

Managing diabetes

Improving services for people with diabetes



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The Healthcare Commission

The Healthcare Commission exists to promote improvements in the quality of healthcare and public health in England and Wales.

In England, the Healthcare Commission is responsible for assessing and reporting on the performance of NHS and independent healthcare organisations, to ensure that they are providing a high standard of care. The Healthcare Commission also encourages providers to continually improve their services and the way they work.

In Wales, the Healthcare Commission is more limited and relates mainly to working on national reviews that cover both England and Wales, as well as our annual report on the state of healthcare. In this role we work closely with the Health Inspectorate Wales, which is responsible for the NHS and independent healthcare in Wales.

The Healthcare Commission aims to:

- safeguard patients and promote continuous improvement in healthcare services for patients, carers and the public
- promote the rights of everyone to have access to healthcare services and the opportunity to improve their health
- be independent, fair and open in our decision making, and consultative about our processes

Executive summary

Diabetes

Diabetes is a life threatening, long term condition which affects more than 1.9 million people in England. Whether Type 1 or Type 2 (box 1), diabetes shortens people's lives and affects their quality of life because of the long term complications.

Box 1: Diabetes

Type 1 diabetes develops most frequently in children, adolescents and younger adults. Pancreatic cells that produce insulin have been destroyed by the body's immune system resulting in a build-up of glucose in the blood. To control blood glucose levels, insulin injections are required at least daily.

Type 2 diabetes is more commonly diagnosed in adults over 40 (although it is increasingly being diagnosed in children). For most people, it is a preventable, lifestyle disease caused by a combination of genetics, unhealthy diet and little physical activity. Either the pancreas is unable to produce enough insulin to control glucose levels or the person has become insensitive to insulin. Diet and lifestyle need to be adjusted and most people with Type 2 diabetes will need to take tablets and/or insulin to control their condition.

Not only is there a human cost to the person with diabetes, but the financial cost to the NHS of caring for people with diabetes is estimated to be around £9 billion every year. With the number of people with diabetes predicted to rise as the population becomes more obese and lives longer, NHS costs will also rise.

Diabetes does not affect everyone in the population equally. People with Type 2 diabetes tend to be overweight or obese, be physically inactive, have a family history of diabetes (including those women who have had diabetes while pregnant) or have South Asian, African, African Caribbean or Middle Eastern descent. People from black and minority ethnic (BME) populations are up to six times more likely to develop diabetes.

Policy context

In 2001, the Government published the diabetes national service framework (NSF). This established 12 national standards, which were aimed at raising quality and reducing variation across diabetes services. A delivery strategy followed in 2003. Since then, the Government has continued to emphasise that diabetes is a national priority by appointing a National Clinical Director and forming a team to support the NSF's implementation.

The NSF recognised that it is important to support people to look after themselves. Caring for yourself, or 'self care', is fundamental to daily living. For people with diabetes, it is about dealing with the impact of diabetes on their daily lives. A growing body of evidence demonstrates that supporting people with long term conditions to care for themselves means that they do better, both in clinical terms and in their quality of life. It also can contain increases in healthcare costs.

Our review

Our review looked at services commissioned by primary care trusts, focusing on how well healthcare systems support adults (aged 17

and over) with diabetes to care for themselves. We assessed primary care trusts with these questions:

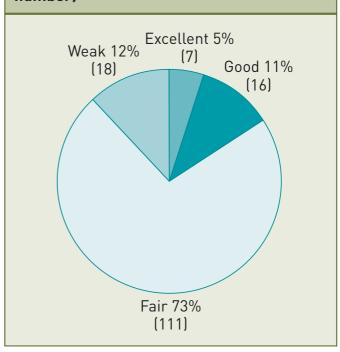
- 1. Are adults with diabetes looking after their condition?
- 2. Do adults with diabetes feel supported to self care through care planning, information and education?
- 3. Do adults with diabetes have key tests and measurements carried out?

We used data from three sources to assess whether primary care trusts were meeting these criteria: the Healthcare Commission's national patient survey of people with diabetes and the Health and Social Care Information Centre's Quality and Outcomes Framework and Hospital Episode Statistics. Each primary care trust received a score in July 2007 on a four-point scale – "weak", "fair", "good" and "excellent" – based on its performance relative to all primary care trusts' performances.

Overall results

Our review scored the performance of the majority (73%) of primary care trusts as "fair" in their work supporting adults with diabetes to care for themselves (figure 1). We are following up 12% of trusts because either we found that their services were "weak", or we could not make an assessment because we had too little information from them about the views of the people with diabetes in their area.

Figure 1: Primary care trusts' overall scores for the review (by percentage and number)



Our review showed that the level of deprivation of a primary care trust is not a factor in how well it supports people with diabetes to look after themselves. We showed that there is a similar spread of overall scores between all trusts and the one-fifth of trusts that have the worst health and deprivation indicators.

Findings

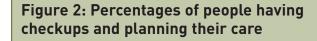
We found that most people with diabetes:

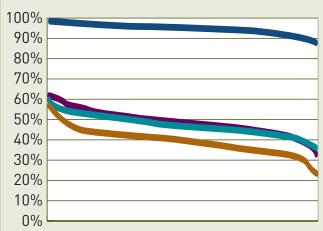
 have regular checkups, at least one a year with a healthcare professional, and most of the key tests and measurements carried out

- reported that they know enough about when to take their medication and how much medication to take
- reported having the key tests carried out that are easily recognisable, for example, having their blood pressure taken or being weighed
- who smoke were offered advice about stopping smoking

While this performance is encouraging, we also found that:

- between 34% and 61% of people with diabetes across all primary care trusts had agreed a plan to manage their condition (figure 2)
- between 1% and 53% of people with diabetes across all primary care trusts reported attending an education course on how to manage their diabetes
- between 16% and 41% of people with diabetes in primary care trusts would like to attend an education course on how to manage their diabetes if they have not been on one already
- between 25% and 50% of people with diabetes in primary care trusts felt that they were good at eating the right foods, knew enough about the food to eat and had 'almost always' received personal advice
- between 14% and 33% of people with diabetes in primary care trusts were good at being physically active, knew enough about physical activity and had 'almost always' received personal advice





Primary care trusts

The percentage of adults with diabetes diagnosed for more than a year, who report that they have had at least one diabetes checkup in the last 12 months

> The percentage of adults with diabetes who have had a checkup who report that they 'almost always'...

- ... discuss ideas about the best way to manage their diabetes at their checkup
- ... agree a plan to manage their condition over the next 12 months at their checkup
- ... discuss their goals in caring for their diabetes at their checkup

Areas for improvement

The review demonstrates that there are some aspects of care that are in great need of improvement in many primary care trusts. To increase the support offered to people with diabetes, there are five areas for improvement needed:

 Better partnership between people with diabetes and their healthcare professionals when planning and agreeing their care.

Annual checkups and most of the key tests and measurements are being carried out. However, many people with diabetes reported that aspects of care planning - discussing ideas and goals together and agreeing a joint plan to manage their diabetes - were not happening. Also, the personal advice that people with diabetes need to help them adopt and maintain a healthy lifestyle needs to be offered to everyone routinely. Not one primary care trust had more than half of people with diabetes reporting that they achieved their lifestyle targets. People with Type 2 diabetes and those from BME populations were more likely to report that key aspects of their care were not being planned.

2. Increasing the number of people with diabetes attending education courses and improving their knowledge of diabetes.

According to our results, some people with diabetes want to go on education courses and have not been offered one, particularly people from BME populations and those with Type 2 diabetes.

However, our results also showed that some people with diabetes need to improve their

knowledge of diabetes. Very few people with diabetes report having all the key tests and measurements carried out because many did not know whether they had had a urine test for protein (a kidney function test). Also, most people did not know their HbA1c value (long term blood glucose level), particularly those people with Type 2 diabetes and people from BME populations.

3. Working more closely with all organisations providing and commissioning diabetes services.

The results of our review demonstrate that in 95% of primary care trusts there is scope to reduce the number of admissions to hospital for diabetic ketoacidosis (DKA) and hypoglycaemic coma. There are two ways to do this. Firstly, there is a need to improve the way in which adults with diabetes prevent and, when necessary, respond to diabetic emergencies – for example, by treating themselves for hypoglycaemic episodes. This can be achieved through patient education.

Secondly, there is a need to look at the way primary care, secondary care and ambulance services work together within the community alongside non-healthcare organisations to prevent cases of DKA through better management and early diagnosis and, including ambulance services, reduce the number of hypoglycaemic episodes being treated in hospital.

4. Increasing the number of people with diabetes having long term blood glucose levels (HbA1c) of 7.4 or a lower safe level.

One of the most important factors in reducing the long term effects of one's diabetes is to have safe blood glucose levels. Our findings showed that once the characteristics of the primary care trust population were taken into account, on average across all trusts, 62% of people with diabetes met the long term blood glucose (HbA1c) target of 7.4. The better performing primary care trusts achieved 65% and the poorer performers achieved 52%.

5. Reducing variation in general practices' achievements.

In all but one of the clinical indicators we used in the review, we found that there was wide variation within primary care trusts of the achievements of general practices. This was for both the outcome indicators, such as achieving long term blood glucose levels (HbA1c) of 7.4. where we found an elevenfold difference in the variation across trusts and the process indicators, such as recording HbA1c tests where we found a twelvefold difference

Our main recommendations

We have summarised our main recommendations as follows.

Healthcare professionals, as part of the multidisciplinary team caring for people with diabetes, should offer appropriate, individual support to each person with diabetes to encourage them to look after their diabetes. Good planning of care is where the patient's experience is considered as important as the healthcare professional's view. The professionals should listen to people with diabetes when coming to agreed, joint plans for their care, giving them the opportunity to talk about what they think they can achieve.

Primary care trusts should implement the National Institute for Health and Clinical Effectiveness (NICE) health technology appraisal on structured education for patients, which says that people with diabetes should be offered education courses, and trusts should assess their current education programmes against the guidelines. They also need to improve the way they commission diabetes services, by reviewing the data submitted by their general practices and supporting the implementation of effective processes for jointly planning care.

Strategic health authorities should monitor the implementation of all the recommendations from this review and the improvement plans of primary care trusts scoring "weak" in the overall assessment.

What is the Healthcare Commission doing next?

We are:

- working with the primary care trusts which most need improvement either to produce plans for how they will improve, or to check that people with diabetes in their area receive, at a minimum, a "fair" service
- monitoring the ongoing performance of all primary care trusts, by following up some of the indicators used in the review
- examining further relationships between the national patient survey of people with diabetes and other data sources. We are also developing methods for examining the quality of primary care services, including diabetes care

Introduction

This report

This report presents a national picture of how well primary care trusts in England are commissioning services to support adults (aged 17 and over) with diabetes to care for themselves. It reports on the quality of support, encourages primary care trusts and healthcare professionals to continue improving services, and highlights the progress of primary care trusts in relation to some of the diabetes national service framework standards.

It is written for a wide audience. This includes people with diabetes and their carers, the public, commissioners of diabetes services in primary care trusts, managers of diabetes services, diabetes networks, and healthcare professionals involved in the care and treatment of people with diabetes.

Individual results for all primary care trusts that participated in the review are on our website at www.healthcarecommission.org.uk. People with diabetes, their carers and members of the public can use this information to check whether their primary care trust is offering the support to enable adults with diabetes to care for themselves. Anyone looking at the information can compare primary care trusts against each other. Also on our website is a leaflet for people with diabetes on key aspects of the review outlining what they should expect, what we found and what they can do next.

Diabetes

What is diabetes?

Diabetes is a serious, long term, progressive condition. There are two major types:

- Type 1 diabetes develops most frequently in children, adolescents and younger adults.
 Pancreatic cells that produce insulin have been destroyed by the body's immune system, resulting in a build-up of glucose in the blood. To control blood glucose levels, insulin injections are required at least daily
- Type 2 diabetes is more commonly diagnosed in adults over 40 (although it is increasingly being diagnosed in children).
 For most people, it is a preventable, lifestyle disease caused by a combination of genetics, unhealthy diet and little physical activity. Either the pancreas is unable to produce enough insulin to control glucose levels or the person has become insensitive to insulin. Diet and lifestyle need to be adjusted and most people with Type 2 diabetes will need to take tablets and/or insulin to control their condition

Who is affected?

Diabetes affects an increasing number of people. By 2006, nearly 1.9 million people in England were diagnosed with diabetes and identified on registers¹, and a further half a million are estimated to have the condition². The total number of people with diabetes (those diagnosed and undiagnosed) is forecast to rise by 15% between 2001 and 2010; 9% of the rise is due to increasing numbers of obese people and 6% to an ageing population².

Diabetes is not equally distributed across the country. The number of people diagnosed with diabetes in some strategic health authority

areas is higher than in others, and in some areas statistical modelling shows that there are many people yet to be diagnosed³.

Although diabetes is becoming more common across all age groups and in all populations, it does not affect everyone in the population equally. Its occurrence, particularly Type 2, is highest among those who are overweight or obese, physically inactive, those with a family history of diabetes (including those women who have had diabetes while pregnant) and people of South Asian, African, African Caribbean and Middle Eastern descent4. People from black and minority ethnic (BME) populations are up to six times more likely to develop diabetes⁵.

Socio-economic deprivation also contributes to an increased risk of diabetes. The most deprived people in the UK are two and a half times more likely to develop the condition⁵.

What are the effects?

The impact of diabetes on people is considerable. Not only is their life expectancy reduced by at least five years, but their quality of life can be affected by the associated long term complications (box 2). An individual with diabetes is more likely to have heart disease, stroke, kidney failure, blindness, depression and a lower limb amputated than a person without diabetes.

"I felt really shattered, felt that my world has ended, that there wasn't anything for me. For that one instant, I felt, that's it I'm going to finish in no time. How am I going to cope with it?" (Person with diabetes)

Box 2: The human costs of diabetes - long term complications

- On average, life expectancy is reduced by more than 15 years in those with Type 1 diabetes, and between five and seven years in those with Type 2 diabetes (at age 55 years)2
- The three most common complications for people with diabetes are all related to their hearts (angina, cardiac failure, myocardial infarction)6
- Diabetes is a leading cause of end stage renal disease⁷ and blindness in people of working age⁸
- Diabetes is the most common cause of non-traumatic lower limb amputation9
- The prevalence of depression is roughly twice as high among people with diabetes as among the general population¹⁰
- People with Type 2 diabetes are at almost twice the risk of dying from any cause in a year than their peers without diabetes, after adjusting for risk factors¹¹
- People with Type 1 diabetes are at over three times the risk of dying from any cause in a year than their peers without diabetes, after adjusting for risk factors¹²

Diabetes has a large and growing financial impact on the NHS. In 2002, £1.3 billion, nearly £4 million every day¹³ or around 5% of total NHS expenditure¹⁴ was used to care for people with diabetes. Estimates from 2006 suggest that total expenditure could be as high as 10% of total NHS expenditure¹⁵, which is planned to be around £92 billion in

2007/2008¹⁶, and means that about £9 billion is being spent on care for people with diabetes, which is over £25 million every day.

Caring for people with diabetes also has an impact on social services expenditure, as it is four times more expensive to care for people suffering from long term complications than those without².

Policy development

The Government's focus on diabetes has grown considerably over the last five to six years. In December 2001, the Government launched the diabetes national service framework (NSF) – 12 national standards aimed at raising quality and reducing variation across diabetes services⁴. The delivery strategy followed in January 2003¹⁷. Together, the publications describe the Government's vision of what services should look like in 2013.

To achieve this vision, the Government appointed a National Clinical Director for Diabetes in 2003 and created the National Diabetes Support Team to work with frontline healthcare professionals in 2004.

The National Institute for Health and Clinical Effectiveness (NICE) issued guidelines for the NHS on the management, care and education of people with diabetes^{18, 19, 20}. In addition, a new General Medical Services (GMS) contract with GPs was introduced in 2004 on behalf of the Government, which contained the Quality and Outcomes Framework (QOF)²¹. Within QOF there are 18 indicators for financially rewarding primary care practitioners for identifying people with diabetes and reaching thresholds for diabetes-related quality targets.

Since 2004, the National Clinical Director for Diabetes has published annual reports to the Secretary of State on the progress made towards the standards. The 2007 report noted that local services are now in a better position to plan, commission and manage high-quality care that centres around patients. This is because more detailed data and information on diabetes care is available, including practical guidance documents and toolkits on commissioning services and educating patients³, (see appendix A for a list of the guidance).

These initiatives have given healthcare professionals a framework when working with people with diabetes to design care to meet their individual needs, deliver that care largely in settings outside hospital, review care and treatment regularly and offer support and education to help them look after themselves.

"It was a shock, certainly. On the other hand, it was a relief to know that there was something that could be done about it."
[Person with diabetes]

The importance of 'self care'

The importance for people with diabetes

For most of the time people with diabetes look after themselves (box 3), spending only a few hours a year with a healthcare professional¹⁷. But with the number of people with diabetes in England predicted to rise to 2.35 million by 2010² as the population ages and obesity levels climb, demand for services will grow and costs will increase. High-quality care that enables people with diabetes to understand and manage their own condition is vital to both helping people live a life that is independent of diabetes and reducing the human and financial costs resulting from complications.

Box 3: What is self care?

In general ...

"Self care is a part of daily living. It is the care taken by individuals towards their own health and wellbeing and includes the care extended to their children, family, friends and others in neighbourhoods and local communities.

"Self care includes the actions individuals take for themselves, their children and their families to stay fit and maintain good physical and mental health; meet social and psychological needs; prevent illness or accidents; care for minor ailments and long term conditions; and maintain health and wellbeing after an acute illness or discharge from hospital."22

For people with a long term condition like diabetes, it is ...

"Self care by definition is led, owned and done by the people themselves. It is the activities that enable people to deal with the impact of a long term condition on their daily lives, dealing with the emotional changes, adherence to treatment regimes, and maintaining those things that are important to them - work, socialising, family.

"The NHS cannot do self care to people, but what it can do is create an environment where people feel supported to self care. This can be done through developing organisational structures and networks, appropriate information, interventions and technology, to give people the opportunity to improve their quality of life, and feel that they are still contributing in their community."23

Research has shown that changing a person's lifestyle can significantly reduce the likelihood of people at high risk (those with the diabetes genes) developing Type 2 diabetes. It can also slow down the progression in those already diagnosed²⁴. This is important given that when people with Type 2 diabetes are diagnosed, around half of them already have one or more of the complications associated with diabetes².

Also, there is evidence from controlled clinical trials suggesting that people with long term conditions have improved clinical outcomes when they take part in programmes teaching skills in managing their conditions, and that these programmes are more effective than education which only provides information²⁵. In other research, self-management programmes for people with long term conditions have improved their health in areas such as depression, tiredness, pain and selfefficacy (their beliefs about their own capabilities to produce effects). Another effect of these programmes is to contain increases in health care costs for the individuals concerned²⁶.

Policy development

Making support available to people with long term conditions to care for themselves is central to the Government's policy, (box 4), forming an integral part of the diabetes NSF (box 4), the long term (neurological) conditions NSF²⁷ and the Department of Health's generic model of care for people with a range of long term conditions²⁸. This is further reinforced in the recent White Papers Choosing health²⁹ and *Our health, our care, our say*³⁰, which highlight the role of prevention in improving the nation's health and the importance of people taking more responsibility for becoming and staying healthy.

Box 4: Empowering people with long term conditions such as diabetes

Diabetes NSF standard 3

"All children, young people and adults with diabetes will receive a service which encourages partnership and decision making, supports them in managing their diabetes and helps them to adopt and maintain a healthy lifestyle."

Quality requirement 1 from the long term (neurological) conditions NSF

"A person-centred service"
This is a main theme that runs throughout the NSF. All people with long-term (neurological) conditions are offered a full assessment of their health and social care needs. In addition, they are to be offered information and education about their condition; the chance to make decisions about their treatment; and to be involved in writing a plan about how their needs will be met (a care plan).²⁷

The Department of Health's 2006 report Supporting people with long term conditions to self care²³ lists key actions for health and social care partners, including developing a strategy to support self care. It also emphasises the importance of skills, training and information in supporting people with long term conditions to take more control.

"There's a huge amount of self-learning. You're given targets right at day one, but it takes a long time to understand the effects of stress, exercise, all these other things going on in your body that affect your blood sugar level and obviously the dose of insulin you're going to take."

[Person with diabetes]

Involvement in planning their own care, combined with education, can help people with diabetes decide how to manage their condition day-to-day. Guidance on the care planning process has been developed by the joint Department of Health and Diabetes UK Care Planning Working Group³¹. Educating patients has been shown to be cost-effective (box 5), and its importance emphasised by the reinstatement in 2006 of the NICE guidance on the use of patient education models for diabetes²⁰. A self-assessment tool for primary care trusts is available to assess the education programmes they commission against the NICE guidelines³².

"The nurses have been absolutely wonderful; they never mind me ringing them up. They just make you feel comfortable – I haven't been a very easy one – they're always tolerant, always caring, always understanding and helpful." (Person with diabetes)

The development of policy continues, as the evidence on what works is published. The latest guidance was published in May 2007³³. The National Clinical Director for Diabetes, Dr Sue Roberts, set out her views on how services need to change to meet the needs of people with diabetes. The message was clear: organised, proactive services in partnership with engaged, empowered patients equal better outcomes.

Box 5: Educating patients

- The diabetes NSF proposes a "supported self care service model" for diabetes and recognises the importance of education in facilitating self management
- The NICE guidance recommends that structured patient education is made available to all people with diabetes at the time of initial diagnosis and then as required on an ongoing basis, based on a formal, regular assessment of need
- In addition to local education programmes, there are two national group education programmes for adults with diabetes that meet the key NICE criteria for structured education. They can be commissioned by trusts for use in their local area. They are:
 - **DAFNE** (Dose Adjustment for Normal Eating) for people with Type 1 diabetes, www.dafne.uk.com/
 - DESMOND (Diabetes Education and Self-Management for Ongoing and Newly Diagnosed) for people with Type 2 diabetes, www.desmond-project.org.uk/
- The cost of educating patients with diabetes depends on the type of programme. Costs for a patient attending a DESMOND course over one full or two half days in a primary care community setting are £66. Costs for DAFNE range from £250 to £290, and research has shown that this becomes cost effective after four years²⁰

About the review

What is a service review?

The Healthcare Commission's service reviews (previously called improvement reviews) look at how well healthcare organisations are improving the care and treatment they provide to patients. We focus on aspects of health and healthcare where there are substantial opportunities for improvement, helping organisations to identify where and how they can better perform. We assess organisations by measuring their performance on key questions that are important to patients and the public and those delivering services.

There are two parts to a service review: a comprehensive assessment of the performance of each organisation taking part in the review, followed by work targeted specifically at those organisations in greatest need of improvement.

Why diabetes?

We identified diabetes as a priority for a number of reasons, including the:

- large numbers of adults with diabetes
- increasing incidence of diabetes, particularly Type 2 diabetes, in all age groups and populations
- unequal way that diabetes affects the population
- reduced life expectancy experienced by adults with diabetes
- high cost of treating diabetes
- substantial evidence about what constitutes good care for adults with diabetes documented in the diabetes national service framework (NSF) and NICE guidelines

What did the review involve?

We looked at services commissioned by primary care trusts, focusing on how well healthcare systems were supporting adults (aged 17 and over) with diabetes to care for themselves. We concentrated on self care because of the following aspects:

- the evidence that helping people with diabetes to care for themselves can delay and prevent the onset of symptoms, reduce complications and therefore reduce the impact of the disease on those people with diabetes and on health and social care services
- the focus placed on self care in the diabetes NSF, NICE guidelines, the Chronic Disease Management model, recent White Papers, the long term conditions NSF and Department of Health guidance
- the lack of evidence available on how well people with diabetes were being supported to self care

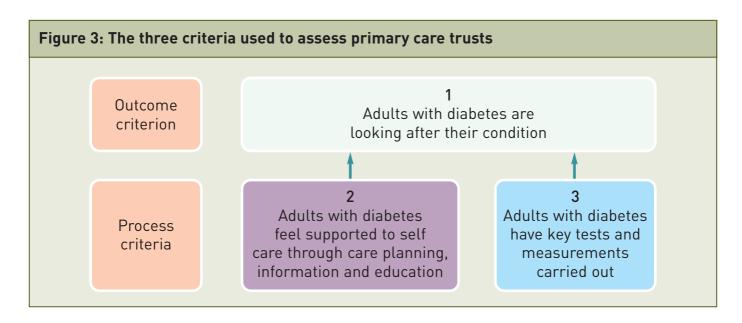
We then developed the content of the review through consultation (box 6).

Box 6: Who and how we consulted when developing the review

We asked people with diabetes and their carers, the public and healthcare professionals which aspects of services for people with diabetes should be included in the review by:

- consulting national experts and those delivering diabetes services
- visiting primary care trusts, general practices and diabetes clinics
- attending diabetes networks and education sessions
- conducting 13 focus groups of people with diabetes and their carers across England, including separate groups of people from black and minority ethnic groups (African Caribbean, Somali, Bengali and other South Asians). The quotes of people with diabetes in this report are from these focus groups
- releasing a draft framework on our website and receiving comments

We used the outcome and process criteria in figure 3 to assess how well primary care trusts were commissioning services to enable people with diabetes to care for themselves.



To assess whether trusts were meeting these criteria, we asked questions (table 1) against each criterion and answered them using data from the following national sources:

- national patient survey of people with diabetes, Healthcare Commission³⁴
- the Quality and Outcomes Framework (QOF), Health and Social Care Information Centre¹
- Hospital Episode Statistics (HES), Health and Social Care Information Centre³⁵

With the data collected about all of the 152 primary care trusts in England in existence on 31 March 2007, we were able to assess whether they were meeting or progressing towards both our review's criteria and also standards 3, 4, 7 and 10 from the diabetes NSF. Each primary care trust received a score in July 2007 on a four-point scale – "weak", "fair", "good" and "excellent" – based on its performance relative to all primary care trusts' performances.

There is information about the content of this review on our website. The framework of assessment for the service review of diabetes³⁶ covers the background to the review, and Service review of diabetes – Technical guidance on analysis and scoring³⁷ shows how each of the indicators is calculated and how the scores are derived.

We carried out a separate statistical analysis of the survey of people with diabetes at a national level. We wanted to find out what the national picture was like, for example, for people with Type 1 and Type 2, and for people from different ethnic backgrounds. We have reported the findings that are statistically significant, and have produced a separate document containing all the findings and more information about how we carried out the analysis³⁴. Further analysis of the whole of the survey is being carried out by the National Centre for Social Research and is due to be published in summer 2007.

Table 1: The framework of assessment for the service review of diabetes		
Criteria	Questions	Source of data
1 Adults with diabetes are looking after their condition	1.1 Are the key measurements for adults with diabetes at recommended levels and are emergency admission rates low?	QOF and HES
	1.2 Do adults with diabetes feel that they are achieving their lifestyle targets?	Survey of people with diabetes
	1.3 Do adults with diabetes feel knowledgeable about their diabetes?	Survey of people with diabetes
2 Adults with diabetes feel supported to self care through care planning, information and education	2.1 Do adults with diabetes report that they have regular checkups, feel involved and know what to do next?	Survey of people with diabetes
	2.2 Do adults with diabetes report that they have received enough information, education and training to self care?	Survey of people with diabetes and QOF
3 Adults with diabetes have key tests and	3.1 Do clinicians carry out key tests and measurements?	QOF
measurements carried out	3.2 Do adults with diabetes report that key tests and measurements are carried out?	Survey of people with diabetes
	3.3 Do adults with diabetes report that ALL key tests and measurements are carried out?	Survey of people with diabetes

Key findings

Overall results

Five per cent (seven) of primary care trusts received an overall score of "excellent" (table 2) and 11% (16) received a score of "good" (figure 4) in commissioning support to help people with diabetes to care for themselves. However, 73% (111) of primary care trusts scored "fair". Although these primary care trusts are meeting minimum requirements and the reasonable expectations of patients and the public, improvements need to be made.

Table 2: The primary care trusts scoring "excellent" for overall results

Bath and North East Somerset PCT

Bournemouth and Poole PCT

Cumbria PCT

Dorset PCT

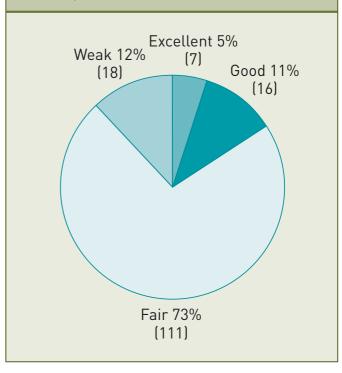
Isle of Wight NHS PCT

Redcar and Cleveland PCT

Western Cheshire PCT

The 12%, (18), of the primary care trusts which scored "weak" fell into two groups. One group (eight) is not commissioning services that offer enough support to people with diabetes to look after their condition. For the second group (10), we were unable to assess their support to people with diabetes because there was no data available for the national patient survey of people with diabetes. The "weak" primary care trusts are a particular area of concern that the Healthcare Commission is following up (see page 51, 'Further action by the Healthcare Commission').

Figure 4: Primary care trusts' overall scores for the review (by percentage and number)



Four of the 10 strategic health authorities (SHAs) are performing better than the others overall (table 3), as these SHAs have the seven primary care trusts scoring "excellent" within them. There are two SHAs that have no primary care trusts scoring "weak", South West SHA and South East Coast SHA. South West SHA is performing better than all SHAs as it has a higher percentage of primary care trusts scoring "excellent" and no primary care trusts scoring "weak".

Table 3: Percentage of primary care trusts with overall scores of "excellent" and "weak" out of all primary care trusts in each strategic health authority (SHA)

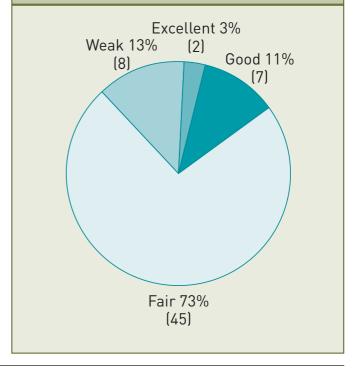
Percentage of primary care trusts scoring "excellent" in each SHA	
South West SHA	21%
South Central SHA	11%
North East SHA	8%
North West SHA	8%
East Midlands SHA	0%
East of England SHA	0%
London SHA	0%
South East Coast SHA	0%
West Midlands SHA	0%
Yorkshire and Humber SHA	0%



Percentage of primary care trusts scoring "weak" in each SHA	
South West SHA	0%
South East Coast SHA	0%
North West SHA	4%
West Midlands SHA	6%
Yorkshire and Humber SHA	7%
North East SHA	8%
South Central SHA	11%
East Midlands SHA	11%
London SHA	26%
East of England SHA	29%

The distribution of overall scores for the Spearhead Group (figure 5)³⁸ of primary care trusts is similar to that for all. These primary care trusts are in the bottom fifth of all trusts with the worst health and deprivation indicators. For example, the life expectancy in these areas, particularly for women, is increasing at a slower rate than in the areas not in the Spearhead Group. The similar spread of overall scores between the Spearhead Group and all trusts shows that the level of deprivation of an area is not a factor in how well primary care trusts support people with diabetes to look after themselves.

Figure 5: Overall scores for primary care trusts in the Spearhead Group (by percentage and number)



Conclusions

Our review shows that the majority of people with diabetes:

- have regular checkups, at least one a year with a healthcare professional, and most of the key tests and measurements are carried out
- reported that they know enough about when to take their medication and how much medication to take
- reported having the key tests carried out that are easily recognisable, for example, being weighed or having their blood pressure taken
- who smoke are offered advice about stopping smoking

However, there are five areas that all commissioners and providers of diabetes services need to focus on to improve the support offered to people with diabetes.

- Better partnership between people with diabetes and their healthcare professionals when planning and agreeing their care, because:
- between 34% to 61% of people with diabetes across all primary care trusts had agreed a plan to manage their condition
- people with diabetes, particularly those with Type 2 diabetes and those people from black and minority ethnic populations, reported that the key aspects of care planning were not happening. For example, between 23% and 58% of people with diabetes in trusts had discussed their goals in caring for their diabetes at their checkup

- there is no primary care trust that has more than half of people with diabetes achieving their lifestyle targets
- 2. Increasing the number of people with diabetes attending education courses and improving their knowledge of diabetes, because:
- in 55% of primary care trusts, 10% of people or fewer reported attending an education course on how to manage their diabetes
- between 16% and 41% of people with diabetes in primary care trusts would like to attend an education course on how to manage their diabetes if they have not been on one already
- those with Type 2 diabetes more than those with Type 1, and those from black and minority populations more than white people, report not attending an education course but wanting to
- in three-quarters of primary care trusts, half the people with diabetes, or less, knew their long term blood glucose (HbA1c) value
- between 19% and 53% of people knew that their urine was being tested for protein, which is a kidney function test
- 3. Working more closely with all organisations providing and commissioning diabetes services, because:
- in 95% of primary care trusts, there is scope to reduce the number of emergency admissions to hospital for diabetes-related complications

- 4. Increasing the number of people with diabetes having long term blood glucose (HbA1c) levels of 7.4 or a lower, safe level. because:
- safe, long term blood glucose levels is one of the most important factors in reducing the long term effects of diabetes
- in primary care trusts, the percentage of people with diabetes achieving this level is between 52% and 65% after taking account of the characteristics of their populations
- 5. Reducing variation in general practices' achievements. because:
- there is a wide variation between general practices on some of the outcome indicators, such as achieving a long term blood glucose (HbA1c) level of 7.4, where we found an elevenfold difference in the variation across primary care trusts and the process indicators, such as recording a long term blood glucose (HbA1c) test, where we found a twelvefold difference
- some people with diabetes are receiving better care than others. All practices should work towards achieving the performance of the better practices

Patterns from our national survey

We found the following patterns in our statistical analysis of the survey of people with diabetes³⁴

Differences by ethnicity

There were some consistent patterns across people from black and minority ethnic (BME) populations. People from all BME groups (with the exception of those from the 'Chinese/ other' group) were less likely than white people to know their HbA1c value, less likely to know when to take their medication and how much to take, and more likely to say they had not attended an education course on managing their diabetes but would like to attend one.

Both Asian people and people from the 'Chinese/other' groups were less likely than white people to have discussed ways to manage their diabetes and less likely to have discussed their goals in caring for their diabetes; they were also less likely to say they had received the right amount of verbal information when first diagnosed or that they had had all the recommended tests in the last 12 months

Both Asian and black people were more likely than white people to say they had been given personal advice about the kinds of food to eat and their levels of physical activity.

Differences by type of diabetes

Those with Type 2 diabetes were less likely than those with Type 1 to know their HbA1c value, less likely to know when to take their medication and how much to take, less likely to say they received the right amount of verbal information when first diagnosed and more likely to say they had not attended an education course but would like to attend one. On the other hand, they were more likely to have been given personal advice about the kinds of food to eat and their levels of physical activity.

Differences by place of checkup

Those having their usual checkups at hospital were less likely than those having them at their doctor's surgery to know when to take

their medication and how much to take, and less likely to have received personal advice on levels of physical activity and the kinds of foods to eat. On the other hand, they were more likely to know their HbA1c value and more likely to have participated in an education course on managing their diabetes.

Differences by number of years since diagnosis

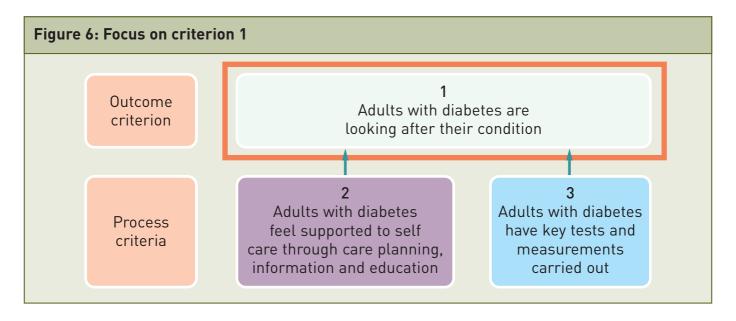
The greater the number of years since respondents' diagnosis, the less likely they were to have received personal advice on levels of physical activity and the kinds of foods to eat or have been offered or have participated in an education course on managing their diabetes. They were less likely to have received the right amount of verbal information when they were first diagnosed. On the other hand the greater the number of years since diagnosis the more likely they were to say that they had had all the recommended tests in the last 12 months.

Differences by long standing health problem

Those people with diabetes with an additional long standing physical or mental health problem were less likely than those without one to have positive experiences for nearly all the indicators examined. The main exceptions were that they were no more or less likely to have been offered an education course on managing their diabetes and no more or less likely to have attended one.

Detailed findings

This section of the report describes in turn the detailed findings of each of the three criteria, beginning with the outcome criterion (figure 6).



Adults with diabetes are looking after their condition

Living with diabetes is challenging. Every day, people with diabetes are juggling decisions on what and how much food to eat with the amount of physical activity they have done, or are going to do. They are also taking their medicine, monitoring their blood glucose levels and watching for signs of hypoglycaemia and long term complications. Diabetes has a major physical and psychological impact on those who develop it.

People with diabetes need help from healthcare professionals to live with their diabetes and to manage their care on a dayto-day basis. They can do this by supporting people with diabetes to make lifestyle changes, to take the right medication, to monitor their blood glucose levels appropriately, and to understand their

condition, in order to keep the risk factors of diabetes at or below recommended levels.

"The doctor goes through in his mind, asking the questions and looking at the blood results and things - you can see him going through all of this one step at a time. He's systematic, no question, I'm pleased with that." (Person with diabetes)

The diabetes NSF recognises the importance of controlling the factors that increase the risk of acute and long term complications and of the part healthcare professionals play in minimising the risk of future recurrence of acute emergency complications. In particular, there are two standards that are relevant.

Table 4: The relevant diabetes NSF standards⁴

Standard 4: Clinical care of adults with diabetes

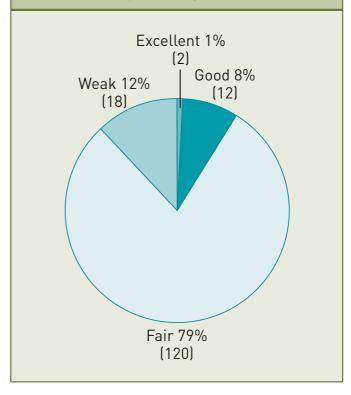
All adults with diabetes will receive highquality care throughout their lifetime, including support to optimise the control of their blood glucose, blood pressure and other risk factors for developing the complications of diabetes.

Standard 7: Management of diabetic emergencies

The NHS will develop, implement and monitor agreed protocols for rapid and effective treatment of diabetic emergencies by appropriately trained healthcare professionals. Protocols will include the management of acute complications and procedures to minimise the risk of recurrence.

Our overall results for the criterion 'Adults with diabetes are looking after their condition' showed that of the 152 primary care trusts in England, two scored "excellent", Dorset PCT and Cumbria PCT.

Figure 7: Primary care trusts' scores for criterion 1 (by percentage and number)



The distribution of criterion scores at strategic health authority (SHA) level is shown in table 5. The two primary care trusts scoring "excellent" are in different regions – one is in South West SHA and the other in North West SHA. The remaining strategic health authorities had none of the primary care trusts in their area achieve "excellent" for this criteria, while nine out of 10 of them had at least one trust scoring "weak".

Table 5: Percentage of primary care trusts scoring	"excellent" and	"weak" in each strategic
health authority (SHA) for criterion 1		

Percentage of primary care trusts scoring "excellent" in each SHA	
South West SHA	7%
North West SHA	4%
East Midlands SHA	0%
East of England SHA	0%
London SHA	0%
North East SHA	0%
South Central SHA	0%
South East Coast SHA	0%
West Midlands SHA	0%
Yorkshire and Humber SHA	0%



Percentage of primary care trusts scoring "weak" in each SHA	
South East Coast SHA	0%
North West SHA	4%
Yorkshire and Humber SHA	7%
South West SHA	7%
North East SHA	8%
South Central SHA	11%
East Midlands SHA	11%
East of England SHA	14%
West Midlands SHA	18%
London SHA	23%

To assess whether adults with diabetes are looking after their condition, we asked the following questions:

- 1. Are the key measurements for adults with diabetes at recommended levels and are emergency admission rates low?
- 2. Do adults with diabetes feel that they are achieving their lifestyle targets?
- 3. Do adults with diabetes feel knowledgeable about their diabetes?

Why did we look at key measurements and emergency admission rates?

The measurements of blood glucose levels (using glycated haemoglobin called HbA1c as a marker), blood pressure and cholesterol levels give an indication of how well an adult with diabetes is managing their condition.

While emergency admission rates for diabetic ketoacidosis and hypoglycaemia indicate how well people with diabetes are supported to cope with acute complications, and how well the healthcare system as a whole, including ambulance services, are working together to reduce emergency admissions.

Diabetes is a condition where glucose builds up in the bloodstream rather than being moved to the body's cells. Exposure to raised blood glucose levels can damage the small blood vessels in the body leading to micro vascular conditions such as visual impairment and blindness, kidney failure and nerve damage (which can lead to foot ulcers and lower limb amputation). There is also a significantly increased risk of people with diabetes, particularly those with Type 2 diabetes, developing cardiovascular disease. This results from damage to the walls of the large blood vessels.

Controlling the levels of glucose in the blood can prevent or delay the development of micro vascular complications and may reduce the risk of people with diabetes developing cardiovascular disease. The HbA1c test is used to measure the average blood glucose level over the previous eight to 10 weeks. Therefore it shows how well people with diabetes are controlling their diabetes over the longer term.

Up to 70% of people with Type 2 diabetes have raised blood pressure⁴. The risk of cardiovascular disease increases as blood pressure increases. Lowering blood pressure in people with diabetes reduces the risk of cardiovascular disease and the micro vascular complications associated with diabetes.

Raised cholesterol levels also increase the risk of cardiovascular disease, so by reducing these levels in people with diabetes who have raised cholesterol levels (over 70% of adults with Type 2 diabetes)⁴, the risk of cardiovascular disease may be reduced.

There are two potentially fatal acute complications of diabetes: diabetic ketoacidosis (DKA) and hypoglycaemia. DKA may lead to drowsiness and hypoglycaemia may lead to confusion and fits. Both can lead to coma. People with diabetes can reduce the occurrences of DKA and hypoglycaemia by recognising the symptoms early and managing to control their diabetes³. Most episodes of hypoglycaemia can be managed outside of hospitals⁴.

To reduce the number of these emergency acute complications, it is important that people with diabetes know what to do and can do it, and that healthcare professionals know how to support them. The healthcare professionals involved are from the acute

hospital, the general practice and the ambulance service which responds to the emergency. Looking at emergency admission rates gives us an indication of how well the health professionals work together as a multidisciplinary team to support people with diabetes.

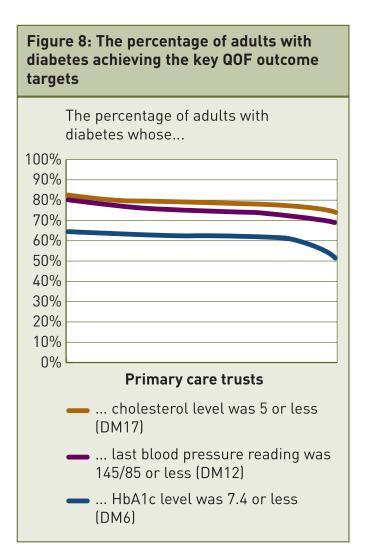
What did we find in the review?

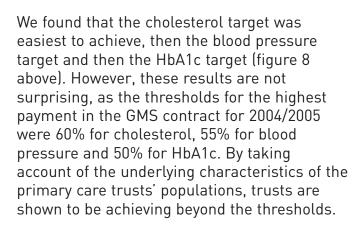
For each primary care trust in England, we used data from the Quality and Outcomes Framework (QOF)¹ and standardised it to take account of the underlying social and demographic characteristics of the populations concerned, for example, the local population's age, gender and level of deprivation³7. We then calculated the percentage of people with diabetes, for a primary care trust and the general practices within it, whose:

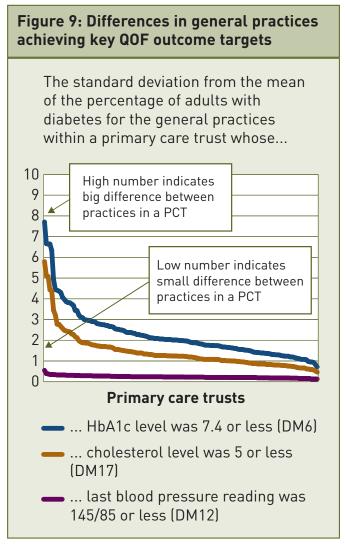
- HbA1c level was 7.4 or less
- last blood pressure reading was 145/85 or less
- cholesterol level was 5 or less

We found that, in all primary care trusts (figure 8):

- between 52% and 65% of people had an HbA1c value of 7.4 or less (with half of all trusts reaching 62% or more)
- between 69% and 80% of people had a blood pressure reading of 145/85 or less (with half of all trusts reaching 75% or more)
- between 74% and 82% of people had a cholesterol level below 5 (with half of all trusts reaching 79% or more)







We also found that there was significantly less difference between practices in each primary care trust achieving the blood pressure target compared to the cholesterol target, and less variation in achieving the cholesterol target compared to the HbA1c target (figure 9). In addition, for the HbA1c target we found that the best primary care trust had 11 times less

variation than the worst. For the cholesterol target there was 13 times less variation and for the blood pressure target, four times less. The smaller differences in practices achieving the blood pressure and cholesterol targets might be because the targets are set too low and are easily achieved by people taking their medication. Whereas, achieving the HbA1c target involves people sticking to complex regimens of taking multiple medications and making lifestyle changes.

Our results showed that primary care trusts are achieving beyond the thresholds set for the QOF payment levels. This is to be celebrated. However, there are still primary care trusts with large variation between the better and poorer achieving general practices, which is a cause of concern.

Our results also showed that more work is required to ensure that adults with diabetes meet the HbA1c target of 7.4. This target that had bigger differences between practices and which was not as different from the QOF payment threshold as the other outcome targets. This means that people with diabetes need to be provided with the knowledge and skills to better control their blood glucose levels. This finding is supported by the March 2007 report from the National Clinical Director for Diabetes to the Secretary of State on the progress towards meeting the NSF standards³.

We pooled three years (2003/2004, 2004/2005 and 2005/2006) of Hospital Episode Statistics (HES) data to look at the emergency admission rates for diabetes ketoacidosis (DKA) and hypoglycaemic coma for each primary care trust's population. We compared the number

of observed admissions (or, those that happened) to what we would expect the number of admissions to be, taking account of the primary care trust's population (see the technical guidance document for information on the calculations)³⁷.

We found that eight primary care trusts (table 6) had admission rates that were significantly lower than expected, while 13 primary care trusts had emergency admission rates that were significantly higher than expected. The remaining primary care trusts (131) did not differ significantly from what was expected.

Table 6: Primary care trusts with emergency admission rates that were lower than expected

Richmond and Twickenham PCT

Kensington and Chelsea PCT

Harrow PCT

Dorset PCT

Sutton and Merton PCT

Berkshire East PCT

West Hertfordshire PCT

East and North Hertfordshire PCT

Our results showed that very few primary care trusts had emergency admissions different from what was expected. The primary care trusts with higher than expected admission rates can learn particularly from the eight trusts with rates lower than expected (for good practice see *The Way Ahead*³. For the remaining 131 primary care trusts, there is room to improve emergency admission rates to be lower than expected.

Why did we look at lifestyle targets?

Changing a person's lifestyle can slow down the progression of diabetes. Between 80% to 90% of people with Type 2 diabetes are overweight or obese [4]. Maintaining a healthy weight by improving diet and increasing physical activity can, in combination, reduce blood glucose levels and the risk of cardiovascular disease. Since blood glucose levels are affected by what a person eats, it is important that people with diabetes understand the effects of the type, amount and timing of food on their condition and are given advice that is culturally appropriate.

"It's the old thing isn't it – people know these things and they take it for granted that everybody else has their knowledge, so they don't explain it to you. They think 'oh surely you know, you've got diabetes'." (Person with diabetes)

What did we find in the review?

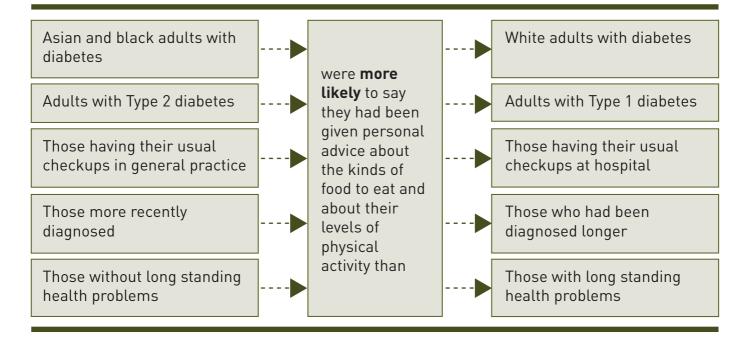
We used data from the 2006 national patient survey of people with diabetes to identify the

percentage of adults with diabetes who felt that:

- they were good at eating the right foods, knew enough about what to eat to help manage their diabetes and had received personal advice about what to eat
- they were good at being physically active, knew enough about the role of physical activity on their diabetes and had been given personal advice about physical activity

For the lifestyle target about food, we found that across all primary care trusts, between 25% and 50% of adults felt that they were good at eating the right foods, knew enough about the food to eat and had 'almost always' received personal advice.

"They put a sticker on the back of the bed 'diabetic' and in the end I stuck it on my head, because they were bringing all sorts of stuff like ice cream with things on and custard." (Person with diabetes)



For the indicator about physical activity we found that between 14% and 33% of adults were good at being physically active, knew enough about physical activity and had 'almost always' received personal advice.

By analysing the corresponding questions in the survey of patients³⁴ we found that the question in the survey which had the most influence on the indicator was about personal advice. Therefore we examined the two questions on personal advice about food and physical activity in our more detailed analyses. We found that:

"They do not know enough if they are not Asian, they do not know enough about the Asian diet. They only know what they have picked up, what they have been taught. It is very important for the Asian community to see an Asian nurse who is more aware. Who knows our everyday foods. What to do and what not to do in the kitchen." [Person with diabetes]

Our results showed that people with diabetes are being supported more in eating the right food than in being physically active. However, there is not one primary care trust with more than half of people with diabetes reporting achieving their lifestyle targets.

This suggests that trusts could be doing more to commission services which offer support, particularly in the form of personal advice, to people with diabetes in achieving their lifestyle targets.

Why did we look at how knowledgeable people were about their diabetes?

The ability to control blood glucose levels is one of the keys to managing diabetes, avoiding acute complications and reducing the risk of developing long term complications. If people with diabetes know their HbA1c level and understand their medication, they are in a better position to look after themselves effectively.

What did we find in the review?

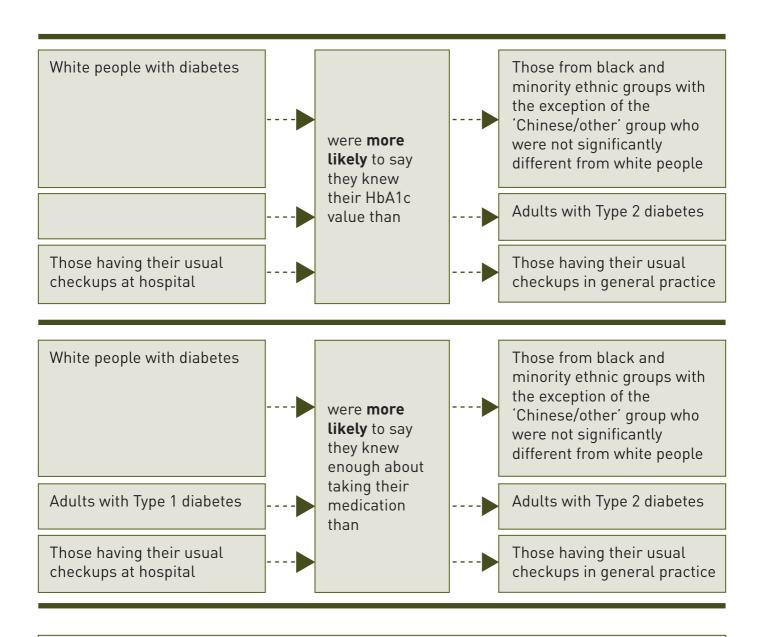
We used data from the 2006 national patient survey of people with diabetes to identify the percentage of adults with diabetes who knew:

- their HbA1c value
- enough about how much medication to take and when

We found that, in all primary care trusts, more people with diabetes knew about taking their medication than what their HbA1c value was.

- 26% to 65% of people knew their HbA1c value (with half of trusts reaching 46% or more). In three-quarters of primary care trusts, 50% of people with diabetes or less knew their HbA1c value
- 80% to 95% of people knew enough about taking their medication (with half of trusts reaching 90% or more)

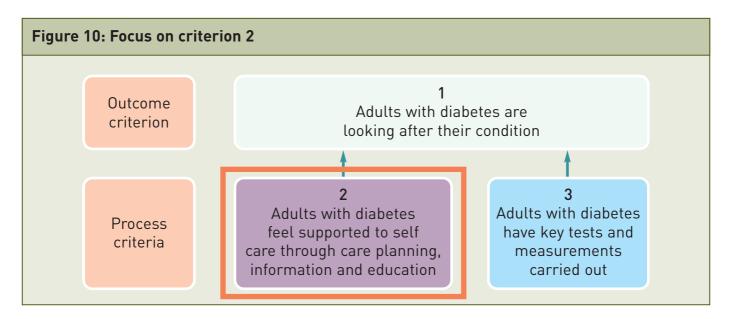
Following detailed analyses of the national survey of people with diabetes³⁴, we found:



Our results showed that the majority of people with diabetes are reporting that they know enough about taking their medication, but the results of the outcome targets shown in the previous section, particularly the HbA1c target, suggest that people may not be being supported to take their medication.

Our results also showed that more needs to be done to support them in knowing what their HbA1c value is, particularly those people with Type 2 diabetes, people from BME populations and those having their usual checkups in hospital.

Adults with diabetes feel supported to self care through care planning, information and education



This section of the report covers the second criterion, which focuses on the processes around supporting people with diabetes to look after themselves (figure 10).

Enabling people with diabetes to jointly decide and agree with healthcare professionals how to manage their condition can encourage people to take more responsibility for their own care³¹. This is good planning of care, where the patient's experience is considered as important as the healthcare professional's view. By combining a care planning approach with verbal and written information and structured education, people with diabetes are able to make more informed choices about how they live their life and how they manage their diabetes.

"It's being able to talk to somebody about what's happening to you and what's going on in your body, because it's horrendous the things you have to go through."

[Person with diabetes]

Table 7: The primary care trusts scoring "excellent" for criterion 2
Bath and North East Somerset PCT
Bournemouth and Poole PCT
Central and Eastern Cheshire PCT
Cornwall and Isles of Scilly PCT
Cumbria PCT
Derbyshire County PCT
Devon PCT
Dorset PCT
Isle of Wight NHS PCT
Knowsley PCT
Northumberland Care Trust
North Tees PCT
North Tyneside PCT
North Lancashire PCT
Sutton and Merton PCT
Trafford PCT

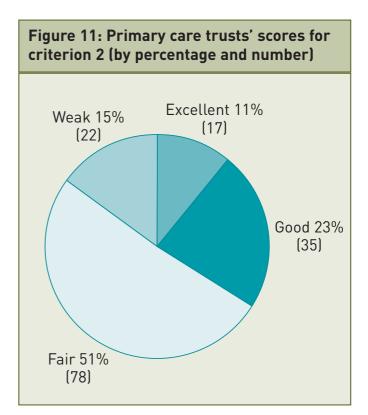
Western Cheshire PCT

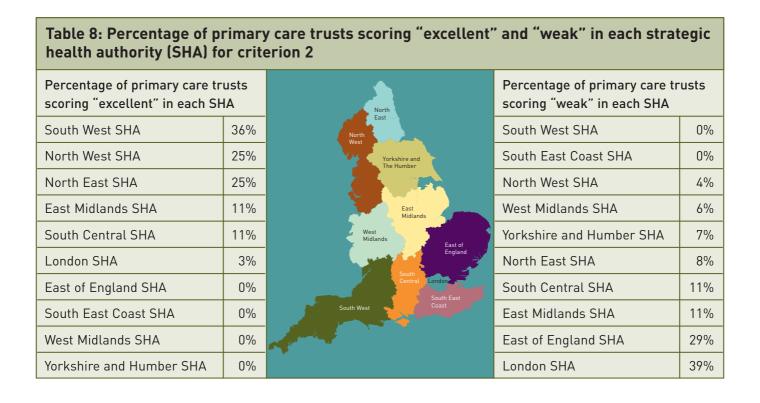
Our overall results for criterion 2: 'Adults with diabetes feel supported to self care through care planning, information and education' showed that of the 152 primary care trusts in England, 17 scored "excellent" (table 7) and 22 scored "weak" (figure 11).

South West SHA has 36% of the primary care trusts in their area scoring "excellent", and none scoring "weak" (table 8). Otherwise, eight out of 10 SHAs had one or more of their trusts scoring "weak".

To assess whether adults with diabetes feel supported to self care through care planning, information and education, we asked:

1. Do adults with diabetes report that they have regular checkups, feel involved and know what to do next?





2. Do adults with diabetes report that they have received enough information, education and training to self care?

Why did we look at regular checkups, feeling involved and knowing next steps?

Regular recall and review of people with diabetes is an important part of diabetes care. An annual review, as recommended in the diabetes NSF, offers an opportunity to screen for long term complications. It also enables people with diabetes to discuss treatment goals and jointly agree a care plan for managing their condition over the next 12 months (see table 9).

The 2006 report from the joint Department of Health and Diabetes UK Care Planning Working Group, Care Planning in Diabetes³¹, describes a model for planning care that can be applied to any consultation or interaction between a healthcare professional and a patient. The model focuses on a partnership between the healthcare professional and the patient and involves asking questions, sharing and discussing information, agreeing action points and documenting the outcomes in a care plan.

"What the professionals need to know is that every single patient they see are individuals. They have different levels of understanding. Some will understand everything very clearly and some won't, they need to pick up on that. Their approach is very important."

[Person with diabetes]

Table 9: The relevant diabetes NSF standard

Standard 3: Empowering people with diabetes

"All children, young adults and adults with diabetes will receive a service which encourages partnership in decision-making, supports them in managing their diabetes and helps them to adopt and maintain a healthy lifestyle. This will be reflected in an agreed and shared care plan in an appropriate format and language. Where appropriate, parents and carers should be fully engaged in this process."

The diabetes NSF delivery strategy (2002) states in paragraph 3.21 that "A care plan is at the heart of a partnership approach to care and a central part of effective care management. The process of agreeing a care plan offers adults active involvement in deciding, agreeing and owning how their diabetes will be managed. Whilst the overall goal is a genuine partnership, the person with diabetes must feel that they are comfortable with what is proposed and that they do not have to bear more responsibility than they wish."

"Just an open question, 'What's it like for you living with your diabetes at the moment? Are you managing well? What are you struggling with? Is there anything you need?' – that's the question I'd like to be asked occasionally."

[Person with diabetes]

What did we find in the review?

We used data from the 2006 national patient survey of people with diabetes to identify the percentage of people with diabetes diagnosed for more than a year who had had at least one checkup in the last 12 months.

We also used the survey to identify the percentage of people with diabetes who have had a checkup who think that they almost always:

- 1. discuss ideas about the best way to manage their diabetes at their checkup
- 2. discuss their goals in caring for their diabetes at their checkup
- 3. agree a plan to manage their condition over the next 12 months at their checkup

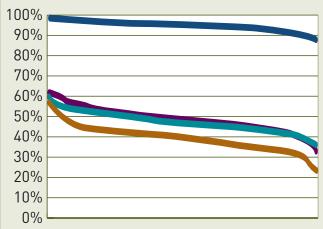
We found that across all primary care trusts, a very high proportion of people with diabetes have had at least one checkup in the last year.

• 88% to 98% of people have had an annual checkup in the last 12 months (with half of trusts reaching 95% or more). In threequarters of primary care trusts, at least 94% of people had had their checkup

However, they were much less likely to discuss their goals at their checkup than they were to discuss their ideas or agree a plan (figure 12):

- 32% to 60% of people had discussed ideas about how to manage their condition (with half of trusts reaching 48% or more)
- 23% to 58% of people had discussed goals (with half of trusts reaching 39% or more)
- 34% to 61% of people had agreed a plan (with half of trusts reaching 46% or more)

Figure 12: Percentages of people having checkups and planning their care

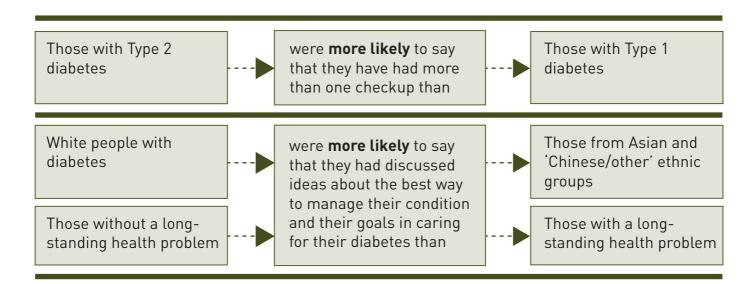


Primary care trusts

 The percentage of adults with diabetes diagnosed for more than a year, who report that they have had at least one diabetes checkup in the last 12 months

> The percentage of adults with diabetes who have had a checkup who report that they 'almost always'...

- ... discuss ideas about the best way to manage their diabetes at their checkup
- ... agree a plan to manage their condition over the next 12 months at their checkup
- ... discuss their goals in caring for their diabetes at their checkup



We found from further analyses of the survey data that 99% of people with diabetes report having a checkup. The one per cent (505 people) who have never had a diabetes checkup are not from one particular group of people, but 94% of them have Type 2 diabetes.

"My doctor doesn't bother. If I don't go even for 6 months the doctor won't chase me up. I have to go and see him then he refers me for a checkup." [Person with diabetes]

"They used to call me but once I didn't go because I was ill, since then they haven't called." (Person with diabetes)

We also found from the further analyses of the survey of people with diabetes that nationally:

"What is the point going to your [doctor] in the first place when you do not have someone to interpret for you."

(Person with diabetes for whom English is not their first language)

"It was like listening to a parrot, who was saying the same thing to all her clients." (Person with diabetes) Our results showed that nearly all people with diabetes are having regular checkups, at least one a year. However, there is scope to improve the annual review process by involving all people with diabetes in planning their care, particularly people who have Asian and 'Chinese/other' origin and those with a long standing health problem.

Why did we look at information, education and training?

Both the diabetes NSF and the NICE guidance on the use of patient education models issued in 2003 and reinstated in 2006²⁰ recognise the importance of patient education in supporting self care. In 2005, the Department of Health and Diabetes UK report *Structured patient education in diabetes* highlighted the valuable role education plays in helping people to manage their condition day-to-day³⁹.

Information (oral and written), education and skills-based training need to be provided to people with diabetes on a one-to-one and group basis from diagnosis onwards. They need to be delivered at times agreed with the individual, in a language that is appropriate and in a format that encourages discussion.

"When I first got diagnosed, I went down to hospital and there were guys in there with no feet, no legs, blind – and I thought what the hell have I come to here? I were scared, I tell you. I felt like going home and putting my head in the gas oven."

(Person with diabetes)

"Unless somebody tells you how to do it, how can you self care? It's important to get that information on day one, so you go away to start your discipline." (Person with diabetes)

Education also needs to include making people aware that if they stop smoking they can reduce the risk of developing the long term complications of diabetes, particularly cardiovascular disease.

What did we find in the review?

We used data from the 2006 patient survey to identify the percentage of people with diabetes who:

1. felt that they received the right amount of verbal and written information when they were diagnosed

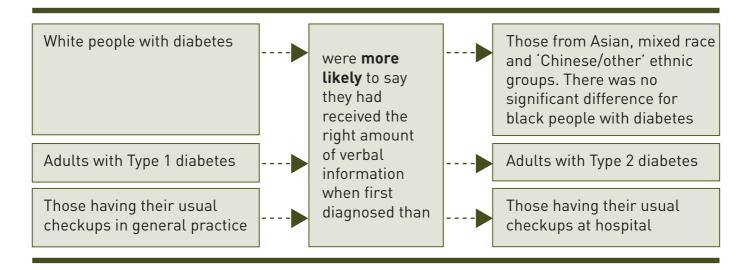
- 2. were offered an education or training course
- 3. have attended a course
- 4. have not attended a course but would like to
- 5. have been offered a course and would like to attend but have not participated because it was not 'suitable'

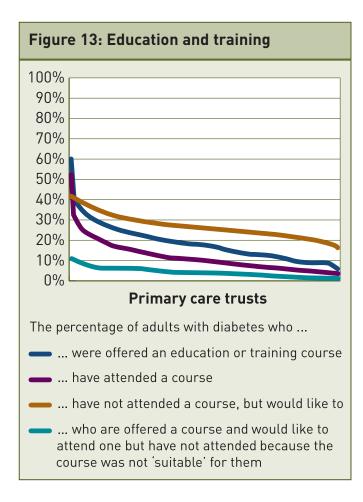
We used data from the Quality and Outcomes Framework (QOF) to identify the percentage of people, for a primary care trust and the general practices within it, who:

6. smoke and whose notes contain a record that smoking cessation advice has been offered in the last 15 months

In terms of information, we found that, across all primary care trusts, between 36% and 67% of people had received the right amount of information on diagnosis. In half of primary care trusts, more than 55% of people had received the right amount of information on diagnosis.

Our findings from further analysis of the national patient survey of people with diabetes were that:





In terms of education and training, we found that across all primary care trusts (figure 13):

- people had been offered an education or training course in every trust, but in two-thirds of trusts, 20% of people or fewer had been offered courses
- approximately half of trusts (55%) had 10% of people or fewer reporting attending a course. Overall, between 1% and 53% of adults had attended a course
- 16% to 41% of people had not attended a course but would like to. In more than half of primary care trusts, one in four people (25%) to over a third (41%) have not attended an education course but would like to

In the survey of people with diabetes, we asked those who have been offered an education course and would like to attend one but have not attended, whether this was because:

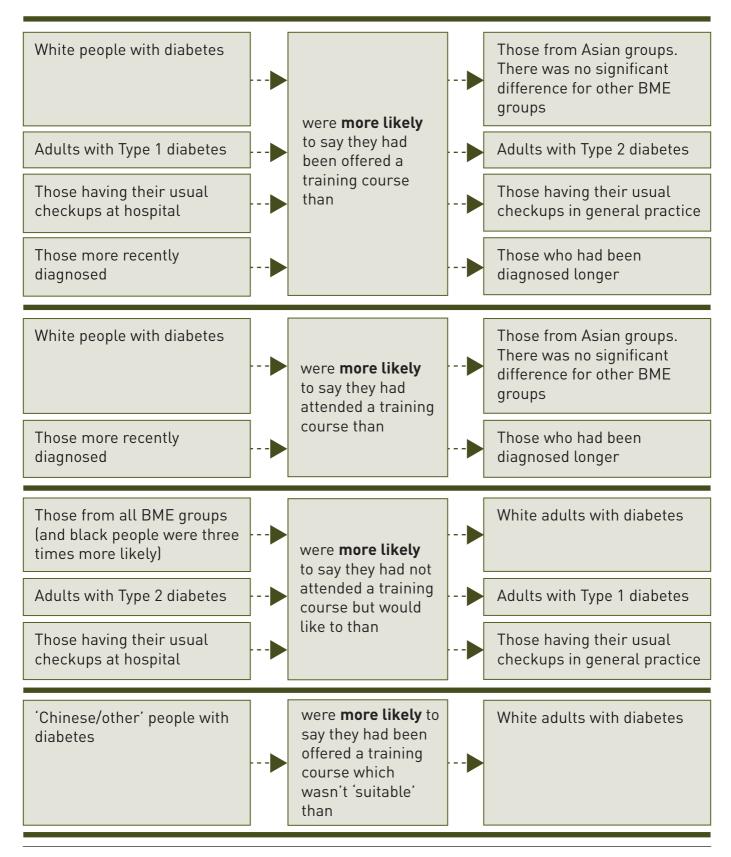
- 1. the location was inconvenient
- 2. the time or day was inconvenient
- 3. the course wasn't suited to their cultural needs
- 4. the course didn't cater for their disability
- 5. there were no male only or female only courses
- 6. they don't like group training
- 7. other reason

In assessing primary care trusts, if the respondent ticked a response from 1 to 6, we concluded that the course offered was not 'suitable'. If the respondent ticked 7, we concluded that there was a reason beyond the trust's control why the person had not attended and therefore the course was 'suitable'.

We found that in all primary care trusts (figure 13), less than 10% of people reported that the course offered to them was not 'suitable'. In half of trusts, between 0% and 3% had not attended a course offered to them because it was not 'suitable'. Therefore the courses that are offered by primary care trusts are in general 'suitable' to people with diabetes.

At a national level, we found that seven per cent of people with diabetes did not attend an education course that was offered to them even though they would like to go on one. The two main reasons for them not attending were that they did not like group training (31%) and the time or day was inconvenient (26%).

From the further analyses carried out on the national survey of people with diabetes we found:



Our analysis of QOF data found that across all primary care trusts, 91% to 98% of people with diabetes who smoke have been offered smoking cessation advice. There was little variation within trusts between better and poorer achieving general practices.

Our results showed that primary care trusts are offering smoking advice to the majority of people with diabetes who smoke. However, our results showed that in just over half of primary care trusts, 10% or fewer of people with diabetes had reported attending a course. The results also showed that between 16% and 41% of people had not attended a course and would like to.

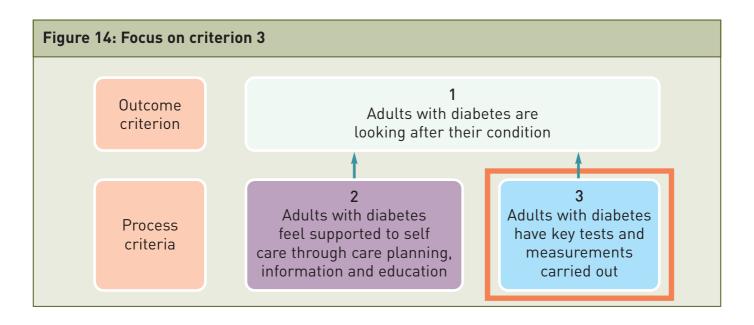
Our results showed that primary care trusts need to adhere to the NICE guidance on patient education by offering education courses to all members of the community, but particularly to people from BME populations, to adults with Type 2 diabetes and those with a long standing health problem.

Adults with diabetes have key tests and measurements carried out

This section of the report covers the third criterion, which focuses on the processes around supporting people with diabetes to look after themselves (figure 14).

People with diabetes need to have certain key tests and measurements carried out at least once a year to give them the information to manage their condition and to check for the signs of progression of the disease. The diabetes NSF described what these key tests should be and which standards they relate to (box 7). In addition to these tests, it is good practice for people with diabetes to have their weight recorded (and body mass index or BMI calculated).

For people with diabetes to manage their condition, whether by themselves or as active partners with their healthcare professionals, they must know that the key tests and measurements have been carried out, and that all of them have been carried out each year.



Box 7: The key interventions and diabetes NSF standards

Clinical care of adults with diabetes

Standard 4

All adults with diabetes will receive high-quality care throughout their lifetime, including support to optimise the control of their blood glucose, blood pressure and other risk factors for developing the complications of diabetes.

Blood glucose (HbA1c) test

- Improving blood glucose control reduces the risk of developing the microvascular complications of diabetes in people with both Type 1 and Type 2 diabetes
- Improving blood glucose control may reduce the risk of people with diabetes developing cardiovascular disease

Blood pressure test

 Controlling raised blood pressure in people with diabetes who have co-existing hypertension reduces their risk of developing both microvascular complications and cardiovascular disease

Cholesterol test

 Reducing cholesterol levels in people with diabetes who have raised cholesterol levels may reduce their risk of cardiovascular disease

Detection and management of long term complications

Standard 10

All young people and adults with diabetes will receive regular surveillance for the long term complications of diabetes.

Eye check

• Regular surveillance for diabetic retinopathy in adults with diabetes and early laser treatment of those identified as having sight-threatening retinopathy can reduce the incidence of new visual impairment and blindness in people with diabetes

Kidney function test (urine test for protein)

• Tight blood pressure and blood glucose control in people with diabetic nephropathy can reduce the rate of deterioration in their renal function, as well as their risk of cardiovascular disease

Foot check

- People with diabetes identified as being at increased risk of developing lower limb complications can reduce this risk by participating in a foot care programme that provides foot care education, podiatry and, where required, protective footwear
- In people with diabetes who develop foot ulceration, prompt intervention can minimise their risk of subsequent disability and amputation

Source: Diabetes NSF⁴ pages 25 and 40

Our overall results for criterion 3, 'Adults with diabetes have key tests and measurements carried out', showed that of the 152 primary care trusts in England, three scored "excellent" – Bath and North East Somerset PCT, Herefordshire PCT and Redcar and Cleveland PCT – and 13 scored "weak".

The three primary care trusts scoring "excellent" on criterion 3 are in South West SHA, West Midlands SHA and North East SHA (table 10). Furthermore, South West SHA had no primary care trusts scoring "weak".

To assess if the key tests and measurements are being carried out, we asked:

- 1. Do clinicians carry out key tests and measurements?
- 2. Do adults with diabetes report that key tests and measurements are carried out?
- 3. Do adults with diabetes report that ALL key tests and measurements are carried out?

Figure 15: Primary care trusts' scores for criterion 3 (by percentage and number)

Excellent 2%

(3)
(13)
(17)
(17)

Table 10: Percentage of primary care trusts scoring "excellent" and "weak" in each strategic health authority (SHA) for criterion 3				
Percentage of primary care trusts scoring "excellent" in each SHA		North East	Percentage of primary care tr scoring "weak" in each SHA	rusts
North East SHA	8%	North West	Yorkshire and Humber SHA	0%
South West SHA	7%	Yorkshire and The Humber	South West SHA	0%
West Midlands SHA	6%		South East Coast SHA	0%
East of England SHA	0%	East Midlands	South Central SHA	0%
East Midlands SHA	0%	West Midlands East of	North West SHA	4%
London SHA	0%	England	West Midlands SHA	6%
North West SHA	0%	Central London	North East SHA	8%
South East Coast SHA	0%	South West Coast	East Midlands SHA	11%
South Central SHA	0%	A CONTRACTOR OF THE PARTY OF TH	East of England SHA	14%
Yorkshire and Humber SHA	0%		London SHA	23%

Why did we look at whether clinicians were carrying out key tests and measurements?

As part of the ongoing monitoring for the long term effects of diabetes, clinicians (healthcare professionals) need to carry out key tests and measurements, and record them in their patients' files. This is important too for people with diabetes as having the results from the key tests and measurements enables them to care for themselves.

What did we find in the review?

We used data from the Quality and Outcomes Framework (QOF) to identify the percentage of people with diabetes, for a primary care trust and the general practices within it, with a record in the last 15 months of:

- HbA1c (blood glucose test)
- blood pressure
- total cholesterol
- BMI
- micro-albuminaria testing (kidney function)
- serum creatinine testing (kidney function)
- presence or absence of peripheral pulses (foot check)
- neuropathy testing (foot check)
- retinal screening (eye check)

"If I go to my doctor to ask him to check my sugar level he says sometimes that he hasn't got the machine or hasn't got the time." (Person with diabetes)

All but a few trusts achieved at least 90% of people with diabetes having all the key tests and measurement recorded. This is not surprising as the top threshold for payment to general practices under the GMS contract is 90% of people for each test. Some primary care trusts are exceeding this 90% level, testing nearly everyone with diabetes should they agree and are not excepted from the test on other grounds. For example, the range for trusts on recording blood pressure is from 95% to 99% of people with diabetes. The best trust had 12 times less variation in their practices achievements than the worst.

The tests which the few primary care trusts did not achieve the threshold for were microalbuminaria testing, retinal screening and presence or absence of peripheral pulses. These were also the tests where we found the biggest difference between general practices' achievements within primary care trusts.

Our results showed that the majority of clinicians are carrying out the key tests and measurements. This is exceptional performance that we can celebrate.

Our results also showed that some primary care trusts have wider variation between their general practices' achievements, and lower achievement overall, on some of the key tests and measurements.

Why did we look at whether people with diabetes report that key tests and measurements are carried out?

"People who take on greater responsibility for the management of their diabetes have been shown to have reduced blood glucose levels, with no increase in severe hypoglycaemic attacks, a marked improvement in quality of life and a significant increase in satisfaction with treatment." (4, page 22)

If people with diabetes know that the key tests and measurements have been carried out, it can indicate their awareness about their diabetes, and that they have taken on responsibility for managing their diabetes.

"They usually tell you your HbA1c, but the last time I had to ask about cholesterol and the other things. You feel like a bit of a nuisance, taking up a bit more of their time for them to explain. They take these blood tests and you don't know what they're testing you for."

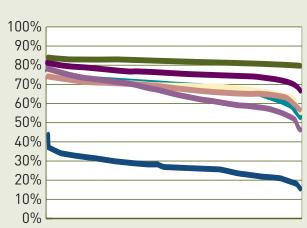
[Person with diabetes]

What did we find in the review?

We used data from the 2006 national patient survey of people with diabetes to identify the percentage of people reporting that they had had, in the last 12 months:

- an HbA1c blood test
- a urine test for protein
- their blood pressure taken
- a cholesterol test
- a photo taken of the back of their eyes (screening for retinopathy)
- their bare feet examined
- their weight taken by a doctor or a nurse

Figure 16: The percentage of people with diabetes reporting whether key tests and measurements are carried out



Primary care trusts

The percentage of adults with diabetes reporting that they had had, in the last 12 months, ...

- ___ ... their blood pressure taken
- ... their weight taken by a doctor or a nurse
- ... a photo taken of the back of their eyes
- ___ ... their bare feet examined
 - ... a cholesterol test
- ___ ... a HbA1c test
- ___ ... a urine test for protein

We found that people with diabetes reported in a similar way to the results from the QOF data on having their blood pressure taken and being weighed (figure 16), as a high percentage said that these had been carried out. Similarly, the lowest percentage of people reported having the urine test for protein carried out, which is the micro-albuminaria test (one of the kidney function tests) in QOF.

We also found that the biggest variation across primary care trusts was the percentage of people with diabetes reporting that they had had a photo taken of the back of their eyes. In addition, across all primary care trusts we found that there were similar percentages of people reporting having cholesterol tests. having their bare feet examined and having HbA1c tests

Our results showed that more people with diabetes report having the key tests carried out that are easily recognisable, for example having their blood pressure taken or being weighed. People with diabetes are less likely to know that their urine is being tested for protein.

Why did we look at whether people with diabetes report that ALL key tests and measurements are carried out?

All key tests and measurements should be carried out each year on every person with diabetes - some will be carried out once and others on a number of occasions. It is unlikely that they will all be carried out in one session. However, for people with diabetes to manage their condition well, they must know that all of the tests and measurements have been carried out in the last year.

"When my son moved and registered with a new doctor, the lady didn't know the difference between Type I and Type II." [Person with diabetes]

What did we find in the review?

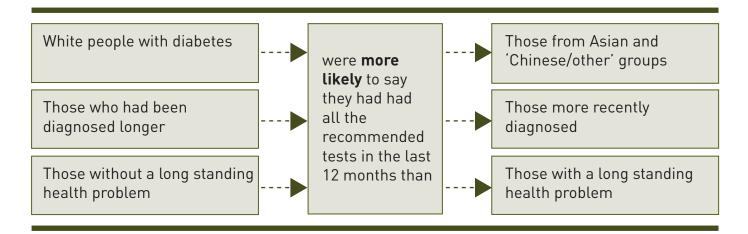
We used data from the 2006 national patient survey of people with diabetes to identify the percentage of people reporting that they had had all of the following in the last 12 months:

- an HbA1c blood test
- a urine test for protein
- their blood pressure taken
- a cholesterol test
- a photo taken of the back of their eyes
- their bare feet examined, and
- their weight taken by a doctor or a nurse

We found that the percentage of people with diabetes reporting that they had had the urine test for protein was directly linked to the performance of primary care trusts. This was the lowest percentage achieved (figure 16) in every primary care trust, and ranged from 19% to 53%, with half of trusts reaching 31% or more.

"I am confused about what I am checking at home and what it means." (Person with diabetes)

From the further analyses carried out on the national survey of people with diabetes we found:



"I like to go to the hospital to see the diabetic nurse and blood pressure nurse... they are very patient... they sit down and they are very good to be with."

(Person with diabetes)

Our results showed that people with diabetes need to know more about the kidney function tests.

Areas for improvement

Our review demonstrated that there are some aspects of care for adults (aged 17 and over) with diabetes that are in greatest need of improvement in most primary care trusts. In this section, we pull together the review's findings against the relevant standards in the diabetes national service framework (NSF) and highlight the five main areas that need to improve in order to support people with diabetes better.

"Diabetes has got an NSF and half the people [healthcare professionals] don't seem to want to follow it. The guidelines in it should be the one mandate you come out with. It basically summarises the things you should expect in your care. In fact, it's the Government standards in diabetic care. Why aren't they [healthcare professionals] following that?" (Person with diabetes)

NSF standard 3: Empowering people with

'All children, young people and adults with diabetes will receive a service which encourages partnership and decision making, supports them in managing their diabetes and helps them to adopt and maintain a healthy lifestyle."

1. Better partnership between people with diabetes and their healthcare professionals when planning and agreeing their care

Annual checkups and most of the key tests and measurements are being carried out. However, many people with diabetes reported that aspects of care planning - discussing ideas and goals together and agreeing a plan to manage their diabetes - were not

happening. People with Asian and 'Chinese/other' origin and those with a long standing health problem were more likely to report this than any other people.

Also, the personal advice that people with diabetes need to help them adopt and maintain a healthy lifestyle needs to be offered to everyone routinely. Not one primary care trust had more than half of people with diabetes reporting achieving their lifestyle targets. Further analyses of the indicator revealed that the poor achievement was due to people not being given personal advice about their levels of physical activity or the kinds of food to eat. The people who were more likely to report this in the survey of people with diabetes were white people, adults with Type 1 diabetes, those having their usual checkups at hospital, those who had been diagnosed longer and those with long standing health problems.

How can primary care trusts improve?

Primary care trusts can implement effective processes for planning care by using the report published by the Department of Health and Diabetes UK on care planning in diabetes in 2006³¹. It gives the policy context and the steps needed to incorporate care planning into diabetes services through good commissioning.

2. Increasing the number of people with diabetes attending patient education courses and improving their knowledge of diabetes

For care planning to be effective, the people living with diabetes need to be engaged in the process. The care planning report³¹ recommends that people with diabetes are offered structured education. This is a key

intervention recommended by the diabetes NSF⁴ and NICE²⁰.

According to our results, very few people with diabetes report having all the key tests and measurements carried out, while the healthcare professionals report doing them. One of the reasons for this may be that people with diabetes do not know what needs to be carried out each year. It could also be because people do not know what is being done to them. The results showed that many people with diabetes did not know whether they had had a urine test for protein (a kidney function test), and that most people did not know their HbA1c value, particularly those people with Type 2 diabetes and people from BME populations. Many people did not know why their blood was tested

Our results also showed that people with diabetes want to go on education courses, particularly people of black and minority ethnic origin, and have not been offered courses. Between 16% and 41% of people with diabetes in primary care trusts have not attended an education course and would like to do so.

How can primary care trusts improve?

Primary care trusts can review their existing patient education courses to check that they are meeting NICE guidelines using the Patient Education (improvement) Tools Project Toolkit³². This includes a tool to help assess the demand for structured education.

NSF standard 7: Management of diabetic emergencies

"The NHS will develop, implement and monitor agreed protocols for rapid and effective treatment of diabetic emergencies by appropriately trained health care professionals. Protocols will include the management of acute complications and procedures to minimise the risk of recurrence."

3. Working more closely with all organisations providing and commissioning diabetes services

The results of our review demonstrate that in 95% of primary care trusts there is scope to reduce the number of admissions to hospital for diabetic ketoacidosis (DKA) and hypoglycaemic coma. There are two ways to do this. Firstly, there is a need to improve the way in which people with diabetes prevent and, when necessary, respond to diabetic emergencies – for example, by treating their own hypoglycaemic episodes. This can be achieved through patient education.

Secondly, there is a need to look at the way primary care, secondary care and ambulance services work together within the community alongside non-healthcare organisations to prevent cases of DKA through better management and early diagnosis and, including ambulance services, reduce the number of hypoglycaemic episodes being treated in hospital.

How can primary care trusts improve?

Primary care trusts are one part of a wider diabetes network that needs to exist and be effective to improve diabetes services. An effective diabetes network should enable better management of diabetes issues that cross organisational boundaries. Primary care trusts can examine their local network using the National Diabetes Support Team's network assessment tool and its supplements⁴⁰.

NSF standard 4: Clinical care of adults with diabetes

"All adults with diabetes will receive highquality care throughout their lifetime, including support to optimise the control of their blood glucose, blood pressure and other risk factors for developing the complications of diabetes."

NSF standard 10: Detection and management of long term complications

"All young people and adults with diabetes will receive regular surveillance for the long term complications of diabetes."

4. Increasing the number of people with diabetes having long term blood glucose levels (HbA1c) of 7.4 or a lower, safe level

One of the most important factors in reducing the long term effects of diabetes on those who have it is to have safe blood glucose levels. Our findings showed that once the characteristics of the primary care trust population were taken into account, on average across primary care trusts, 62% of people with diabetes met the long term blood glucose target of 7.4 set in the Quality and Outcomes Framework (QOF). The better performing primary care trusts achieved 65% and the poorer performers achieved 52%.

For the 2006/2007 QOF, the HbA1c target is set at 7.5 because of a discrepancy with NICE guidance that has been rectified. This could mean that more people with diabetes will be

seen to be below the appropriate long term blood glucose level. However, if primary care trusts and general practices can support people better, there might be a shift change with many more people achieving safer HbA1c levels. By monitoring the clinical outcome data closely, primary care trusts can instigate good commissioning procedures to achieve better outcomes.

How can primary care trusts improve?

Primary care trusts, alongside their general practices, can participate fully in the National Diabetes Audit and regularly examine the clinical outcomes and care pathways for their diabetes populations. They can compare themselves against other primary care trusts and initiate improvements to clinical care regularly.

5. Reducing variation in general practices' achievements

In all but one of the QOF indicators we found that there was wide variation within primary care trusts of general practices' achievements. for both the outcome indicators such as achieving HbA1c level of 7.4, where we found an elevenfold difference in the variation across trusts, and the process indicators, such as recording an HbA1c test, where we found a twelvefold difference. Some people with diabetes are receiving better care than others. All practices should work towards achieving the performance of the better practices.

One of the reasons for the extent of this variation could be the variation in the level of exception reporting. Exception reporting is a valid method to stop general practices being penalised if, for example, someone refused to have their HbA1c test. The General Medical Services (GMS) contract lists the criteria for patients to be excepted⁴¹, and primary care

trusts and QOF assessors check that people have been excepted based on these criteria, as well as checking that general practices follow all the guidance associated with the GMS contract.

In 2004/2005, general practices' exception reporting varied from 0% to 85.8% of patients across all the QOF domains, and it was found that the higher the percentage of patients that were excepted, the higher the practices' achievement⁴². In October 2006, the British Medical Association (BMA) published further guidance on exception reporting in order to help practices, primary care trusts and QOF assessors be consistent in their approach to exception reporting⁴¹. The guidance was to take effect on 1 April 2006. The Healthcare Commission is carrying out further work examining QOF achievement.

How can primary care trusts improve?

Primary care trusts can examine the variation in their general practices' achievements, and compare themselves against other trusts, using the review's data on our website. They can use the commissioning toolkit produced by the Department of Health in collaboration with a number of organisations to help improve the way they commission diabetes services⁴³. They can also review the BMA's guidance on exception reporting to ensure that as many people with diabetes as possible are being included in QOF.

Recommendations

The following Healthcare Commission recommendations are about improving the clinical outcomes for people with diabetes by offering them the appropriate support to help them look after themselves. The diabetes NSF outlines the standards that those delivering

diabetes services should be working to and aiming for. Primary care trusts, as the commissioners of diabetes services, should commission against these standards and towards what people with diabetes need. Healthcare professionals, as part of the multidisciplinary team caring for people with diabetes, should:

- offer appropriate, individual support to each person with diabetes to encourage them to look after their diabetes
- 2. listen to the person with diabetes to come to a joint agreement about their priorities and their plan for their care, giving them the opportunity to talk about what they think they can achieve
- 3. offer support to people with diabetes on how to manage diabetic ketoacidosis and hypoglycaemic attacks
- 4. participate in the national clinical audit of people with diabetes and take appropriate action to improve clinical outcomes
- 5. review the number of people with diabetes excepted from QOF and make the appropriate changes to the way care is organised to include as many people as possible

Primary care trusts should:

- implement the NICE health technology appraisal on structured patient education and assess their current education programmes against the guidelines
- 2. work with those delivering diabetes services to reduce the incidence of diabetic ketoacidosis and, with ambulance services, improve the support

offered to people with diabetes to manage hypoglycaemic attacks

- 3. participate in the national clinical audit of people with diabetes and take appropriate action to improve the clinical care and outcomes of the people with diabetes in their areas
- 4. with their local primary and secondary care clinicians, and their diabetes networks or similar bodies, examine their results from the service review and their local reports on the results of the survey of people with diabetes, to check that their existing models of care are providing the diabetes services as well as intended
- 5. improve the way they commission diabetes services, for example by reviewing the QOF data in their general practices (and comparing the variation of their general practices within their trust), and supporting the implementation of effective processes for planning care

Strategic health authorities should:

- 1. monitor the implementation of the recommendations from this review
- 2. monitor the improvement plans of primary care trusts scoring "weak" in the overall assessment

Further action by the Healthcare Commission

Working with the primary care trusts most in need of improvement

The Healthcare Commission has begun working with the primary care trusts that need the most improvement, based on our findings

in this review. These primary care trusts fall into two groups: those assessed as "weak", and those that were assessed as "weak" because there was no national patient survey data available to assess them fully.

The first group of primary care trusts is required to produce improvement plans showing how they will improve the services provided to people with diabetes. Once quality assured, the plans are signed off by the primary care trust, its strategic health authority and the Healthcare Commission. The Healthcare Commission and the relevant strategic health authority will monitor the primary care trusts' progress.

The second group of primary care trusts is required to produce statements of assurance to the Healthcare Commission containing evidence that the people with diabetes in their areas are receiving, at a minimum, a "fair" service that enables them to care for themselves. If the primary care trust is unable to assure the Healthcare Commission, the trust will be required to produce an improvement plan.

The Healthcare Commission is working with the National Diabetes Support Team and the National Clinical Director of Diabetes to ensure that improvement plans are relevant and realistic, and that the statements of assurance contain the appropriate evidence.

Monitoring ongoing performance

The Healthcare Commission intends to monitor the performance of primary care trusts in future years by using a small number of indicators selected from the framework of assessment for this review. The indicators will focus on the areas that are most beneficial to the clinical outcomes of people with diabetes. During 2007/2008, we are developing the

process for how we will monitor the performance of our previous reviews. It will apply to this review once primary care trusts have had an opportunity to improve on their initial assessments. We will release further details in due course.

Further work

The Healthcare Commission is examining the data from the national survey of people with diabetes, Hospital Episode Statistics (HES) and the Quality and Outcomes Framework (QOF) in more detail. We are also developing methods for examining the quality of primary care services, including diabetes care.

References

- 1 Health and Social Care Information Centre (2005-06) Quality and Outcome Framework data (QMAS database)
- 2 Yorkshire and Humber Public Health Observatory (2006) Key Facts: Diabetes
- 3 Department of Health (March 2007) The Way Ahead: The Local Challenge
- 4 Department of Health (2001) National Service Framework for Diabetes: Standards
- 5 All Parliamentary Group for Diabetes and Diabetes UK (November 2006) Diabetes and the disadvantaged: reducing health inequalities in the UK
- 6 NHS Information Centre and National Clinical Audit Support Programme (2006) National Diabetes Audit: Key findings about the quality of care for people with diabetes in England incorporating registrations from Wales 2004/05
- 7 Ansell D et al. (December 1999) The 2nd Annual Report of the UK Renal Registry
- 8 Bunce C, Wormald R (2006), Leading causes of certification for blindness and partial sight in England and Wales, BMC Public Health 2006. 6:58
- 9 Fox C, Mackinnon M (1999) Vital Diabetes, Class Health
- 10 Katon W, von Korff M, Ciechanowski P et al. (2004) Behavioral and clinical factors associated with depression among individuals with diabetes. Diabetes Care: 27:914-920

- 11 Mulnier H, Seaman H, Raleigh V, Soedamah-Muthu S, Colhoun H, Lawrenson R (2006) Mortality in people with Type 2 diabetes in the UK, Diabetic Medicine 23 (5): 516-521
- 12 Soedamah-Muthu S, Fuller J, Mulnier H, Raleigh V, Lawrenson R, Colhoun H (2006) All-cause mortality rates in patients with type 1 diabetes mellitus compared with a non-diabetic population from the UK general practice research database, 1992-1999, Diabetologia 49 (4): 660-666
- 13 Wanless, D. (2002) Securing Our Health: Taking a Long-Term View - Final Report. London. HM Treasury
- 14 Williams R, Gillam S, Murphy M, Holmes J, Pringle M, Bootle S, Bottomley J, Baxter H, Chandler F (2002) The True Costs of Type 2 Diabetes in the UK - Findings from T2ARDIS and CODE-2 UK. Monograph of studies supported by GlaxoSmithKline. GlaxoSmithKline UK, Uxbridge
- 15 Department of Health (June 2006) Turning the Corner: Improving Diabetes Care
- 16 Department of Health (March 2007) Department of Health Business Plan 2007-08
- 17 Department of Health (2003) National Service Framework for Diabetes: Delivery Strategy
- 18 National Institute of Clinical Excellence (2004) Type 1 diabetes: diagnosis and management of type 1 diabetes in children, young people and adults

- 19 National Diabetes Support Team (2006) NICE and Diabetes: A summary of relevant guidelines
- 20 National Institute of Clinical Excellence (2003) Guidance on the use of patient-education models for diabetes: Technology Appraisal 60
- 21 NHS Confederation and the General Practitioners Committee of the British Medical Association (2003) *Investing in General Practice: The New General Medical Services Contract*
- 22 Department of Health (January 2005) A compendium of practical examples across the whole system of health and social care
- 23 The Department of Health (2006)
 Supporting people with long term conditions
 to self care: a guide to developing local
 strategies and good practice
- 24 Tuomilehto J, Lindstrom J, Eriksson J G, et al. (May 2001) Prevention of type 2 diabetes mellitus by changes in lifestyle among subjects with impaired glucose tolerance*, N Engl J Med 3; 344(18): 1343-50
- 25 Bodenheimer et al. (2002) Patient selfmanagement of Chronic Disease in Primary Care, The Journal of the American Medical Association, Vol 288 No 19 November 2002
- 26 Grossel E, Cronan T (2000) Cost analysis of self management program for people with chronic illness American Journal of Community Psychology, 28 (4): 455-480
- 27 Department of Health (2005) National Service Framework for Long Term Conditions

- 28 Department of Health (2005) Supporting People with Long Term Conditions – An NHS and Social Care Model to support local innovation and integration
- 29 Department of Health (2004) Choosing Health – Making healthy choices easier
- 30 Department of Health (2006) Our health, our care, our say: a new direction for community services
- 31 Department of Health and Diabetes UK Care Planning Working Group (2006) Care Planning in Diabetes
- 32 National Diabetes Support Team,
 Department of Health and Diabetes UK
 (2006) How to Assess Structured Diabetes
 Education: An improvement toolkit for
 commissioners and local diabetes
 communities
- 33 Department of Health (2007) Working together for better diabetes care
- 34 Healthcare Commission (2007) National survey of people with diabetes: Statistical methods
- 35 The Information Centre (2007) Hospital Episode Statistics 2005-06
- 36 Healthcare Commission (2007) Service review of diabetes: Supporting self-care for adults with diabetes Framework of assessment
- 37 Healthcare Commission (2007) Service review of diabetes Technical guidance on analysis and scoring

- 38 Department of Health (2006) Letter from Caroline Flint, 14 September 2006 Health Inequalities: Revised list of Spearhead Group Primary Care Trusts (Gateway reference 70851
- 39 Department of Health, Diabetes UK (2005) Structured patient education in diabetes
- 40 National Diabetes Support Team (2006) Beyond Boundaries: a guide to diabetes networks
- 41 British Medical Association and NHS Employers (October 2006) Guidance on Exception Reporting
- 42 Doran T, Fullwood C, Gravelle H, Reeves D, Kontopantelis E, Hiroeh U, Roland M (2006) Pay-for-Performance Programs in Family Practices in the United Kingdom, New England Journal of Medicine 355: 375-84
- 43 The Department of Health (2006) Diabetes Commissioning Toolkit

Appendix A Data and information available to help those who commission and provide diabetes services

The results for each primary care trust from the **Healthcare Commission's** national survey of people with diabetes are on our website. www.healthcarecommission.org.uk

The National Diabetes Support Team has produced, in collaboration with other organisations, tools and guides to support the delivery of the diabetes national service framework, as well as provided examples of good practice and online forums to discuss problems and solutions. For example, the Commissioning Toolkit provides guidance on how to commission effective, high quality services.

www.diabetes.nhs.uk

The National Diabetes Audit (NDA), run by the Health and Social Care Information Centre, National Clinical Audit Support Programme, enables routine data collection, analysis and feedback, including benchmarking across primary care trusts.

www.icservices.nhs.uk/ncasp/pages/audit topics/diabetes

DiabetesE is a standardised, web-based, self-assessment tool that measures and benchmarks performance and encourages improvement. The NDA and DiabetesE complement each other to provide an integrated view of diabetes services in an area.

www.diabetese.net

The Quality and Outcomes Framework (QOF), part of the GP contract introduced in 2004, is a system of paying primary care practitioners for identifying people with diabetes and measuring their outcomes against a range of indicators. The number of people identified with diabetes increased by about 100,000 over the two years that data has been available (from 2004/2005 to 2005/2006). www.ic.nhs.uk/services/gof

The PBS phase 2 diabetes population model, developed by the Yorkshire and Humber Public Health Observatory, estimates diabetes prevalence and number by area, gender, age and ethnicity, and includes an adjustment for geographical variations in socio-economic deprivation.

www.yhpho.org.uk/PBS_diabetes.aspx

Hospital Episode Statistics (HES) are nationally available data collected on all aspects of hospital care, and some are specific to diabetes.

www.hesonline.nhs.uk

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