

# Measuring patient experience in diabetes care in England and Wales: proof of concept from the Patient Experience of Diabetes Services (PEDS) pilot

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## Abstract

Collecting patient experience information is now very important for the NHS. A detailed questionnaire to record patient experience of diabetes services has been developed and piloted in paper form. However, the costs of using a paper-based system means that this cannot be used nationally. The questionnaire has therefore been put into a web format and this paper reports on a pilot feasibility study asking patients to fill out their experiences using their home computers. Patients recruited from general practice and hospital diabetes clinics were able to successfully complete the questionnaire online. Compared with national prevalence figures, more people with type 1 diabetes than with type 2 diabetes took part in the study.

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**Key words:** patient experience, web-based questionnaire, diabetes, feasibility pilot

## Introduction

The NHS has caught the feedback bug.<sup>1</sup> There are now a number of regular NHS surveys of general patient experience carried out in England. Peoples' emotional and practical response to illness and the responsiveness of health providers and systems to their needs matters hugely to all users of healthcare and has a direct influence on other dimensions of quality.<sup>1</sup> This is particularly true in the management of long-term conditions like diabetes, where treatment success is critically dependent on a successful partnership between people with diabetes and the healthcare professionals supporting

them in their care.<sup>2</sup> The experience of patients with long-term conditions is positively related to other aspects of healthcare quality, including their engagement with and adherence to information, clinical processes and outcomes.<sup>3</sup> Patient experiences can also be used as a driver for quality improvement.

Diabetes can be described as an exemplar chronic disease. In England and Wales the National Diabetes Audit (NDA) has provided annual reports comprising quantitative data on care processes, treatment target attainment and disease outcomes since 2004.<sup>4</sup> However, the NDA had not previously collected data on patient experience. The continuing care experience of a person with diabetes is crucial to the management of their condition, and standards for diabetes patient experience were enshrined in the Diabetes National Service Framework standard 3,<sup>5</sup> and in quality statements 1–5 of the NICE Diabetes Quality Standards.<sup>6</sup> A questionnaire to assess these standards was designed and tested in three health economies by the Picker Institute in 2010.<sup>7</sup> Its results were received favourably, but the costs and logistic problems of using this paper-based system have precluded widespread use.

So, in an effort to complement its quantitative assessments with patient experience measurements, the NDA has adopted and updated the previously piloted questionnaire and developed a web-based version. It consists of 10 web pages covering 37 aspects of patient experience including care planning, receiving health checks, knowledge and education. This pilot proof of concept study was carried out to see if people with diabetes could be encouraged to successfully complete the web-based forms on their home computers in sufficient numbers to make a national rollout of the collection of patient experience information in this format feasible.

## Methods

The Patient Experience of Diabetes Services (PEDS) survey used a web-based questionnaire to collect data from people with diabetes using the questionnaire from the Picker Institute that had been validated in paper form.<sup>7</sup> The questionnaire was reviewed by people with diabetes and representatives from the clinical community to ensure that the content reflected current practice and guidelines.

The questionnaire could only be completed online. No other methods were available. All questions relating to the patient's experience of the diabetes service were mandatory, while demo-

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**Table 1** Service participation in the Patient Experience of Diabetes Services (PEDS) pilot and completed PEDS survey numbers

	Number of services registered for PEDS pilot	Number of services for which surveys completed	Number of GP practices	Number of hospitals/trusts	Number of other specialist services	Total completed patient surveys
England	58	40	12	27	1	658
Wales	2	2	1	1	0	56

graphic information such as birth year and postcode were optional. The survey was designed to ensure comprehensive question completion, but there were a few questionnaires with a small number of data items missing due to technical issues. No data were recorded or analysed on patients who began the survey but did not complete it.

The data collection period was open from 14th November 2013 to 31st January 2014. Respondents had between seven and 11 weeks to complete the online survey, depending on when their service completed registration and when they received their invitation.

Any service delivering diabetes care in England and Wales was eligible to participate in the PEDS survey pilot. The pilot was publicised through a range of communication channels and networks. Participating services agreed to:

- Register their service for a Health and Social Care Information Centre (HSCIC) account via an online form, providing contact details and some information about their service
- Either send out a letter to all their patients with diabetes or to give out an invitation in clinic (or both), using a template provided that included their unique service ID
- Encourage all of their patients to participate in the survey
- Have their service level reports published on a publically available website ([www.hscic.gov.uk](http://www.hscic.gov.uk))
- Take part in an evaluation of the PEDS survey pilot.

In order to minimise the burden on the service staff, each of the participating services was provided with (1) template letters displaying the service's unique ID, with explanation and instruction to patients for completing the survey; and (2) promotional posters.

In order to maximise response rates, the PEDS survey pilot sites were provided with feedback and regular updates on survey completion rates.

## Results

Sixty services registered for the survey and 42 of these sent responses, giving a response rate of 70%. A total of 714 responses were received from patients attending these 42 services (see Table 1).

Compared with the population with diabetes included in the 2011/12 NDA, a greater proportion of the people responding to the survey had type 1 diabetes (39.1% vs. 8.7%) and the proportion with type 2 diabetes was lower (57.3% vs. 90.6%). This probably reflects the fact that the majority of services participating in the PEDS survey pilot were specialist services likely to have

a higher proportion of patients with type 1 diabetes.

The age profile of people participating in the survey was younger than for all people with diabetes included in the NDA; 48.6% of people who completed a PEDS survey were <60 years old compared with 36.5% of people with diabetes included in the 2011/12 NDA.<sup>8</sup> A higher proportion of PEDS respondents were in the least deprived quintiles and the majority of respondents were of white ethnicity.

The geographical distribution and the proportion of specialist services in the pilot are probable influences on the differences in characteristics between those responding to PEDS and all people included in the NDA.

19.5% of respondents reported that they had attended the service once over the past year, 30.7% had attended twice, 27.7% had attended three or four times and 20.3% more than four times.

All further questions were oriented to experience of care at the particular named service. Results from the care planning section are given as an illustration.

## Care planning

Survey respondents were asked about care planning discussions with healthcare professionals.

- 73.1% reported that they had discussed their ideas and goals about the best way to manage their diabetes completely with the clinic staff
- 93.0% reported that the health professional they saw had explained things clearly and 79.4% had discussed and agreed a plan about how to manage their diabetes until their next appointment
- 65.7% of respondents felt confident about managing their diabetes as a result of their diabetes appointments in the last 12 months.

## Free text comments

People who completed the PEDS survey had the opportunity to provide free text comments suggesting improvements they would like to see. Some examples of these comments are given below:

- More discussion, explanation and advice during appointments
- Doctors and nurses to listen more and ensure patients feel they are treated with sufficient respect, and as individuals rather than with a generalised approach
- Increasing continuity of care by seeing the same healthcare professional rather than a different person each time
- Better communication from retinal screening services to clinics

- Ensuring that foot checks are carried out regularly and increasing access to foot care
- Difficulties obtaining test strips, blood glucose diaries and insulin injection pens
- Appointments delayed or rushed due to shortage of clinic staff
- A need for more support on initial diagnosis
- A preference for more coordinated services, particularly timing of blood testing and multidisciplinary clinic appointments.

### Discussion

The PEDS survey pilot tested an online-only approach to measure patient experience in GP and specialist diabetes services. Overall there was enthusiasm among service providers and patients about being involved in a survey. PEDS has established a foundation approach to reporting data on patient experience at service provider and national level, and uncovered useful learning to guide a national rollout. The pilot confirmed that there would be sufficient numbers of respondents from each service to provide robust comparative survey reports, both at service level and nationally.

The survey produced a rich amount of data describing patient experiences of their diabetes services. The results of patient described experiences of diabetes care obtained from this web-based survey are in line with those reported from the largely paper-based survey conducted in three NHS regions by the Picker Institute in developing and testing the original questionnaire.<sup>7</sup>

However, as this was a pilot survey from a limited number of services, the data included in this report should not be viewed as representative of the experiences of all people with diabetes, but rather as illustrative of the sorts of information that a national survey could provide. Compared with population prevalence figures there was a greater percentage of people with type 1 diabetes completing the survey, probably reflecting the fact that more people were recruited from hospital clinics than general practice. This could have implications for a national rollout.

The rate of survey completions seemed to be at least partially dependent upon the patient population served; high levels of socioeconomic deprivation or large numbers of elderly patients appear to have negatively impacted completion of the online-only facility. There will be need to consider the timing and length of any national survey period. The pilot coincided with Christmas, and this had a detrimental impact on survey promotion and completion. The most suitable time of year in which the survey should be run may be different between primary and specialist services; for example, September to December is the period for flu vaccinations so a large number of people with diabetes visit their GP surgery during this



### Key messages

- Patient experience of diabetes services is important but difficult to collect in large numbers
- A web-based questionnaire format has been developed
- Patients have successfully completed this on their home computers

time. This might therefore be a prime time to advertise the survey and encourage participation. However, due to winter pressures, a different season might be better for acute hospital-based services.

We conclude that the PEDS survey completed online is an economical and effective way of recording and reporting diabetes patient experience, but requires some modifications to make it less burdensome for care providers and more comprehensively acceptable to patients. We believe it lays the foundations for an approach to patient experience surveys for people with long-term conditions that will help to shape and improve future service delivery.

**Conflict of interest** All 4 authors work for the National Diabetes Audit. They have no conflicts of interest.

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