our findings were limited by the fact that, on the study's completion, respondents were only beginning to experience the effects of the transfer of a specialist model of diabetes care to general practice (see Table 1), and some had yet to be discharged from hospital or attend their first practice-based review. Consequently, their accounts were informed by expectations more than actual experiences of practice-based diabetes care/reviews. Thus, we conducted followup interviews in 2006, 4 years after the initial interviews. We sought to explore respondents' longer-term experiences of, and views about, the devolvement of their diabetes care/reviews to

Respondent	Gender	Age (2006)	SES*	Location of review				Primary-care
				Round 1 (baseline)	Round 2 (6 months)	Round 3 (12 months)	Round 4 (48 months)	professionals undertaking reviews at Round 4
R1	Male	40	1	Hospital	Hospital	Hospital	Hospital	N/A
R6	Female	75	3M	GP	GP	GP	GP	Nurse led
R8	Female	52	ЗN	GP	GP	GP	GP	GP led
R9	Male	67	2	Hospital	Hospital	Hospital	Shared care	GP led
R14	Female	43	2	Hospital	Hospital	Shared Care	GP	GP and nurse led
R15	Female	64	3M	Hospital	GP	GP	GP	GP and nurse led
R16	Male	63	3N	Hospital	Hospital	Shared care	GP	GP led
R17	Male	80	1	Hospital	GP	GP	GP	GP led
R19	Male	66	2	Hospital	Hospital	GP	GP	GP led
R22	Male	65	ЗN	Hospital	Hospital	GP	GP	Nurse led
R23	Male	44	2	Hospital	GP	GP	GP	GP and nurse led
R24	Male	61	3M	Hospital	Hospital	GP	GP	GP and nurse led
R25	Male	64	3M	Hospital	Hospital	GP	GP	GP led
R28	Female	47	3M	Hospital	Hospital	Hospital	GP	GP and nurse led
R30	Female	69	3M	Hospital	Hospital	Hospital	GP	GP and nurse led
R33	Male	49	4	Hospital	Hospital	Hospital	Shared care	GP led
R35	Female	73	3M	Hospital	GP	GP	GP	GP and nurse led
R36	Male	68	ЗN	Hospital	Hospital	Hospital	GP	GP and nurse led
R37	Female	62	3M	GP	GP	GP	Hospital	Previously nurse led
R39	Female	64	3N	GP	GP	GP	Hospital	Previously GP and nurse led

Table 1 Respondent details and location of diabetes reviews

\*Social class was assessed using the Registrar General's social class method.

general practice. The objective was to provide recommendations for the delivery and assessment of future care for T2DM patients in order to maximize opportunities, and minimize any problems, arising from changes in diabetes service provision.

# Methods

#### Recruitment and sample

Our recruitment strategy is detailed elsewhere.<sup>14,15</sup> In 2002, we recruited 40 patients from general practices and hospital clinics across the Lothian region of Scotland. The final sample reflected the demographic spread of people with T2DM in Lothian/Scotland. We obtained ethical approval to keep respondents' details for recontact if they gave written consent. Of the 21 members of the original cohort who consented, 20 were re-interviewed in 2006 (one had died in the interim). There were no obvious differences between this subgroup and the original cohort in terms of demographic characteristics, service contact, or earlier talk about, and reported satisfaction with, diabetes services and health professionals. Table 1 provides information for this subgroup of 20 respondents, whose accounts form the focus of this paper. All of these respondents were White. We conducted separate studies, using bi-lingual researchers, to establish the experiences and service needs of ethnic minority patients, findings from which are substantively different to those described in this paper, and are reported elsewhere.<sup>18–22</sup>

#### Data collection

As in their earlier interviews, respondents, at follow-up, were invited to talk about: their contact with diabetes services and health-care professionals since their last interview (and their understandings of why their service contact had changed over time); their likes/dislikes about the types of health professionals encountered, the care received and the location of this care; their expectations of, and preferences for, their future diabetes care; and their recommendations for future service delivery. Interviews also explored respondents' disease perceptions and experiences of disease self-management over time. This enabled us to situate respondents' (changing) views about services within the broader contours of their lives and circumstances. All interviews were tape-recorded and transcribed in full.

## Data analysis

A thematic analysis was undertaken of the 20 respondents' earlier and follow-up interviews by JL, DR and MD.<sup>23</sup> For each respondent, all four interviews were read back-to-back, particular attention being paid to any changes that had taken place in their contact with services and health professionals and the respondent's views about these. Within respondent accounts were compared and contrasted with between respondent accounts using the constant comparative method, enabling the identification of overarching themes which, together, united these data.<sup>24</sup> The final coding frame, which reflected the original questions posed to respondents and emergent themes was developed once the three team members had independently reviewed all data and reached consensus on key issues and findings. QSR N6 (NVD\*IST), a qualitative software package (QSR International Pty Ltd., Melbourne, Australia), was used to facilitate data coding/retrieval.

Below, data extracts are tagged with individual respondent's identifying number and interview round (e.g. R37.4 is respondent 37's Round 4 interview). Findings did not appear to differ according to respondents' age, gender and social class.

## Results

At follow-up, most respondents had experienced practice-based diabetes care/reviews for several years (see Table 1), with only one respondent, who was insulin treated, receiving hospitalbased care/reviews throughout. In line with broader changes in diabetes service provision, respondents, at follow-up, reported greater awareness of, and contact with, diabetes clinics within their own general practices. Some also indicated that practice nurses had played a greater role in their diabetes reviews over time.

While respondents continued to express general support for receiving diabetes care/reviews in general practice, their views tended to be more complex and ambivalent than those previously expressed, with many now presenting practicebased care as a 'mixed blessing'. When respondents expressed views about transitions in their diabetes care and the location of their current care, their accounts were informed by a variety of understandings and experiences, which crosscut the findings reported below. These include: earlier experiences of receiving hospital-based care/reviews; subsequent and/or ongoing experiences of receiving diabetes care in general practice; broader experiences of health service contact; and a perceived hierarchy within the medical profession, in which the expertise of consultants was ranked higher than that of GPs and nurses respectively: as one respondent summed up, 'when I started work at 15, you got a problem, your GP sent you to a specialist, so I've grown up with that' (R9.4). These understandings and experiences cross-cut the findings presented below.

Understandings of location of, and transitions in, diabetes care

Respondents accounted for discharge from, or non-referral to, a hospital diabetes clinic in several, overlapping ways. Some, like R25, simply inferred or assumed that they did not require hospital-based care because their diabetes was well-controlled: 'I'm pretty stable and there's a lot worse people with diabetes than what I have' (R25.3). Others, like R34, reached this understanding in light of information from health professionals. This respondent described receiving a letter from her consultant, which stated that 'the results of the blood test ... were excellent, average blood glucose or HbA1c of 6.6. This shows your diabetes is well controlled. As we discussed, [I] don't think we need to see you back here in the hospital' (R34.4). Many also attributed the (re)location of their diabetes care to general practice partly to broader resource constraints within the NHS (resource constraints, and an ensuing rationing of health services being issues which, as some respondents observed, were receiving a lot of attention in the media). R14, for instance, speculated that she had not been referred to hospital because, 'everything's done so much in the community now, the NHS is a mess, it really is, they haven't got the resources tae look after you' (R14.4). R15.4 similarly suggested that her care had been moved to general practice because, 'they're maybe just saying 'oh well, we'll save money, never mind her'.

#### Practice-based care: a mixed blessing

It was partly because of the above inferences and understandings that respondents tended to present practice-based care/reviews as a mixed blessing. On the positive side, respondents described gaining satisfaction and peace of mind from their perception/understanding that their disease did not require hospital-based care, such as R25 who claimed to be 'quite happy' when he found out about his discharge from hospital, 'because I must be quite stable, if you like er or I've got it stabilised' (R25.3). R23, likewise, talked about how his hospital discharge had affirmed his success in getting his disease under control: 'I am managing it so well myself [that] I don't really need any real intervention from anybody else' (R23.4). In addition, most respondents highlighted the (continued) benefits of accessing all of their diabetes care locally.

On the negative side, some respondents expressed resentment that their 'reward' for 'doing what I'm told' (R15.4) and thereby achieving good control, was receiving what they saw as lessened or inferior care to others: 'I can understand why the ones on insulin go to hospital cos they need it more, they're more at risk of taking hypers and hypos and more complications and things like that. Where I think cos, I'm not a problem case, I'm at the back of the queue' (R14.4).

Being at the back of the queue, for some, meant no longer having access to the integrated. 'one stop' services previously encountered in hospital. This included R25, who, as described above, had initially claimed to be happy about his hospital discharge. However, at follow-up, this respondent talked about wanting a re-referral because: 'I felt as though I was better treated ... I went in, they took your blood, you got your results, you went in, seen the doctor. Eh then he would refer you to the dietitian, eye clinic, whatever, all in there eh, and I thought that was a really good service' (R25.4). Others described feeling 'short-changed' by receiving reviews in general practice because of their perception that, even with diabetes training, GPs could never acquire the same level of expertise as consultants: 'if all you do is diabetes then you know a lot more about it than a specialist GP who doesn't see as wide or as many people' (R37.3). One such respondent, who likened a lead GP to 'a territorial as opposed to a regular soldier', talked about how he had been 'almost disappointed' when he was discharged from hospital. As he explained, this was not only because he saw consultants as providing 'reassurance and almost the ultimate knowledge', but also because his earlier consultant-led reviews had made him feel 'important' and 'valued' because 'someone so senior is investing their time in you' (R23.4).

Some respondents experienced less-frequent reviews in tandem with their care being transferred to general practice. Although most attributed this to having successfully managed their disease, many also perceived their less-frequent reviews as arising partly from general practices offering a lesser standard of care to hospitals. This included R25 who speculated that practice staff 'couldn't care less' because 'every time I went up she [practice nurse] would say, "Oh I'll take your blood the next time." It's six months at least before I have my blood checked' (R25.4). These respondents often described wanting more contact/reviews with health professionals in general practice. Sometimes this was to receive praise, encouragement and affirmation of compliance: 'Because while I know I'm managing it, but it's good to hear somebody else say, y'know, that I'm managing it well as well' (R23.4). In other cases, the onerous nature of self-management could lead to feelings of insecurity, with respondents wanting 'just maybe a wee bit of reassurance that you're doing your tests ... and that's alright you know, and you're doing things right' (R39.3).

## Practice care is 'good enough'

Since respondents tended to perceive practicebased care as connoting that their disease was under control, most also regarded this care as being 'good enough' to meet their current needs. As R37 commented, 'do you really need to the see the professor if there's not much change?' (R37.4).

Importantly, however, this perception of practice-based care as being 'good enough' also seemed to be reinforced by accumulated experiences of receiving diabetes reviews. Initially, respondents tended to talk about being the focal point of attention in these reviews, particularly those initially received in hospital, and liking the 'fuss' (R35.1) and 'attention' (R25.1) received.<sup>16</sup> However, over time, and particularly once medications had been prescribed for blood glucose control, respondents often presented their reviews as having become briefer and more standardized, with treatment decisions cohering around blood test results, rather than dialogue about lifestyle and patient preference.<sup>25</sup> Hence, enthusiasm for hospital reviews could abate, with respondents suggesting that the 'standardized' care now received could be, and indeed was, easily replicated in the general practice setting.

R17, for instance, talked very favourably in an early interview about a lengthy consultation he had received when he was initially referred to hospital. In this, he had had 'a very helpful discussion with [consultant] who implied that I was marginally above er the limit. I think it was something like 7.6, whereas they hoped it was 7.5 ... and, after considerable amount of thought, he decided not to give me drugs, erm suggested that I watch my diet' (R17.2). When he was next reviewed in hospital, R17 was informed that his blood glucose had risen and, 'as I rather expected, he recommended that I do go on to a tablet' (R17.3). This and all subsequent reviews were described as only lasting 'a few minutes' and focusing on decisions about whether his tablets needed to be changed, such as when 'the chappy had obviously looked at my results and said "your number has gone up a shade... so I think we might need to increase your Metformin dosage'" (R17.4).

As a result of these cumulative experiences, R17, who, at follow-up, had recently been moved from a shared-care arrangement to practice-based care claimed to be happy about this, despite an earlier insistence on wanting to be reviewed by the 'top man' (R17.1). As he explained: 'everybody just takes blood, y'know, and makes some conclusion from it I suppose. Eh, I think to myself that they're – what they're learning and telling me [in general practice] is just the same about the same as I get from the [hospital]. They're doing a certain routine testing which I suppose could be done somewhere else' (R17.4).

R22 conveyed a similar idea when she suggested that the health professionals who had conducted her reviews in hospital and subsequently in general practice all simply seemed to 'follow a trend eh that says, eh a table that says, right you're on two [tablets] for three years, then you go up to five, that, y'know' (R22.4).

Understandings of referral to hospital in the later stages of the disease

At follow-up, two respondents had recently been referred to hospital, one because they required insulin treatment (R8), the other because of early signs of kidney failure (R9). Both understood this referral to have happened because their condition had deteriorated. Hence R8 conveyed relief about her GPs' decision 'to call in the big boys' (R8.4), and R9 described feeling 'happier in the specialist section' as problems and complications 'will be picked up much more quickly' (R9.4).

Perceptions/experiences of care received from staff in general practice

#### Nurses

Although, as already described, respondents tended to regard GPs as having adequate expertise to conduct practice-based reviews, they were more ambivalent about nurses taking on this role, as happened in nurse-led clinics and those run jointly by a nurse and GP.

Respondents described nurses (whether they were known to have received specialist diabetes training or not) as being highly competent in delivering routine and basic aspects of their diabetes care/reviews, such as weighing them, and taking blood and urine samples: 'she can take blood and no[t] leave a mark, whereas Dr [Y] (intake of breath) bruised' (R22.4). Nurses were also praised for their ability to give clear information and advice about diabetes and technical aspects of self-management, such as how to use blood glucose self-monitoring equipment. Alongside these skills, respondents described valuing the opportunities that had arisen to ask questions opportunistically during clinical interactions, which, in some cases, they had felt 'too embarrassed' to ask a 'time-stretched' lead GP (R39.4). During the course of clinical interactions, some also described nurses performing a motivational role, such as giving R33 'a row' after she gained weight 'to help get me back on track' or, saying to R17 that 'I'd been a really good lad' when blood test results improved.

Respondents, however, tended to regard nurses' skills and expertise as complementing, rather than being able to replace, those offered by doctors. This was partly because they struggled to reconcile the notion of a 'nurse specialist' with notions of a nurse being 'just the nurse' (R15.4). As R25 elaborated: 'I think the title "nurse" would not make you think, not less of the nurse themselves as a person, but what training have they had to be called a specialist in that field?' (R25.4). Hence this respondent, who currently attended nurse-led reviews, described wanting to be 'instantly referred to a GP' if future blood tests indicated that a change in treatment might be required. Other respondents described how they had gained reassurance from observing the nurse 'go in there and come back from the doctor' during their reviews (R15.4), or from seeing the lead GP themselves act as 'the final arbiter' (R37.4) after, for instance, the nurse had reported that 'my weight's not too bad, my blood's ok, everything's not too bad' (R39.4).

#### Lead GPs and continuity of care

Many respondents who had attended a hospital diabetes clinics described encountering different consultants on each occasion, and highlighted the attendant frustrations of having to tell 'enumerable health professionals, junior doctors, senior doctors and so on that I don't smoke, that I drink 12 or something units of alcohol a week' (R17.4). Hence, some highlighted the potential benefits of having their reviews in general practice on the grounds that this would enable them to be 'treated by people who you are familiar with and people who you know' (R39.1). However, such expectations were not always realized as some respondents, following discharge from hospital, discovered that the lead GP for diabetes was not their regular or preferred doctor or, more problematically, was someone whom they disliked. This included R36 who described the lead GP as having 'an ice cool manner' and recounted how 'I had to go for a blood test or something and the nurse said "you'll be going to [lead GP] now" and I thought "oh no". But of course I never said a word, I just said "oh really". She said "yes, he's gonnae take charge of all the diabetics." So I thought, "that's it"" (R36.4).

Following their transfer to general practice, other respondents described actively seeking out the lead GP for diabetes for 'whatever's wrong with me, even if it means waiting another day' (R9.3) because, even when presenting for a nondiabetes-related reason, 'he's aware of me having it' (R35.4). However, the majority (including R36) chose to continue to see their preferred GP within the practice, or one who could be seen quickly, which meant their contact with the lead GP was restricted to their (annual) reviews. This resulted in situations, for instance, where respondents presented to their own GPs with side effects of diabetes medications rather than the lead GP who had prescribed them. Others perceived there to be a clear demarcation between an 'ordinary' GP and the 'diabetes doctor' within their practice: 'I think, I get the feeling he's kind of specialising you know, he's not a general practitioner as such' (R30.3). Because of this erroneous perception, some respondents thought that they could only raise issues and concerns with the lead GP during a review if they considered these to be directly connected to their diabetes.

## Discussion

Our longitudinal study has found on-going, if more limited, patient support for the provision of diabetes care in general practice. Respondents, at follow-up, continued to appreciate the convenience of local services, and gained reassurance from their perception/understanding that practice-based reviews signified that their disease was well-controlled. Moreover, it was partly because of these positive disease perceptions that they tended to see the diabetes expertise in general practice as being 'good enough' to meet their current health-care needs. This was particularly the case when reviews were conducted or overseen by a lead GP (although nurse input was valued) and/or when respondents perceived their reviews to have become standardized over time and across hospital and general practice settings. At the same time, disappointment and resentment could arise from respondents' perception that, by attending practice-based reviews, they were receiving inferior clinical care and/or less-frequent checkups to others.

One of the presumed benefits of practicebased diabetes care is the potential to access more holistic and better relational continuity of care. However, as this study has highlighted, this may not be realized as patients may see healthcare professionals for diabetes management to whom they would not normally present for other health issues. While patients implicated 'micro' issues, such as disliking certain professionals or wanting quick appointments, an observation echoed elsewhere,<sup>26</sup> broader organizational trends may also be salient. Specifically, as we have seen, the introduction of mini-clinics in general practice run by GPs and practice nurses with specialist expertise may result, albeit unintentionally, in patients' diabetes care being ghettoized within this setting. To enable more holistic and better relational continuity of diabetes care to be achieved in general practice settings, it may be necessary to revisit the model of care, so that more GPs are enabled to provide diabetes care rather than it being restricted to a single lead within each practice. At the very least, there is a need to ensure patients do not continue to hold onto the erroneous belief that the expertise of the diabetes lead is restricted to diabetes.

Alongside the restructuring of diabetes services, clinical guidelines, such as those for the management of hyperglycaemia,<sup>27</sup> and the introduction of QOF standards in the UK, may also be implicated in respondents' experiences at follow-up of receiving less person-centred and more standardized diabetes care/reviews. Introducing QOF standards was intended, and has been shown to be effective in, promoting equity and efficiency in the delivery of diabetes care.<sup>28</sup> However, by only giving financial incentives for achievement of process and outcomes in diabetes care, OOF standards, like other initiatives intended to promote quality and equity at the population level, may undermine the delivery of individualized and inter-personal aspects of health care.<sup>29</sup> To deliver the kind of patientcentred care recommended for the self-management of diabetes,<sup>30</sup> it may be necessary for current guidelines and standards to be revisited and expanded. To achieve more patient-centred care, performance indicators and measures may also need to be developed which do not rely on, or are restricted to, easily collectable data and/or standard population measures.<sup>29</sup>

Some respondents, following discharge to general practice, expressed a need for more frequent contact, mainly for praise and/or

reassurance. However, providing clinical contact solely for reassurance of well-controlled patients may not be a good use of resources, may encourage dependency among and patients. Hence, other forms of support may be more appropriate for these patients; for example, greater use of peer 'buddies' and support groups, albeit such schemes need to be properly evaluated. Some patients expressed concerns that a lessened frequency of reviews had arisen because general practices offered a lesser standard care. This finding underscores the importance of educating and informing patients about the pathways of diabetes care now established, to reassure them that frequency of review depends more on clinical need than location of care, and that similar care guidelines are followed in both hospital clinics and general practices. As our respondents implicated the rationing of health care on the relocation of their diabetes care/reviews to general practice, patients with other chronic conditions who undergo similar transitions in their care may need the same kinds of reassurance to those described here.

By following, and comparing, the experiences of the same people over time, our longitudinal design has shown that patients' views about their current diabetes care may be informed by, and shift in light of, their earlier experiences of diabetes service contact. This issue was made evident, for instance, in the observation that a former discharge from hospital may foster a perception of successful disease management, which may itself lead to a reduced expectation of the care one needs or is entitled to.<sup>15</sup> Like Gately et al.,<sup>31</sup> we also found that patients may bring 'habitual', 'routinized' and 'stereotypical' perceptions to their current health-care encounters, arising from a history of health service contact, such as their notion or understanding that hospital consultants have greater expertise than GPs and nurses respectively. This may help to account for why, despite supporting practice nurse involvement in their diabetes care/reviews and valuing the 'soft skills' they offered, respondents were generally resistant to their taking on the clinical roles and responsibilities which, for them, have traditionally been the remit of doctors.

The finding that perceptions of, and views about, current diabetes services are partly informed by previous service contact has important implications for future work on patient satisfaction and the development of appropriate measures to evaluate it. The incorporation of patients' experiences of care into the measurement and evaluation of patient satisfaction has already been recommended.<sup>32,33</sup> However, our findings suggest that, if this is to be performed effectively, a broad-ranging concept of experience needs to utilized, one which should potentially include, and take account of, a patient's history of health service contact.

Taking account of patients' former service contact is also important in interpreting some of our findings. Consideration needs to be paid, for instance, to the timing of the initial interviews to coincide with the early phases of the devolvement of diabetes care/reviews to general practices in Lothian. At that time, and within this particular location, most respondents' practices were in the process of establishing their own diabetes clinics; hence the majority were referred to hospital following diagnosis. As suggested elsewhere,<sup>16</sup> the knowledge and experience of initially being referred to a hospital 'specialist' may have undermined respondents' confidence in their own GPs' expertise. This may be less likely to happen now that specialist clinics are more firmly established within general practices in Lothian and other parts of the UK, where the devolvement of diabetes services to primary care settings has generally been more progressed. It is also likely that patients will express less disappointment about being reviewed in general practice if they have not had the experience of attending integrated, one-stop reviews in hospital, a matter which could be usefully explored by looking at a future cohort of newly diagnosed patients. As this study was located within the UK healthcare system, some of the findings may not be generalizable to other countries, which may have different health policies and funding structures and different practices in relation to

the delivery of diabetes care across primary and secondary settings.

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#### References

- 1 Department of Health. *The NHS Plan.* London: Department of Health, 2000.
- 2 Goyder EC, McNally PG, Drucquer M, Spiers N, Botha JL. Shifting of care for diabetes from secondary to primary care, 1990–5: review of general practices. *British Medical Journal*, 1998; **316**: 1505– 1506.
- 3 Whitford DL, Roberts SH. Changes in prevalence and site of care of diabetics in a health district, 1991– 2001. *Diabetic Medicine*, 2004; 21: 640–643.
- 4 Department of Health. *Quality and Outcomes Framework: Guidance*. London: Department of Health, 2004.
- 5 Bagust A, Hopkinson PK, Maslove L, Currie CJ. The projected health care burden of Type 2 diabetes in the UK from 2000 to 2060. *Diabetic Medicine*, 2002; **19**: 1–5.
- 6 Audit Commission. Testing Times: A Review of Diabetes Services in England and Wales. London, UK: Audit Commission, 2000.
- 7 Hurwitz B, Goodman C, Yudkin J. Prompting the clinical care of non-insulin dependent (type II) diabetic patients in an inner city area: one model of community care. *British Medical Journal*, 1993; **306**: 624–630.
- 8 Haggerty JL, Reid RJ, Freeman GK, Starfield BH, Adair CE, McKendry R. Continuity of care: a multidisciplinary review. *British Medical Journal*, 2003; 327: 1219–1221.
- 9 Alazri MH, Neal RD, Heywood P, Leese B. Patients' experiences of continuity in the care of type 2 diabetes: a focus group study in primary care. *British Journal of General Practice*, 2006; **56:** 488–495.

- 10 Escudero-Carretero MJ, Prieto-Rodríguez M, Fernández-Fernández I, March-Cerdá JC. Expectations held by type 1 and 2 diabetes mellitus patients and their relatives: the importance of facilitating the health-care process. *Health Expectations*, 2007; 10: 337–349.
- 11 Pooley CG, Gerrard C, Hollis S, Morton S, Astbury J. 'Oh it's a wonderful practice ... you can talk to them': a qualitative study of patients' and healthcare professionals' views on the management of type 2 diabetes. *Health & Social Care in the Community*, 2001; 9: 318–326.
- 12 Murphy E, Kinmonth AL, Marteau T. General practice based diabetes surveillance: the views of patients. *British Journal of General Practice*, 1992; 43: 279–283.
- 13 Smith SM, O'leary M, Bury G *et al*. A qualitative investigation of the views and beliefs of patients with Type 2 diabetes following the introduction of a diabetes shared care service. *Diabetic Medicine*, 2003; 20: 853–857.
- 14 Lawton J, Parry O, Peel E, Douglas M. Diabetes service provision: a qualitative study of newly diagnosed Type 2 diabetes patients' preferences and views. *Diabetic Medicine*, 2005; 22: 1246–1251.
- 15 Lawton J, Peel E, Parry O, Araoz G, Douglas M. Lay perceptions of type 2 diabetes in Scotland: bringing health services back in. *Social Science & Medicine*, 2005; **60**: 1423–1435.
- 16 Parry O, Peel E, Douglas M, Lawton J. Patients in waiting: a qualitative study of type 2 diabetes patients' perceptions of diagnosis. *Family Practice*, 2004; 21: 131–136.
- 17 Peel E, Parry O, Douglas M, Lawton J. Diagnosis of type 2 diabetes: a qualitative analysis of patients' emotional reactions about information provision. *Patient Education & Counseling*, 2004; **53**: 269–275.
- 18 Lawton J, Ahmad N, Douglas M, Hanna L, Bains H, Hallowell N. We should change ourselves, but we can't': accounts of food and eating practices amongst British Pakistanis and Indians with type 2 diabetes. *Ethnicity and Health*, 2008; **13**: 305–319.
- 19 Lawton J, Ahmad N, Hanna L, Douglas M, Hallowell N. Diabetes service provision: a qualitative study of the experiences and views of Pakistani and Indian patients with type 2 diabetes. *Diabetic Medicine*, 2006; 23: 1003–1007.
- 20 Lawton J, Ahmad N, Hanna L, Douglas M, Hallowell N. "I can't do any serious exercise": Barriers to physical activity amongst people of Pakistani and Indian origin with type 2 diabetes. *Health Education Research*, 2006; **21**: 43–54.
- 21 Lawton J, Ahmad N, Hallowell N, Hanna L, Douglas M. Perceptions and experiences of taking oral hypoglycaemic agents amongst people of Pakistani and

Indian origin: qualitative study. *British Medical Journal*, 2005; **330**: 1247–1249.

- 22 Wilson SL, Shepherd CK, Lawton J. Perceptions of Type 2 diabetes mellitus (T2DM) among Chinese patients living in Scotland. *Psychology & Health*, 2008; 23(Suppl. 1): 274.
- 23 Glaser B, Strauss A. *The Discovery of Grounded Theory*. Chicago: Aldine, 1967.
- 24 Strauss A, Corbin J. Basics of Qualitative Research: Grounded Theory Procedures and Techniques. London: Sage, 1990.
- 25 Lawton J, Peel E, Parry O, Douglas M. Patients' perceptions and experiences of taking oral glucose lowering agents: a longitudinal qualitative study. *Diabetic Medicine*, 2008; 25: 491–495.
- 26 Turner D, Tarrant C, Windridge K *et al.* Do patients value continuity of care in general practice? An investigation using stated preference discrete choice experiments *Journal of Health Services Research and Policy*, 2007; **12**: 132–137.
- 27 Heine RJ, Diamant M, Mbanya J-C, Nathan DM. Management of hyperglycaemia in type 2 diabets. *British Medical Journal*, 2006; **333:** 1200–1204.

- 28 Khunti K, Gadsby R, Millett C, Majeed A, Davies M. Quality of diabetes care in the UK: comparison of published quality-of-care reports with results of the Quality and Outcomes Framework for Diabetes. *Diabetic Medicine*, 2007; 24: 1436–1441.
- 29 Campbell SM, Roland MO, Buetow SA. Defining quality of care. *Social Science and Medicine*, 2000; **51**: 1611–1625.
- 30 Funnell MM. Empowerment and self-management of diabetes. *Clinical Diabetes*, 2004; 20: 123–127.
- 31 Gately C, Rogers A, Sanders C. Rethinking the relationship between long-term condition self-management education and the utilisation of health services. *Social Science and Medicine*, 2007; 65: 934– 945.
- 32 Hankins M, Fraser A, Hodson A, Hooley C, Smith H. Measuring patient satisfaction for the Quality and Outcomes Framework. *British Journal of General Practice*, 2007; **57:** 737–740.
- 33 Baker R, Streatfield J. What type of general practice do patients prefer? Exploration of practice characteristics influencing patient satisfaction *British Journal of General Practice*, 1995; **45:** 654–659.