

Diabetes

The views of people with diabetes

Key findings from the 2006 survey



Findings from a national survey of people with diabetes indicate that the majority of people with diabetes have had tests to check for complications with their diabetes within the last 12 months, but improvement is needed in the number of people attending education courses to help manage their diabetes.

In autumn 2006 almost 125,000 adults (aged 16 and over) with diabetes were sent a questionnaire by their local primary care trust (PCT) asking about their experiences of services provided by the NHS. The survey involved about 1,500 general practices from all 152 PCTs in England. Responses were received from 68,500 people; a response rate of 55%.

In 2001, the Government published a National Service Framework for people with diabetes, highlighting twelve 'standards of care and delivery'. The survey asked about the experiences of patients in relation to key aspects of the national framework and a range of issues identified by patients as important to them. These included diagnosis, check-ups, tests, self-management, psychological support, education and training.

This summary document highlights key national findings from the survey. However, many of the findings vary considerably across the country and further detail, including the results of the survey for each trust, is available on the Healthcare Commission's website at www.healthcarecommission.org.uk.

Key findings

- 73% of respondents said that they were given the right amount of verbal information at the time of diagnosis, though only 57% reported receiving the right amount of written information
- fewer than 1% of respondents reported that they had never had an annual check-up to assess their condition
- the majority of respondents reported that they had undergone tests within the last 12 months to check for complications with their diabetes
- of those admitted to hospital as an inpatient in the last 12 months (19% of all respondents), 68% reported that all staff were aware that they had diabetes. One in ten said that 'none' of the staff provided what they needed to manage their diabetes; 11% 'rarely or never' received food suitable for their diabetes as an inpatient, and 9% 'rarely or never' received meals at a time that was suitable for them in terms of managing their diabetes
- only 11% of respondents said that they had participated in a course to help manage their diabetes; of those who had not participated in a course, about a quarter (26%) said they wanted to
- 17% of respondents did not know what type of diabetes they had

Diabetes type

Seventeen per cent of all respondents said that they did not know which type of diabetes they had. Of those who did report their type, 17% said that it was Type 1 and 83% said that it was Type 2. In interviews with people with diabetes during the development of the questionnaire, it was clear that some people were confused about their diagnosis. We asked further questions concerning the use of insulin and their age at the time of diagnosis, to classify those who did not know what type of diabetes they have. This information was also used to reclassify those who thought they knew but whose answers to subsequent questions suggested that they were mistaken.

Using this approach, 7% of respondents to the survey were classified as 'definitely' Type 1, and 6% as 'probably' Type 1 (13% in total). This proportion is similar to the estimate by Diabetes UK that up to 15% of people with diabetes have Type 1. A further 61% of survey respondents were classified as 'definitely' Type 2, and 26% as 'probably' Type 2 (87% in total).

Diagnosis

Not surprisingly, those identified as having Type 1 diabetes had been diagnosed at an earlier age (on average at 28 years) than those with Type 2 (on average at 57 years).

All respondents were asked whether they had been given enough information (verbal and written) at the time of diagnosis. Seventy-three per cent said that they had received the right amount of verbal information, 20% said that they had received too little information, and 1% said that they had received too much. Six per cent did not receive any verbal information. There is no evidence of recent improvement in giving verbal information – the figures are the same regardless of whether patients were diagnosed in the last year or before.

People were less likely to receive written information at the time of diagnosis although in this case there are signs of recent improvement. Fifty-seven per cent said they had received the right amount (for those who had been diagnosed in the last year, the figure was 61%) and 18% had received too little (15% for those diagnosed in the last year). Twenty-three per cent of people (21% for those diagnosed in the last year) said that they had not received any written information at the time of diagnosis and 2% said that they received too much written information (3% for those diagnosed in the last year).

Check-ups and annual reviews

Reassuringly, fewer than 1% of all respondents reported that they had never had an annual review. The majority (78%) of annual reviews took place at a GP surgery, with others at a hospital clinic (19%) and a few 'somewhere else' (1%). Three per cent of those that had an annual review reported that they had not received one in the last 12 months. Most (60%) of the respondents said that it was 'very convenient' for them to get to their check-up, 33% that it was 'fairly convenient', 5% that it was 'not very convenient' and 2% that it was 'not at all convenient'. People were also asked whether their doctor or nurse had their up-to-date diabetes records to refer to when they went for their check-up. Nearly all (92%) said that they 'always or almost always' did, but 6% said 'sometimes' and 1% said 'never'.

Tests in the last 12 months

In the last 12 months the majority of respondents had checks carried out on their HbA1c levels – a special blood test to measure how well diabetes is controlled (91%), blood pressure (98%), cholesterol levels (89%), feet (83%) and weight (91%). Likewise, a high proportion reported having had a photo taken of the back of their eyes, to check for retinopathy (80%). Fewer respondents had seen a dietitian (23%).

The majority of people also reported having had a urine test in the last 12 months (87%). Of these people, 33% did not know the purpose of the test, 37% said it was to check for protein (which is used to check kidney function), and 49% said it was to test for glucose. Respondents could tick more than one box, so percentages may add up to more than 100.

Table 1 shows the average across England for the percentage of respondents receiving various tests or checks within the last 12 months. These percentages vary widely across the country.

Tests in the last 12 months	England average
HbA1c	91%
Knew HbA1c value (of people who had received a HbA1c test)	47%
Given HbA1c value in writing (of people who had received a HbA1c test)	13%
Want HbA1c results sent to them directly (of people who had received a HbA1c test)	61%
Urine test	87%
Blood pressure	98%
Given blood pressure results in writing (of people who had received a blood pressure test)	10%
Cholesterol	89%
Given cholesterol results in writing (of people who had received a cholesterol test)	11%
Photo taken of back of eyes (retinography)	80%
Bare feet examined	83%
Weighed by a doctor or nurse	91%
Saw a dietitian	23%

Care plans

Almost half of the respondents (47%) reported that they 'almost always' agreed a plan ('care plan') to manage their diabetes every 12 months although 30% said 'rarely or not at all'. However, as people aren't necessarily familiar with the term 'care plan', we also asked them whether they had 'discussed their ideas about the best way to manage their diabetes'. Forty-eight per cent reported that they 'almost always' did but a much smaller proportion (18%) said 'rarely or not at all'. Similarly, 39% of respondents said they 'almost always' discussed their goals in caring for their diabetes with 27% saying this happened 'rarely or not at all'.

Thirty-one per cent of respondents said they were 'almost always' given the chance to discuss different medications, 40% said 'rarely or not at all' and 29% said 'some of the time'. Forty-five per cent reported that they were 'almost always' given personal dietary advice, but for 18% it was 'rarely or not at all'. Discussion of physical activity was less likely than for diet or medication: 34% said 'almost always, and 28% answered 'rarely or not at all'. The findings for all questions on care planning varied by PCT.

Self-management and knowledge

Seventy-five per cent of respondents said that they knew enough about what to eat to help them manage their diabetes themselves, while 7% reported that they would like to know 'a lot' more. Twenty-two per cent said that they were 'very good' at eating the right foods with only 2% considering that they were 'not at all good' - these figures varied by PCT.

Sixty-eight per cent said they that knew enough about the role of physical activity in managing diabetes compared with only 7% who answered that they would like to know 'a lot' more. The survey found that people were less likely to use exercise than diet to manage their diabetes. Fifteen per cent of respondents reported that they were very good at being physically active ('to help you manage your diabetes'), while 46% said that they were 'fairly good', 29% that they were 'not very good', and 10% that they were 'not at all good' - again these results varied by PCT.

Insulin and other medication

A quarter of respondents used insulin to control their diabetes, 63% used tablets, 51% used diet and 23% used physical activity (multiple responses were allowed). Of people with Type 1 diabetes, 98% reported using insulin to control their diabetes, 22% used diet, 12% used tablets and 14% used physical activity. In contrast, 69% of people with Type 2 diabetes used tablets to control their diabetes. They were more likely to control their diabetes with diet (55%) and physical activity (25%), with fewer reporting using insulin (18%).

The majority of respondents (86%) were also on medication for a condition other than their diabetes. Of these, the most common type of medication was for high blood pressure (71%), followed by high cholesterol (68%).

Almost all respondents said that they had enough information about when to take their medication (93%) and how much medication to take (94%).

Education and training

Eleven per cent of people who responded to the survey said that they had participated in an education course to help them manage their diabetes. This figure varied considerably by PCT. Of those people that had participated in a course, around half (47%) reported last attending a course more than two years ago, 24% one to two years ago, 15% between six months and a year ago, and 14% within the last six months.

Sixty-three per cent of people said that the course had been 'very easy' to understand, 33% that it had been 'fairly easy', and 4% said that it had been 'quite' or 'very' difficult to understand. The minority who said it had been difficult to understand were asked to say why (multiple responses were allowed). Forty per cent said that it was taught in a way that was difficult to understand, 19% said that the course did not suit the way they preferred to learn, 10% said that the course did not cater for their disability, 3% said that the course was not suited to their cultural needs, and 9% said that the course was not taught in their first language.

Just over a quarter (26%) of respondents who had never participated in a course reported that they had wanted to. Of these people, only 7% said that they had been offered the opportunity to go on a course, but had not been able to attend.

Psychological and emotional support

Only 3% of people considered that they had needed to see a specialist for psychological support to help them cope with their diabetes, and just over half (53%) of these people said they had actually seen a specialist.

All respondents were asked whether they had received emotional support from a range of people – health professionals as well as family and friends (multiple responses were allowed). Emotional support came most commonly from doctors (33%) while 19% of respondents said they had received emotional support from a nurse, 10% from 'a family member or friend', and 3% from a support group for patients.

Hospital stays

Nineteen per cent of respondents had been admitted to hospital as an inpatient in the last 12 months, for any reason (not just diabetes). The majority (68%) said that all of the hospital staff were aware they had diabetes, while 3% said that none of the staff were aware of this.

Almost a quarter (24%) said they had been visited by someone from the diabetes specialist team during their stay. Fifty-eight per cent of people said that 'all' of the hospital staff had 'helped provide what was needed' for them 'to manage their diabetes' while in hospital, with 10% answering 'none'.

Eighty per cent said they were 'almost always' able to take their diabetes medication in the way that they wanted to, while 9% answered 'rarely or never'.

Respondents were also asked about the food served in hospital: 66% said that the choice of food served was 'always or almost always' suitable for them, with 11% answering 'rarely or never'. Sixty-nine per cent said that the timing of meals was 'always or almost always' suitable for them, in terms of their diabetes, while 9% said the timing was 'rarely or never' suitable.

Next steps

Understanding what patients think about the treatment they receive is crucial to improving the quality of care being delivered by the NHS, and to ensuring that local health services meet the needs of patients. The results from this survey will be used by NHS trusts to identify and address areas for improvement. We will also work with the National Centre for Social Research to report on the results from the survey in more detail. This will be followed by an analysis of variations across PCTs, groups of patients and population characteristics. We will publish further information on this later in the year.

In 2007, the Healthcare Commission is carrying out a service review of diabetes to assess the quality of healthcare for adults with Type 1 and Type 2 diabetes in England. The purpose of the review is to improve the services commissioned by PCTs, to ensure that adults with diabetes are given the support that they require to look after themselves.

Our report on the review, which we plan to publish in summer 2007, will include the final results of our assessments and the steps that we will be taking to work with those trusts most in need of improvement. Where we identify concerns that standards are not being met, we will use that information in our processes for assurance. Most importantly, we will encourage all trusts to use the results of our review to drive improvement.

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