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The management of adult diabetes services in the NHS

Summary

1 Diabetes is a chronic condition where the body does not produce enough insulin to regulate blood glucose levels. In 2009-10, there were an estimated 3.1 million people aged 16 years and older with diabetes in England, of which 2.34 million were diagnosed and 760,000 were undiagnosed. We estimate that NHS spending on diabetes services in 2009-10 was at least £3.9 billion, or around 4 per cent of the NHS budget.

2 Around 10 per cent of people diagnosed with diabetes (240,000 people) have type 1 diabetes which occurs when the body produces no insulin. People usually develop type 1 diabetes before the age of 40, often during the teenage years. The remaining 90 per cent (2.1 million people) have type 2 diabetes, which occurs when the body cannot produce enough insulin to function properly, or when the body's cells do not react to insulin. The risk of developing type 2 diabetes increases with age, and is strongly linked to obesity and ethnicity.

3 With structured education and appropriate support most people with diabetes can manage their condition themselves by, for example, eating a healthy diet, monitoring their blood glucose level, and taking insulin or glucose-lowering medication as needed. However, they also need regular checks to monitor treatable risks for diabetic tissue damage and to detect the early damage itself so that treatment can be given to prevent deterioration. In 2001, the Department of Health (the Department) published the National Service Framework for Diabetes (the Framework). The Framework set out the key interventions necessary to raise the standard of care provided by NHS organisations and healthcare professionals involved in delivering diabetes services, including as a minimum nine basic checks, or care processes, to detect the early signs of complications. The National Institute for Health and Clinical Excellence (NICE) has also set treatment standards for blood glucose, cholesterol and blood pressure, which, when achieved, reduce the risk of a person with diabetes developing complications.

4 We examined whether the NHS in England is meeting the standards of care for diabetes set by the Department in 2001, and how effectively the Department and local commissioners of diabetes services have supported those responsible for delivering the expected improvements in diabetes care. Our report focuses on people aged 16 and over diagnosed with either type 1 or type 2 diabetes. Diabetes in pregnancy, and children and young people with diabetes, are outside the scope of our study because different clinical standards apply.

Key findings

5 Treating diabetes is a significant and growing challenge for the NHS. The percentage of the population diagnosed with diabetes in England more than doubled between 1994 and 2009. Rising levels of obesity and the changing age and ethnic structure of the population of England are expected to contribute to a further rise in the number of people with diabetes. The total number of people with diabetes is expected to increase by around 700,000 from 3.1 million in 2010 to 3.8 million in 2020. The rise in the diabetic population means that absolute numbers of diabetes-related complications are increasing, even though the rates of some complications have stabilised. An increase in the number of people with diabetes will have a major impact on NHS resources unless the efficiency and effectiveness of existing services is substantially improved.

6 The Department has set clear standards for good diabetes care and is working to improve its information on whether the NHS achieves them. These standards, which were originally set out by the Department in 2001, have since been reinforced by NICE. The Department's aims were to improve health outcomes, raise the quality of diabetes services, and reduce variations between them. Since publishing the Framework, the Department has improved the identification of people with diabetes on GP practice registers, so that it can monitor their care more systematically. The Department has also supported the establishment of national clinical audit, and the development of a range of tools, guidance and datasets to support commissioners of diabetes services.

7 In 2009-10, national clinical audit data found that only half of the increasing number of people with diabetes received all the recommended care processes that could reduce their risk of developing diabetes-related complications. People with diabetes require regular review of clinical indicators of disease progression. Despite the Department setting clear standards for good diabetes care, analysis from general practice records in the 2009-10 *National Diabetes Audit* found that under half (49 per cent) of people with diabetes received all the care processes recommended for the monitoring of risk factors for tissue damage. Without regular monitoring and treatment, this damage can lead to complications such as blindness, amputation and kidney disease, which significantly affect patients and NHS resources.

8 Less than one in five people with diabetes are achieving recommended treatment standards that reduce their risk of developing diabetes-related complications. The risk of developing complications can be minimised if people with diabetes achieve recommended treatment standards to control blood glucose, blood pressure, and cholesterol levels. Our analysis found that in 2009-10, 16 per cent of people with diabetes achieved all three treatment standards combined. Sixty-nine per cent of people with diabetes failed to achieve one or more of the three treatment standards and 15 per cent were not tested at all, putting both groups at a higher risk of developing future complications.

9 There is significant variation in the quality of care received by people with diabetes across the NHS. In 2009-10, the *National Diabetes Audit* found that the percentage of people with diabetes receiving all nine recommended care processes varied from 6 per cent up to 69 per cent between primary care trusts. There were also large variations across the NHS in the percentage of patients achieving treatment standards such as recommended levels for glucose control, and developing diabetes-related complications such as end-stage kidney disease. These variations cannot be explained by need or spending alone and are likely to be influenced by the local organisation and management of health services.

10 The Department has not managed effectively the performance of primary care trusts in delivering diabetes services or held them to account for poor performance. The Department holds information to assess performance but there is a lack of accountability for primary care trusts who fail to ensure that the recommended standards of care are met. Between 2006-07 and 2009-10, the percentage of people with diabetes receiving the recommended standard of care increased from 36 per cent to 49 per cent. Most primary care trusts improved during the period but the extent of this improvement was highly variable. Some primary care trusts improved from a very low starting point, while others improved only a small amount from a higher starting point. No primary care trust achieved the aim of delivering all nine basic care processes to all people with diabetes, with the highest performing trust achieving a figure of 69 per cent.

11 The Department's cost data do not capture the full costs of diabetes nationally. Spending on diabetes services has increased from £0.9 billion in 2006-07 to £1.3 billion in 2009-10. These figures are likely to be a substantial underestimate because of a lack of good-quality cost data for primary care and community services, which provide the majority of care, and because of the way in which costs are assigned to hospital activity. We estimate that the total cost of diabetes to the NHS in 2009-10 was at least £3.9 billion.

12 The NHS does not clearly understand the costs of diabetes at a local level, and so lacks clarity about the most effective ways to deliver diabetes services. Our visits to primary care trusts identified a variety of different approaches to delivering diabetes services, with some led by GP practices, some led by hospital and specialist services, and some led by intermediate community services. While the Department expects NHS organisations to deliver services in ways which best meet the needs of their local population, a lack of good-quality cost data means that primary care trusts lack clarity on the cost of their chosen delivery model, or what benefits they have achieved. We also found variation in patient education, diabetes training for NHS staff, and in providing diabetes specialist nurses, despite evidence to show that such interventions lead to long-term cost savings.

13 We estimate that through better understanding and management of people with diabetes, the NHS could save £170 million a year. Through earlier detection and management of diabetes-related complications in primary care, fewer people with diabetes would require more costly specialist treatment. We estimate that the NHS could save some £170 million a year by reducing hospital activity, and changing the way in which diabetes patients are managed. If the NHS could:

- reduce hospital admissions (excluding readmissions) for people with diabetes by 10 per cent, it could save £34 million a year by avoiding excess hospital activity;
- reduce insulin errors in hospital by 50 per cent, it could save at least £3.25 million a year by improving patient care;
- reduce late referrals to specialist foot teams by up to 50 per cent, it could save at least £34 million a year by decreasing the number of major amputations among people with diabetes; and
- ensure safer discharge from hospital for people with diabetes, it could save £99 million a year through reducing emergency readmissions to the same rate as for people of the same age without the condition.

Conclusion on value for money

14 The Department estimates that spending on diabetes services increased from £0.9 billion in 2006-07 to £1.3 billion in 2009-10. These figures are likely to be a substantial underestimate and are based on incomplete data. We estimate that a more accurate cost in 2009-10 was £3.9 billion.

15 In 2001, the Department set out clear minimum standards for what constitutes good diabetes care, including nine basic care processes, to reduce the risk of people developing avoidable diabetic complications. These complications diminish quality of life and place a significant burden on the NHS. Since the Department published these standards, there have been improvements in the level of care that people with diabetes receive but a number of significant issues still need to be addressed. In particular, variations in services and outcomes need to be reduced across the NHS and delivery of some care processes needs to be increased. In 2009-10, the *National Diabetes Audit* recorded that 49 per cent of people with diabetes received the full set of nine care processes (an increase from 36 per cent in 2006-07). Eighty-four per cent of patients were at greater risk of developing avoidable complications due to them not achieving desired standards for blood glucose, blood pressure and cholesterol in 2009-10. It is also estimated that up to 24,000 people die each year from avoidable causes related to their diabetes. On the basis of this performance against the expected levels of care, the low achievement of treatment standards and the high number of avoidable deaths we conclude that diabetes services in England are not delivering value for money.

The Department's view on value for money

16 The Department considers that good progress has been made in improving services for people with diabetes since the National Service Framework was published in 2001, and that there are some positive indicators of value for money in the Department's expenditure on diabetes. However, the Department recognises that a number of significant issues still need to be addressed – in particular that variations in services across the country need to be reduced and delivery of some care processes increased – before value for money from expenditure on diabetes is achieved across the board.

Recommendations

17 Our recommendations are set against the background of planned changes to the structures for commissioning NHS services set out in the *Health and Social Care Act (2012)*. Under these changes, local clinical commissioning groups – comprising groups of GP practices, doctors, nurses, and other health and social care professionals – will become responsible for resourcing and commissioning most secondary care services. An NHS Commissioning Board will be established to lead the system, and will also be responsible for directly commissioning primary care services and some specialist services. The NHS Commissioning Board will be nationally accountable to the Department for whether the NHS improves outcomes against selected indicators of good quality healthcare.

18 One of the main tasks of the NHS Commissioning Board is to ensure the NHS remains financially stable as well as achieving continuous improvement in quality. The current economic climate means that there is likely to be little or no growth in NHS funding over the next five years. With the significant rise in the number of people in England with diabetes, the NHS Commissioning Board must therefore ensure that services for this large population are adequate, and deliver the recommended standards of care. This will help minimise the additional costs to the NHS from complications, arising because standards are not being met.

a **The number of people with diabetes in England is projected to increase to 3.8 million people by 2020.** The Department and Public Health England should consider what further steps they will take to change this projection. In addition, in its agreement with the NHS Commissioning Board, the Department should ask specifically for improvements in outcomes for diabetes. Furthermore, the NHS Commissioning Board should include appropriate indicators within the Commissioning Outcomes Framework to ensure a local focus on delivering all nine care processes.

b **Payment mechanisms currently available to GPs are failing to ensure sustained improvements in outcomes for people with diabetes.** The current system of incentives needs to be reviewed and renegotiated to improve outcomes for people with diabetes in accordance with clinical practice recommended by the Framework and, more recently, by NICE. GPs should only be paid for diabetes care if they ensure all nine care processes are delivered to people with diabetes. The threshold at which GPs are remunerated for achievement of treatment standards should also be reviewed and increased at regular intervals.

c **Many people with diabetes currently experience poor levels of care following admission to hospital and, in 2009-10, significant numbers of these people developed avoidable complications owing to medication and other errors.** The Commissioning Outcomes Framework and the NHS Commissioning Board's guidance should make it a requirement for clinical commissioning groups' contracts with providers to specify that diabetes care should be delivered by appropriately trained professionals.

d **There is significant variation in the quality of care received by people with diabetes across the NHS.** The NHS Commissioning Board should state what specific actions it will take to ensure that people with diabetes across England receive recommended standards of care. The NHS Commissioning Board should also: introduce effective systems of governance and accountability to minimise variation and inequality in diabetes care across England; promote adherence to good clinical practice; and ensure that national data are reconciled at regular intervals. Reducing variation will improve outcomes and reduce cost, enabling the NHS to better manage the increased number of people with diabetes in the long term.

e **With access to education and support, many people with diabetes can manage their condition effectively, yet few people with diabetes receive patient education.** The NHS Commissioning Board should work with clinical commissioning groups and providers to ensure that people with diabetes are offered education and support in how best to manage their condition. Improved patient education and awareness of the early signs of complications could reduce admissions to acute and specialist services for people with diabetes.

f **The Department and the NHS lack clarity about how to ensure effectiveness in diabetes services and do not clearly understand the total costs of treating diabetes in the NHS.** The NHS Commissioning Board should ensure that cost data are available to clinical commissioning groups to support them in meeting the recommended standards of care for people with diabetes locally. The NHS Commissioning Board and Monitor (the sector regulator for healthcare in England) should work to develop tariffs to incentivise providers appropriately to maximise achievement of improved outcomes.