STATE OF THE NATION

Challenges for 2015 and beyond

England

DIABETES UK
CARE, CONNECT, CAMPAIGN.



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About Diabetes UK

Diabetes UK is the leading UK charity that cares for, connects with, and campaigns on behalf of people affected by and at risk of diabetes:

- We help people manage their diabetes effectively by providing information, advice and support.
- We campaign with people with diabetes and with healthcare professionals to improve the quality of care across the UK's health services.
- We fund pioneering research into care, cure and prevention for all types of diabetes.
- We campaign to stem the rising tide of diabetes.

Foreword



If it was announced that a new condition had emerged that was doubling in prevalence every 17 years, and 13 million people were already directly affected or at serious risk, this would be seen as an epidemic and a national crisis. Last year's State of the Nation report commented on the absence of national plans to improve the quality of diabetes care and reduce complications, and to tackle the rising incidence of this condition. While the former has not yet materialised, we are encouraged by the announcement of a Type 2 diabetes prevention programme in the NHS Five Year Forward View.

With nearly 10 million people in England at high risk of developing Type 2 diabetes, such a programme is due urgently, and – as highlighted in this year's report – it is not too late to reverse the rise of Type 2 diabetes.

During 2014, we welcomed four national diabetes audit reports, covering care processes and treatment targets, inpatients, children and young people, and – for the first time – pregnancy in women with diabetes. We also launched 'Diabetes Watch' – our online tool for people with diabetes and professionals to look at and compare CCG-level data.

This means we now have comprehensive national and local pictures of the healthcare received by people with diabetes. Unfortunately, while the audit reports indicate some signs of progress, there is clearly a long way to go before everyone with diabetes receives high quality care.

What is particularly striking is that some people with diabetes – those with Type 1, working age people, and people living in certain parts of the country – are receiving considerably worse routine care than other people with diabetes, and are achieving poorer outcomes. This puts them at greater risk of serious complications, which can lead to disability and premature death, and are very expensive for the NHS.

People with diabetes are also failing to receive the support they need to self-manage their condition effectively – again, elevating the risk of long-term complications. Few people are offered or attend diabetes education, have personalised care plans, or have access to emotional support and specialist psychological care.

As well as highlighting this situation, our State of the Nation report sets out a range of actions to address the challenges England faces. There are real opportunities for the incoming government, health services, local authorities, and others, to prevent millions of people from developing Type 2 diabetes, and help make the impact less severe for those who are diagnosed with diabetes of all types. We urge these organisations to act on our proposals and implement them over the coming months.

The overarching messages from this State of the Nation report are that good care now for everyone with diabetes, and a greater focus on prevention, can save money in the longer term – money that would otherwise be spent on treating avoidable complications, and on caring for people with avoidable cases of Type 2 diabetes.

We all have to act before the number of people with diabetes overwhelms our health and social care systems and consumes an even greater proportion of the NHS budget.

These are messages that the Government, the NHS, and the country as a whole cannot afford to ignore.

Banbara Young

Barbara Young Chief Executive

The state of the nation: diabetes in 2014

Diabetes is an increasingly urgent health issue

Diabetes is the fastest growing health threat of our times and an urgent public health issue¹. Since 1996, the number of people living with diabetes has more than doubled.

3.2 million people in England now have diabetes:

- 2.7 million people or 6 per cent of the adult population have been diagnosed with diabetes²
- a further 500,000 people are estimated to have Type 2 diabetes, but do not know it3
- more than 700 people learn they have diabetes every day that's one person every three minutes4.

Another 9.6 million people in England are at high risk of getting Type 2 diabetes, and that number is rising dramatically every year⁵.

If nothing changes, by 2025 more than four million people in England will have diabetes6.

Diabetes is expensive to treat and manage

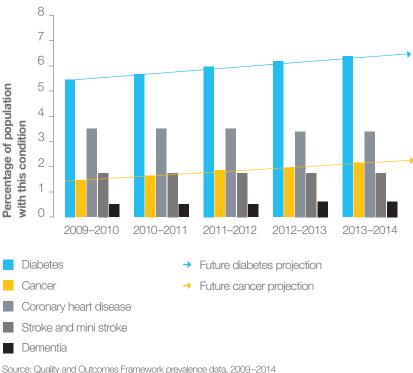
Diabetes accounts for around 10 per cent of the annual NHS budget. This is nearly £10 billion a year, or £1 million every hour⁷.

Eighty per cent of NHS spending on diabetes goes on managing complications, most of which could be prevented8.

One in 20 people with diabetes incurs social services costs. More than three-quarters of these costs are associated with residential and nursing care9.

The total cost (including direct care and indirect costs) associated with diabetes in the UK is currently estimated at £23.7 billion. These costs are predicted to rise to £39.8 billion by 2035-367.

Prevalence of diabetes is more than three times higher than prevalence of all cancers combined, and is increasing



Diabetes can cause serious complications and early death

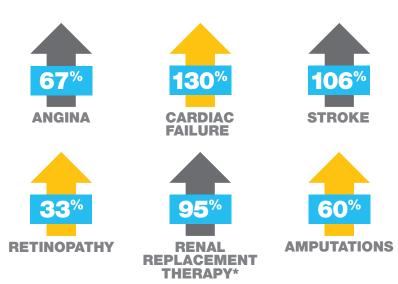
Every year, around 20,000 people with diabetes die early¹⁰.

People with diabetes are also at greater risk of developing one or more severe health complications.

Diabetes is:

- responsible for more than 100 amputations a week¹¹
- the leading cause of preventable sight loss in people of working age¹²
- a major contributor to kidney failure, heart attack, and stroke¹³.

Between 2007 and 2012, avoidable complications increased significantly¹⁴



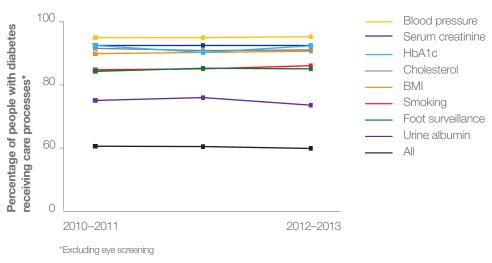
*Term used for life-supporting treatments required to treat end stage kidney disease

Poor diabetes care and outcomes now will drive up future costs and complications

Too many people with diabetes are still not receiving all of the vital annual checks for the effectiveness of diabetes treatment, cardiovascular risk factors, and the emergence of early complications¹⁵.

Some population groups, particularly those with Type 1 diabetes, and working age people, routinely receive poorer care and are less likely to meet treatment targets.

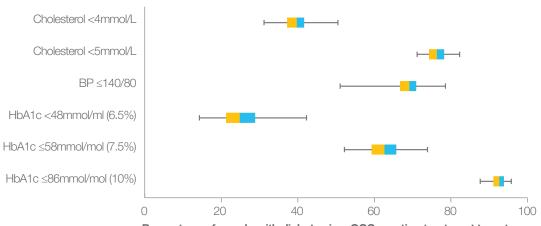
There has been little change in the percentage of people with diabetes receiving recommended care processes – and some things are getting worse



Source: National Diabetes Audit 2012–13 (figures for England and Wales)

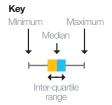
There are significant variations between clinical commissioning group areas. People with diabetes living in some areas receive better care and treatment than people living in other areas. They are also more likely to meet recommended treatment targets.

Across CCGs, there are large variations in achievement rates for HbA1c, cholesterol and blood pressure treatment targets



Percentage of people with diabetes in a CCG meeting treatment targets

Source: National Diabetes Audit 2012–13 (figures for England)



It is not too late to reverse these trends

Although millions of people are at high risk of Type 2 diabetes, 80 per cent of these cases can be prevented.

To halt the rise in Type 2 diabetes requires widespread implementation of:

- the NHS Health Check programme to identify people at risk of Type 2 diabetes
- a Type 2 diabetes prevention programme to support those identified as being at high risk
- measures that help everyone to maintain a healthy weight.

Effective diabetes care and self-management now can reduce the long-term cost and impact of complications.

Everyone with diabetes – no matter their age, where there live, or the type of diabetes they have – needs to receive the best care possible. They also need to be supported to self-manage their condition effectively.

We need action now to:

- increase the availability of all of the recommended care processes for everyone with diabetes
- ensure all people with diabetes are supported to meet recommended treatment targets
- implement integrated pathways of diabetes care across all local health systems
- improve access to, and uptake of, a range of appropriate education and learning opportunities
- fully implement collaborative care planning
- improve access to a range of specialist diabetes healthcare professionals, in all care settings.

The challenges for 2015 and beyond: what needs to happen over the next five years

If action is not taken now, the longer-term costs and consequences associated with diabetes will be severe – for individuals, the NHS, and wider society. We need to focus on preventing Type 2 diabetes, improving diabetes care, reducing avoidable complications, and supporting people with diabetes to manage their condition effectively.

Preventing Type 2 diabetes

While there is nothing that can be done to prevent Type 1 diabetes, Type 2 diabetes can often be prevented or its onset delayed. This can be done by identifying those at high risk of developing Type 2 diabetes, and implementing effective risk reduction interventions – a diabetes prevention programme.

However, the main risk identification programme – NHS Health Check – is still not being implemented fully across England. Referral to risk reduction programmes for those identified as high risk is inconsistent.

Obesity – the most significant risk factor for Type 2 diabetes – is increasing. This situation can be addressed by a range of individual and whole population interventions designed to help people maintain a healthy weight.

What needs to happen

- The new government needs to:
 - continue to commit funding for the NHS Health Check programme
 - support a Type 2 diabetes prevention programme for people identified at high risk
 - coordinate a plan to reduce obesity in the general population.
- Public Health England and NHS England need to ensure the national evidence-based Type 2 diabetes prevention programme, committed to in the NHS Five Year Forward View, includes appropriate identification, follow up and interventions for people at high risk of Type 2 diabetes.

- **Local authorities** need to fully implement the NHS Health Check programme to increase levels of risk identification, and ensure those at high risk are referred to an effective diabetes prevention programme.
- **Health and wellbeing boards** need to support programmes to prevent Type 2 diabetes, by having strategies:
 - for whole population prevention, designed to reduce obesity and encourage healthier diets and increased activity
 - to identify and target people at high risk of Type 2 diabetes
 - to ensure there is a Type 2 diabetes prevention pathway.

Improving diabetes care

NICE recommends everyone with diabetes receives nine care processes every year to check the effectiveness of diabetes treatment, cardiovascular risk factors, and the emergence of complications.

Too few people get these checks, though, and achieve the recommended targets. There are significant variations between different population groups and geographical areas.

What needs to happen

• **CCGs** need to develop and implement performance improvement plans for all of the recommended care processes and treatment targets.

Reducing complications through increased access to diabetes specialists

Diabetes is a complex condition, often requiring specialist skills and knowledge. People with diabetes need access to a range of specialist healthcare professionals, in hospital and other healthcare settings, so complications can be prevented and treated effectively.

Without immediate action, the long-term costs and implications of diabetes will be severe. Good care now, and a greater focus on prevention, will save money in the future

However, for some people, this kind of specialist care is not available. Diabetes specialist nurses – who are integral to providing cost-effective care and preventing complications – are having their positions cut or downgraded¹⁶. Moreover, many healthcare professionals lack the competence needed to identify diabetes or the early signs of complications.

What needs to happen

- CCGs need to:
 - ensure all healthcare staff have access to continuing professional development in diabetes care, by incorporating requirements in contracts with service providers
 - recognise the role of diabetes specialist nurses, and other specialist teams, in delivering cost-effective diabetes services.
- Healthcare service providers need to:
 - increase the availability of specialist diabetes inpatient teams and multidisciplinary foot care teams to ensure all people with diabetes have access to specialist care and support
 - ensure all healthcare professionals are competent in diabetes identification and care, within their scope of practice.

Implementing integrated care pathways

Integrated pathways of care across primary, community and specialist care are the ideal way of ensuring people with diabetes get the support and treatment they need, at the right time and place. This model of care focuses on the patient's perspective, and can deliver value for both the individual and the health system. However, it is still not widespread.

What needs to happen

 CCGs need to work with service providers to design and implement integrated pathways of care across local health systems. Health and wellbeing boards need to promote integrated approaches to diabetes prevention and care by developing a long-term vision for achieving fully coordinated care, and initiating the changes required to deliver it.

Improving education for self-management

Diabetes is a serious condition but, if managed well, people can live long and full lives. Supported self-management is the key to successful day-to-day diabetes management.

Access to diabetes education and information is an essential part of effective self-management. However, very few people with diabetes are offered structured education, and even fewer attend a programme.

What needs to happen

- Clinical commissioning groups (CCGs) need to increase the availability and uptake of a range of diabetes education and learning opportunities
- Healthcare professionals need to encourage their patients to attend learning opportunities.

Rolling out collaborative care planning

Collaborative care planning involves people with diabetes and clinicians working together to agree goals, develop and implement action plans, and monitor progress¹⁷. It has been shown to improve the skills and knowledge of both parties, and enable people with diabetes to make positive changes. Despite this, it is still not widely used.

What needs to happen

- **CCGs** need to explicitly commission collaborative care planning, and the training and systems needed to support it
- **Healthcare professionals** need to engage with patients with diabetes through collaborative care planning.

Preventing Type 2 diabetes

Type 2 diabetes accounts for 90 per cent of all cases of diabetes¹⁵. The number of people with Type 2 diabetes is increasing – from 1.7 million in 2006 to more than 2.5 million in 2014¹⁸.

Moreover, 9.6 million people in England are at high risk of getting Type 2 diabetes, and that number is rising every year⁵.

Unlike Type 1 diabetes, which is not preventable, up to 80 per cent of cases of Type 2 diabetes can be delayed or prevented¹⁹. This can be done by:

- widespread implementation of a Type 2 diabetes prevention pathway
- helping people to maintain a healthy weight, through whole population-level interventions.

A diabetes prevention pathway to identify and support people at high risk of developing Type 2 diabetes

The NHS Health Check programme can help to identify many of the individuals who are at high risk of developing Type 2 diabetes. It is estimated that, if fully implemented, this programme could prevent 4,000 people a year from developing diabetes²⁰.

Since 2013, local authorities have been responsible for implementing the Health Check programme. While many local authorities are making good progress with this, others are not.

Overall, the percentage of the eligible population being offered a Health Check is increasing. However, uptake needs to improve. In 2013–2014, less than half of the people offered a Health Check in England actually had one²¹.

- The Department of Health should guarantee ongoing financial support for the NHS Health Check programme, and incentivise local authority improvement.
- NHS England and Public Health England should:

 develop a national, evidence-based diabetes prevention programme, as proposed in the NHS Five Year Forward View, building on the NHS Health Check programme
 - clarify where responsibility lies for commissioning and evaluating lifestyle interventions.
- NHS England should mandate appropriate follow up and management of people identified as being at high risk of Type 2 diabetes through the GP contract.
 - Local authorities should:
 - work with NHS England to improve the entire diabetes prevention pathway, ensuring people attend a Health Check, receive a quality check, and are followed up appropriately
 - initiate local awareness-raising campaigns, particularly among those groups that the Health Check programme is failing to reach.
- Health and wellbeing boards should:
 - make prevention of Type 2 diabetes a priority in the Joint Health and Wellbeing Strategy
 - set out their local strategy for improving the availability and take up of the Health Check programme, and for ensuring those at high risk have access to a diabetes prevention programme.

While identifying people who are at high risk of getting Type 2 diabetes is critical, this is just the first step in a prevention pathway. Those individuals with modifiable risk factors then need to be supported to reduce their weight.

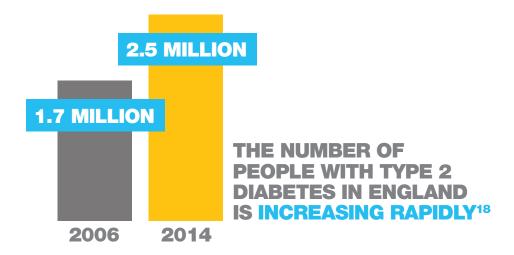
NICE guidance specifies that people identified as being at high risk of Type 2 diabetes should be offered intensive lifestyle interventions. However, it is unclear whether this is happening in all cases – or, indeed, who is responsible for referrals and follow up – and the provision of intervention programmes is patchy. This means the Health Check programme will not deliver the health and economic benefits that it should.

Helping everyone to maintain a healthy weight

Being overweight or obese is the most significant risk factor for Type 2 diabetes, and accounts for 80 to 85 per cent of the risk of developing this condition²². Maintaining a healthy weight, eating a balanced diet, and being active, are therefore the most effective ways of preventing Type 2 diabetes.

However, there has been a marked increase in obesity over the past 20 years. In England, 61 per cent of adults and 30 per cent of children are now overweight or obese²³. Almost nine out of every 10 people diagnosed with Type 2 diabetes are overweight²⁴.

If we are going to reverse these trends, and stop the sharp rise in Type 2 diabetes, more must be done to support all parts of the population to make healthier choices. Individuals are often working hard to achieve a healthy weight. Government, the NHS, local authorities, employers, and the food and drinks industry need to match that determination.



What needs to happen now?



The new government should:

- encourage the food and drinks industry and retailers to promote healthier choices to consumers
- continue to support a consistent front-of-packet labelling system
- legislate on reformulation of foods to reduce overall calorie intake
- consider taxation of unhealthy foods
- restrict the marketing of foods high in salt, sugar and fat to children
- invest in national awareness-raising campaigns.



Health and wellbeing boards and local authorities should ensure:

- information about obesity and strategies to target it are included in Joint Strategic Needs Assessments
- design of the local environment and services promotes active lifestyles and access to healthy food.

15 Healthcare Essentials for everyone with diabetes

Every person with diabetes needs the recommended treatment and services, regardless of their age, ethnicity, where they live, and whether they have Type 1 or Type 2.

The Diabetes UK 15 Healthcare Essentials set out the care that all people with diabetes should expect to receive from their healthcare team every year. They include the nine care process checks recommended by NICE²⁵, and provide a starting point for ensuring everyone gets high quality and effective care.

Education and care planning enable people to make the most of the 15 Healthcare Essentials. Education helps them to understand and manage their condition. Care planning involves collaborative working between people with diabetes and their healthcare teams to develop and achieve individual goals.

- Get your blood glucose levels (HbA1c) measured at least once every year. This will measure your overall blood glucose control and help you and your healthcare team set a target.
- Have your blood pressure measured and recorded at least once a year, and set a personal target that is right for you.
- Have your blood fats, such as cholesterol, measured every year. You should have a target that is realistic and achievable.
- Have your eyes screened for signs of retinopathy every year.
- Have your feet checked. The skin, circulation and nerve supply of your feet should be examined annually. You should then be told if you have any risk of foot problems and how serious they are.
- Have your kidney function monitored annually. This should involve two tests: a urine test for protein and a blood test to measure kidney function.

- Have your weight checked and your waist measured to see if you need to lose weight.
- **Get support if you are a smoker,** including advice and support on how to quit.
- Engage in care planning discussions with your healthcare team to talk about your individual needs and set targets.
- Attend an education course in your local area to help you understand and manage your diabetes.
- Receive care from a specialist paediatric team if you are a child or young person.
- Receive high-quality care if admitted to hospital from specialist diabetes healthcare professionals, regardless of whether or not you have been admitted due to your diabetes.
- Get information and specialist care if you are planning to have a baby as your diabetes control has to be a lot tighter and monitored very closely. You should expect care and support from specialists at every stage, from preconception to postnatal care.
- See specialist diabetes healthcare professionals to help you manage your diabetes, such as podiatrists, ophthalmologists, and dietitians.
- Get emotional and psychological support. Being diagnosed with diabetes and living with a long-term condition can be difficult, and you should be able to talk about issues and concerns with specialist healthcare professionals.

Variations in diabetes care and outcomes

Having the right care is essential for the wellbeing of everyone with diabetes, and can help reduce the risk, severity, and costs of complications.

An integral part of this is the receipt of the NICE-recommended care processes. These are the annual checks for the effectiveness of diabetes treatment (HbA1c), cardiovascular risk factors (blood pressure, serum cholesterol, BMI, smoking), and emergence of early complications (foot checks, eye screening, and two tests for kidney function).

Unfortunately, the 2012–2013 National Diabetes Audit showed that annual completion rates for eight²⁶ of these care processes continue to plateau – at 60 per cent. Moreover, there are worrying variations in the care and treatment received by some population groups, and in different parts of the country.

People with Type 1 diabetes receive poorer care than people with Type 2

People with Type 1 diabetes – of all ages and ethnic groups – routinely receive worse care and treatment than people with Type 2 diabetes.

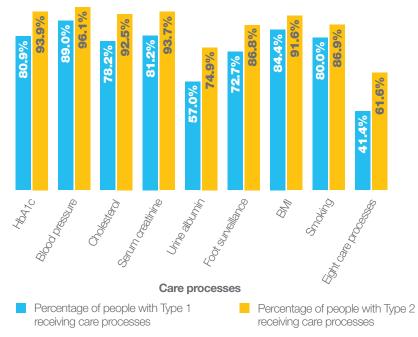
In 2012–2013, fewer people with Type 1 diabetes received each of the eight recommended care processes. Overall, only 41 per cent of people with Type 1 diabetes received all eight care processes, compared with 62 per cent of people with Type 2. People with Type 1 were also less likely to meet the recommended treatment targets for blood glucose (HbA1c) and cholesterol¹⁵.

In 2012–13, very few people with Type 1 accessed structured education. This was offered to 2.4 per cent of people with Type 1 diabetes, compared with 6 per cent of those with Type 2. Only 1.1 per cent of people with Type 1 diabetes, and 1.6 per cent with Type 2, actually attended structured education¹⁵.

The outstanding message from this (audit) report is the need to address the substantially worse routine care and treatment in younger people with Type 1 and Type 2 diabetes and in people with Type 1 diabetes at all ages. Given the potential adverse consequences for these younger people of disability and premature mortality in middle life, designing better systems of care for them would yield considerable health benefits.

Foreword, National Diabetes Audit 2012–13

People with Type 1 diabetes receive fewer checks than people with Type 2



Source: National Diabetes Audit 2012-13 (figures for England)

Working age people receive poorer care

People of working age with Type 1 or Type 2 diabetes are less likely than older people to receive the recommended care processes and meet treatment targets.

For example, in the under 40s, only 29 per cent of people with Type 1 diabetes and 46 per cent with Type 2 received eight care processes. In comparison, more than 60 per cent of people in the 65 to 79 age group received all these processes¹⁵.

Three treatment targets – relating to glucose control (HbA1c), blood pressure, and cholesterol – should be monitored and met in all people with diabetes. Again, there were variations between age groups, and older people did better.

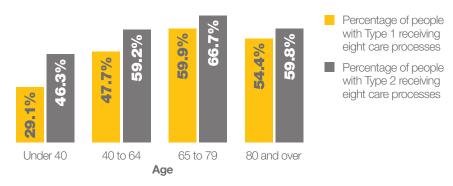
Only 15 per cent of people with Type 1 diabetes in each of the under 65 age groups met all three treatment targets, compared with more than 20 per cent in the older age groups. Similarly, the targets were met by less than one-third of people with Type 2 diabetes in the younger age groups, but more than 40 per cent of those aged 65 and above¹⁵.

Too many children and young people also receive poor care

Children and young people are even less likely to receive the recommended care processes. In 2012–2013, only 12 per cent of young people aged between 12 and 19 had all their care processes recorded²⁷. Although this figure had almost doubled – from 6.7 per cent in 2011–2012 – it continues to be well below results for adults with Type 1 diabetes²⁸.

Children and young people also have problems controlling their diabetes. One in four had worryingly high HbA1c levels (over 80mmol/mol). This proportion was even higher among children from ethnic minorities²⁷.

Working age people are less likely to receive eight diabetes care processes than older people

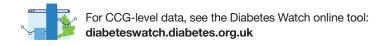


Source: National Diabetes Audit 2012-13 (figures for England and Wales)

There are geographical variations in care and outcomes

As highlighted throughout this report, there are considerable variations between CCGs in terms of care process completion rates and the achievement of treatment targets in all people with diabetes. This shows that where a person lives has a significant impact on their ability to receive the care they need and achieve good outcomes.

Would you want to live in a place where less than 10 per cent of people with Type 1 diabetes meet all their treatment targets?¹⁵







NICE recommends an annual HbA1c check to measure a person's overall blood glucose control. Blood glucose control is essential to avoid serious complications.

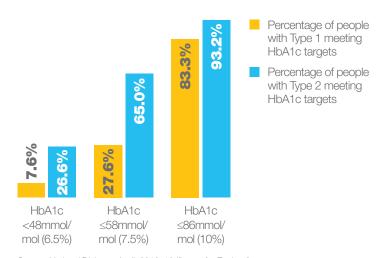
This check is carried out frequently. In 2012–2013, more than 90 per cent of all people with diabetes were recorded as having an annual HbA1c check¹⁵.

People with Type 1 diabetes were much less likely to receive this check, though – only 80 per cent, compared with 94 per cent of people with Type 2. This situation is getting worse – in 2010–2011, the figure for people with Type 1 diabetes was 86 per cent¹⁵.

There has been a worrying lack of progress with achieving the NICE-recommended treatment targets for HbA1c. Of particular concern is that:

- substantial numbers of people have exceptionally high-risk glucose levels
 17 per cent of Type 1 and 7 per cent of Type 2 patients had HbA1c equal to or above 86mmol/mol
- people with Type 1 diabetes were much less likely to reach recommended targets than people with Type 2 diabetes
- there were significant regional variations. For the treatment target of equal to or above 58mmol/mol, for example, there was a range of 30 percentage points between the highest- and lowest-performing CCGs¹⁵.

People with Type 1 diabetes are less likely to meet recommended HbA1c targets than people with Type 2



Source: National Diabetes Audit 2012–13 (figures for England)

Blood pressure

A quarter of people with diabetes do not meet recommended blood pressure targets – increasing their risk of complications

People with diabetes have about twice the risk of developing a range of cardiovascular diseases (including heart disease and stroke), compared with people who do not have diabetes.

Cardiovascular disease (CVD) is a major cause of death and disability in people with diabetes, accounting for 44 per cent of fatalities in people with Type 1 diabetes and 52 per cent in people with Type 2¹³.

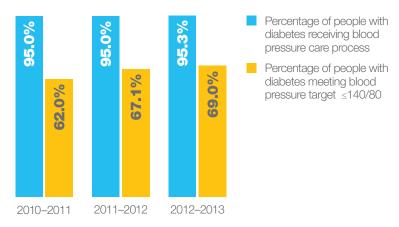
Poor blood pressure control further increases the risk of developing this complication, and of suffering a stroke in particular. It also increases the risk of kidney disease. NICE recommends people with diabetes have their blood pressure measured at least once a year, and recommends treatment targets.

In 2012–2013, 95 per cent of people with diabetes had their blood pressure checked – a similar figure to previous years. However, only 69 per cent of those people met the recommended treatment target – a small improvement from 2011–2012¹⁵.

Unlike the targets for HbA1c and cholesterol, people with Type 2 diabetes were less likely to meet the treatment target for blood pressure. People aged under 40 with Type 1 diabetes did better than those in other age groups, and people with Type 2.

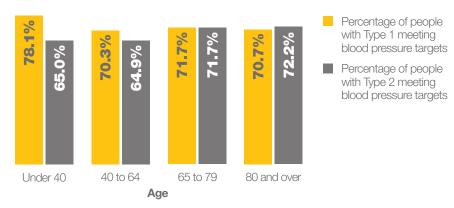
There was a considerable variation in blood pressure target achievement rates by CCG, for patients with both types of diabetes. The range between the best and worst CCGs was greater than 30 percentage points¹⁵.

Most people get their blood pressure checked, but more than a quarter do not meet recommended targets



Source: National Diabetes Audit 2012-13 (figures for England and Wales)

People under 65 with Type 2 diabetes are less likely to meet blood pressure targets than those with Type 1



Source: National Diabetes Audit 2012–13 (figures for England and Wales)

Many people are not getting their cholesterol checked, and are not meeting recommended targets

Poor cholesterol control also increases the risk of developing cardiovascular disease. It is important, therefore, that people with diabetes have their cholesterol checked annually, and have realistic and achievable targets.

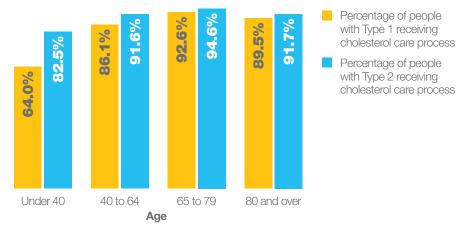
In 2012–2013, 92 per cent of people with Type 2 diabetes received a cholesterol check. Only 78 per cent of people with Type 1 had this essential check, though¹⁵.

Younger people with Type 1 or Type 2 diabetes were less likely to have their cholesterol checked than those aged over 40. This check was carried out in only 64 per cent of people with Type 1 in the under 40 age group, and 82 per cent of those with Type 2 in that age group.

Around a quarter of all people with diabetes did not meet the cholesterol treatment target of <5mmol/L, and 60 per cent did not meet the tougher target of <4mmol/L.

As with treatment targets for HbA1c and blood pressure, there were large variations in achievement rates across CCGs. This indicates there is considerable scope for improvement in many areas.

Younger people, particularly those with Type 1 diabetes, are less likely to have their cholesterol checked



Source: National Diabetes Audit 2012–13 (figures for England and Wales)

Actions to improve care processes and outcomes

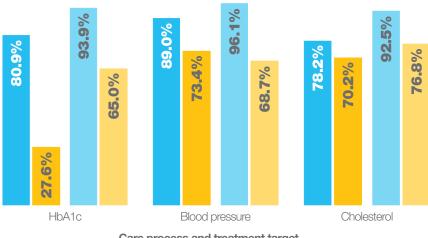
To reduce the risk of serious complications, it is essential that everyone with diabetes receives all of the checks for HbA1c, blood pressure and cholesterol. They should also be supported to achieve the recommended treatment targets.

Measurement of these three care processes is relatively high, particularly in older people with Type 2 diabetes (more than 90 per cent for each process). However, improvements are needed in all people with Type 1 diabetes, in the working age population with Type 2 diabetes, and in many CCG areas.

Considerable progress is required in relation to the treatment targets. In 2012–2013, only 36 per cent of people with diabetes met all three targets – the same as in 2011–2012. There were also variations between different population groups, and between CCGs, which need to be addressed. Notably:

- only 16 per cent of people with Type 1 diabetes met all the treatment targets, compared with 37 per cent of people with Type 2
- working age people were less likely to achieve treatment targets than those aged 65 and over
- the range of CCG target achievement varied by 20 to 30 percentage points.
 In some CCGs, less than 10 per cent of people with Type 1 diabetes met all the treatment targets¹⁵.

While HbA1c, blood pressure and cholesterol are often measured, many people do not achieve recommended treatment targets



Care process and treatment target

- Percentage of people with Type 1 diabetes receiving care process
- Percentage of people with Type 2 diabetes receiving care process
- Percentage of people with Type 1 diabetes meeting treatment target*
- Percentage of people with Type 2 diabetes meeting treatment target*

*HbA1c ≤58mmol/mol (7.5%), BP ≤140/80, Cholesterol <5mmol/L

Source: National Diabetes Audit 2012-13 (figures for England)

What needs to happen now?

All CCGs need to set themselves performance improvement targets and implement plans of action

In particular, CCGs in the bottom 25 per cent need to take steps to achieve levels of performance similar to the middle 50 per cent, as a matter of urgency.



CCGs need to ensure that all people with diabetes have access to the support they need to selfmanage effectively, and that the local health system is designed to deliver this

Diabetes is a complex condition, which can be difficult to manage on a daily basis. Effective self-management is essential, and makes up around 95 per cent of care. Psychological and emotional support, education and information, and personalised care planning are key components of self-management, helping people with diabetes to understand and cope with their condition.

CCGs need to work with healthcare providers to ensure emotional support and specialist psychological care are available for those with identified needs, as part of an integrated diabetes service.

CCGs also need to make sure a range of education and learning opportunities are available, including structured education programmes, peer support, and online information and learning.



NHS England needs to ensure CCGs are rolling out care planning - and are supporting people with diabetes to engage in the care planning process

Care planning is an ongoing, collaborative process, requiring the active engagement of people with diabetes and healthcare professionals.

Care planning enables clinicians and people with diabetes to discuss HbA1c, blood pressure and cholesterol levels, agree individual goals and the support needed to reach them, and monitor progress. It also facilitates regular discussions about why particular medication has been prescribed, whether it is working, and whether changes are needed.

CCGs and healthcare providers need to work together to make care planning a reality for all people with diabetes, and support clinicians to have the competence to deliver this. NHS England should ensure care planning can be rolled out in all CCGs.

This is about more than providing a personal care plan to everyone with a long-term condition – which is already an NHS commitment. Collaborative care planning should replace traditional care for people with diabetes, as part of an integrated system that focuses on the patient's perspective.



Primary healthcare professionals need to make use of information prescriptions to help people with high blood pressure, HbA1c, or cholesterol

Information prescriptions provide people with diabetes with information and support that enables them to live well with their condition.

Information prescriptions are being embedded into primary care IT systems. It is up to healthcare professionals to use these new tools to support care planning and behavioural change in their patients.

Eye screening

Retinopathy is a serious complication that can affect anyone with diabetes. Diabetic retinopathy accounts for around 7 per cent of people who are registered blind²⁹. People with diabetes also have an increased risk of developing glaucoma and cataracts.

Keeping blood glucose, blood pressure and cholesterol levels under control can help to reduce the risk of developing retinopathy. People with diabetes should also have their eyes screened for retinopathy every year, to ensure problems are identified and treated as early as possible.

All people aged 12 and over with diabetes should be offered annual screening appointments in their local authority area. In 2013–2014, uptake of appointments was 80 per cent in England³⁰. However, there were variations across the country – in the best-performing eye screening programmes, uptake was more than 90 per cent; in the worst, it was less than 70 per cent.

As the early stages of retinopathy are often symptomless, it is vital that people with diabetes understand the risks of developing this complication and the actions they can take. This includes being encouraged and enabled to attend their eye screening appointment. Primary healthcare professionals and screening service providers have important roles to play in ensuring this happens.

Less than half of people realise diabetes can cause blindness.

Ipsos MORI survey for Diabetes UK, 2014





- Everyone with diabetes needs to be informed about the risks to their sight and preventative measures, as part of care planning with their healthcare professionals, and through participation in learning opportunities.
- **GPs** should check that patients have attended their annual retinal screening appointment, and that they are aware of and understand the results. This should be integrated within overall diabetes care.
- Eye screening service providers must deliver services that are accessible and convenient for all people with diabetes including the working age population, people with particular needs, and hard-to-reach groups.
- **Providers** with relatively low take-up rates need to review how screening services are configured. Diabetes networks should be involved in the review and design of local services.

5 Foot checks

Every week, around 100 leg, foot or toe amputations are carried out on people with diabetes – but 80 per cent of these can be prevented

If diabetes is poorly controlled, it can lead to nerve damage, poor circulation, and reduced feeling in the feet and legs. This, in turn, can lead to serious foot problems, such as ulcers, and may result in amputation.

Around 6,000 people with diabetes have leg, foot or toe amputations each year in England¹¹. Amputations and foot ulcers have a huge impact on quality of life. They also cost lives – up to 80 per cent of people die within five years of having an amputation³¹.

People with diabetes are more likely to be admitted to hospital with a foot ulcer than with any other complication of diabetes. Foot ulcers and amputations are very costly to the NHS – accounting for around $\mathfrak{L}1$ in every $\mathfrak{L}150$ the NHS spends each year³².

Up to 80 per cent of amputations are potentially preventable, through improved awareness among people with diabetes about their risk status and the actions to take, and access to good-quality structured care³³.

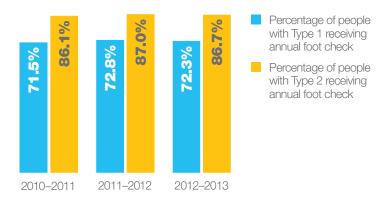
Annual foot checks

NICE recommends all people with diabetes have their feet checked every year. This enables levels of risk of foot problems to be assessed, and action to be taken accordingly. People with diabetes should be given advice on prevention or, if problems already exist, referred to a specialist foot protection service.

Despite this, 28 per cent of people with Type 1 diabetes and 13 per cent of people with Type 2 diabetes are still not receiving an annual foot check¹⁵. These figures have hardly changed over recent years.

We are also continuing to see significant variations between CCG areas. In the best-performing areas, more than 90 per cent of people with diabetes had their feet checked in 2012–2013; in the worst, only 75 per cent did. The gap is even greater in people with Type 1 diabetes¹⁵.

People with Type 2 diabetes are more likely to have an annual foot check than people with Type 1



Source: National Diabetes Audit 2012–13 (figures for England and Wales)



For CCG-level data, see the Diabetes Watch online tool: diabeteswatch.diabetes.org.uk

Integrated foot care services

The risk of amputation can be reduced through provision of an integrated foot care pathway, with trained staff in community foot protection services and quick access to multidisciplinary specialist teams³⁴. These teams can save more than four times their cost³².

The percentage of hospitals with multidisciplinary foot care teams has been increasing – from 61 per cent in 2010 to 72 per cent in 2013. However, this still means more than a quarter of hospitals are without such a team³⁵.

It is vital that people with foot infections or ulcers are seen by a member of a multidisciplinary team within 24 hours of referral. While improvements have been made, in 2013 more than one-third of patients did not receive input from this team in this timeframe³⁵.

Foot protection in hospital

People with diabetes are at risk of developing a foot ulcer during their stay in hospital. These risks can be reduced if their feet are examined during admission, and actions are taken to prevent ulcers from developing.

The percentage of inpatients with diabetes who developed a foot ulcer fell significantly between 2010 and 2013 – from 2.2 per cent to 1.4 per cent. However, in 2013, only 42 per cent of people had their feet examined at any point during their hospital stay. This suggests there is still considerable room for improvement³⁵.



Less than half of people realise diabetes can lead to foot ulcers and amputations.

Ipsos MORI survey for Diabetes UK, 2014

- All people with diabetes need to receive a high-quality foot check each year. They should be told their risk of foot problems and understand how to care for their feet.
- Poor-performing CCGs need to take action to increase the availability and uptake of foot checks particularly in people with Type 1 diabetes, younger people, and any hard-to-reach groups.
- CCGs need to ensure an integrated foot care pathway is being delivered across primary, community, and specialist care services. This includes having a multidisciplinary foot care team and a foot protection service in every area.
- All hospitals should have processes in place to ensure:
 - people with foot ulcers are referred to a multidisciplinary foot care team within 24 hours of being admitted
 - all people with diabetes have their feet checked during their stay, and preventative actions are taken to reduce the risk of a foot ulcer developing.

6 Kidney function

People with diabetes are at increased risk of developing kidney disease, but a quarter do not receive a vital screening test

Kidney disease is more common in people with diabetes than the general population, and is an expensive complication to treat. It accounts for 21 per cent of deaths in people with Type 1 diabetes and 11 per cent in people with Type 2¹³.

Keeping blood glucose levels and blood pressure well controlled can greatly reduce the risk of kidney disease developing. Annual checks are also essential to ensure problems are identified early.

NICE recommends two tests: a urine test for protein – which is a sign of possible kidney problems – and a blood test to measure kidney function.

While the blood test was measured in a high percentage of patients with diabetes in 2012–2013 (92.5 per cent overall), measurement of the urine test was the lowest of all of the NICE-recommended care processes¹⁵.

In 2012–2013, only 74 per cent of all patients received the urine albumin screening test. Recorded rates for completion of this test were particularly low in people with Type 1 diabetes (57 per cent) and in people aged under 40 (44 per cent in people with Type 1; 59 per cent in people with Type 2)¹⁵.

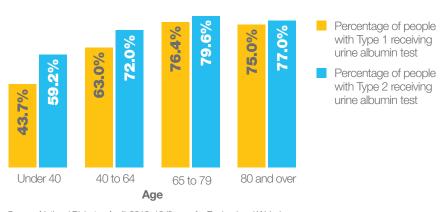
Only 10 per cent of people realise diabetes can lead to kidney failure.

Ipsos MORI survey for Diabetes UK, 2014





Younger people, particularly those with Type 1 diabetes, are less likely to receive a urine albumin test



Source: National Diabetes Audit 2012-13 (figures for England and Wales)

- People with diabetes and their healthcare teams need to understand why urine albumin tests are important, and ensure they happen.
- CCGs need to review the National Diabetes Audit data on urine albumin screening for their area, set targets for improvement, and implement action plans to achieve these targets.

Weight

People with diabetes who are overweight or obese are at increased risk of complications and need access to support to help them manage their weight

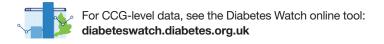
People with diabetes have a higher chance of developing cardiovascular disease (CVD) than the general population³⁶, and being overweight or obese increases that risk. Weight loss can improve blood pressure, cholesterol and blood glucose levels, which are CVD risk factors.

In 2012–2013, more than 1.62 million people with Type 2 diabetes had their body mass index (BMI) recorded (91 per cent of people with Type 2). Of these people, 86 per cent were classed as overweight or obese. In comparison, 62 per cent of the 133,000 people with Type 1 diabetes whose BMI was recorded were overweight or obese³⁷.

People with either type of diabetes who were obese were least likely to meet all the treatment targets for blood glucose (HbA1c), blood pressure and cholesterol. This puts them at an increased risk of developing complications like CVD¹⁵.

While the majority of people with diabetes had their weight monitored and BMI calculated, it is unclear what – if any – support was provided to those people who would benefit from losing weight, and need help to do this. There is a lack of information about referrals to weight management programmes or other support services, and about their effectiveness.

It is also unclear whether people with diabetes are getting support to help them lose weight or prevent weight gain. This is an important factor, as individuals may need specific advice based around their type of diabetes and how their condition is being managed (including use of medication that can lead to weight gain).



People with diabetes of a normal weight are more likely to meet all treatment targets



25.0 to 29.9 (Pre-obesity)

Percentage of people with diabetes meeting treatment targets, by BMI class

40.0+ (Obesity class III)

- <18.5 (Underweight)
 30.0 to 34.9 (Obesity class I)
 18.5 to 24.9 (Normal weight)
 35.0 to 39.9 (Obesity class II)
- Source: National Diabetes Audit 2012–13 (figures for England and Wales)

- GPs and other healthcare professionals should identify people with diabetes who need support to lose weight, refer them to appropriate services, and monitor their progress.
- CCGs need to commission a range of services and programmes to help people with diabetes to manage their weight (and address the behaviours that influence weight), and evaluate the effectiveness of these programmes.

Smoking increases the risk of life-threatening complications, but many people with diabetes continue to smoke

Smoking further increases the risks of suffering the serious complications – like heart attack, stroke, and amputation – that are associated with diabetes. People with diabetes should have their smoking status checked and, if they smoke, be given help to stop.

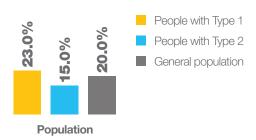
In 2012–13, 86 per cent of people with diabetes in England had their smoking status recorded. Only 80 per cent of people with Type 1 diabetes received this check, though, compared with 87 per cent of people with Type 2¹⁵.

There were also wide variations in CCG performance. In the highest-performing areas, this check was carried out in more than 95 per cent of diabetes patients, while in the lowest it was carried out in 65 per cent.

Smoking prevalence was higher in people with Type 1 diabetes. Of the people whose smoking status was recorded, 23 per cent of those with Type 1 diabetes, and 15 per cent with Type 2, were current smokers.

That many people with Type 1 diabetes are continuing to smoke is particularly worrying. Their long exposure to diabetes already heightens their risk of complications.

Smoking prevalence in people with recorded smoking status



Source: National Diabetes Audit 2012-13 (figures for England and Wales)

- CCGs should make sure smokers with diabetes, particularly people at risk of foot problems, neuropathy, or other complications, are being identified and referred to smoking cessation services.
- GPs and other healthcare professionals should use care planning sessions to support people with diabetes who need to stop smoking, refer them to appropriate sources of advice, and check their progress.
- All healthcare professionals involved in caring for people with diabetes should ensure smokers are getting the support they need to quit.

Personalised care planning

Care planning is a continuous process, in which patients and clinicians work together to agree goals, identify support needs, develop and implement action plans, and monitor progress¹⁷. It has been shown to improve the skills, knowledge and experiences of patients and healthcare professionals, and can enable people with diabetes to make positive changes to their behaviour³⁸.

This approach recognises that a person with diabetes knows most about their condition and should be actively involved in decisions about how it will be managed. Effective care planning can happen only where an engaged and empowered patient is able to work with healthcare professionals who are committed to partnership working and have the skills needed to do this.

Personalised care planning is one of the core components of integrated diabetes care, and relies on all elements of the 'house of care' framework being in place. This framework describes the key elements involved in delivering a care and support system that is centred and coordinated around the needs of each person with diabetes.

According to a recent Diabetes UK online survey, care planning is still not widely used. Only 40 per cent of respondents said they had developed a care plan with their healthcare professional, and decided this by discussing their individual needs and setting targets³⁹.

In Wolverhampton, the care planning process is initiated through a questionnaire sent to patients prior to their annual review appointment. This includes a list of questions for patients to consider and use to identify their priorities. The patient's responses are discussed at the consultation and an action plan is designed, in collaboration with their clinician, to inform their ongoing care⁴⁰.

What needs to happen now?

Personalised, collaborative care planning should replace traditional routine care for people with diabetes, as part of an integrated system that focuses on the patient's perspective of care. To achieve this:

CCGs need to:

- provide training in care planning for healthcare professionals and GP practices and incentivise attendance through an enhanced services payment
- commission the support needs identified in the care planning process.

Healthcare providers need to:

- adapt their working practices, including finding ways to free up clinician time to engage in care planning
- look at how they could make better use of their information systems to facilitate the care planning process.

Healthcare professionals need to:

- take up training and other learning opportunities about care planning
- encourage and enable all patients with diabetes to participate in collaborative care planning.

Education and support for self-management

Supported self-management is integral to the successful daily management of diabetes. Personalised care planning, psychological and emotional support, and access to information and learning can all contribute to effective self-management⁴¹.

NICE recommends that people with diabetes are offered patient education programmes, both around the time of diagnosis and on a regular basis. This can help to provide them with the knowledge, skills and motivation to self-manage their diabetes effectively throughout their lives.

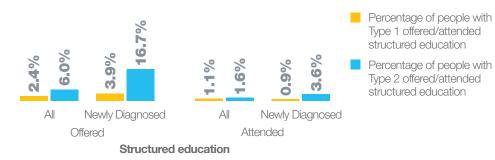
Despite this, in 2012–2013, structured education was recorded as being offered to only 2.4 per cent of people with Type 1 diabetes and 6 per cent of people with Type 2. These figures were only slightly better for people who were newly diagnosed with diabetes – 3.9 per cent of people with Type 1 and 16.7 per cent of people with Type 2¹⁵.

Even more concerning is that only 1.1 per cent of people with Type 1 diabetes, and 1.6 per cent with Type 2, were recorded as actually attending structured education.

This may be because they do not understand the benefits of attending such a course, because the timing is inconvenient for working age people, or because the venue is difficult to get to. For some people, just the idea of 'education' may be off-putting. For others, the waiting times for education programmes are too long.

In Lambeth and Southwark, various actions have been taken to improve uptake of diabetes education programmes, including reminder telephone calls, evening and weekend sessions, shorter courses, and delivering sessions in different languages. These initiatives helped to increase levels of participation in both boroughs⁴².

Few people with diabetes were offered structured education, and even fewer attended a course



Source: National Diabetes Audit 2012–13 (figures for England and Wales)

Education about diabetes can equip people with the skills to manage their condition effectively, but only a handful of people attend courses

My practice nurse has offered me excellent support throughout the time I have had diabetes. The course I went on really helped me and I feel the support I have received has helped me to keep my diabetes under good control.

I was offered an education course for people newly diagnosed with diabetes. It is held at a local hospital, which would be convenient but it is always on the same day of the week, at a time when it is impossible for me to attend. I have enquired about alternative courses but have been told that none are available. So I have had no education apart from my very brief conversations with my GP.

What needs to happen now?



A different approach to education and learning is needed, which includes:

- the delivery and funding of appropriate learning initiatives, designed to meet the needs of a wide range of people with diabetes - including peer support and online learning
- new terminology to refer to education and learning. which is user friendly and encourages take up.



Healthcare professionals should discuss access to learning opportunities as part of the care planning process, and record patient attendance. They should explain the benefits of attending learning programmes in a clear and compelling way.



CCGs need to:

- ensure appropriate learning opportunities are available for all people with diabetes, and they are encouraged to take up those opportunities
- review the uptake of learning and education programmes, and identify and address local barriers
- have systems that check the effectiveness of local learning and education programmes, including quality assurance and audit.

Care for children and young people

Around 96 per cent of the 24,000 children and young people in England with diabetes have Type 1²⁷. Unlike Type 2 diabetes, Type 1 diabetes cannot be prevented, and tends to develop earlier in life.

Early identification of Type 1 diabetes is vital

Around 15 per cent of cases of Type 1 diabetes are diagnosed after children develop Diabetic Ketoacidosis (DKA) – where abnormally high blood glucose levels can lead to organ damage, coma or death⁴³. It is crucial, therefore, that Type 1 diabetes is identified early.

Everyone who spends time with children and young people needs to be aware of the symptoms of Type 1 diabetes. Simply put, these are the 4Ts: Toilet; Thirsty; Tired; Thinner.

Quality healthcare for children and young people

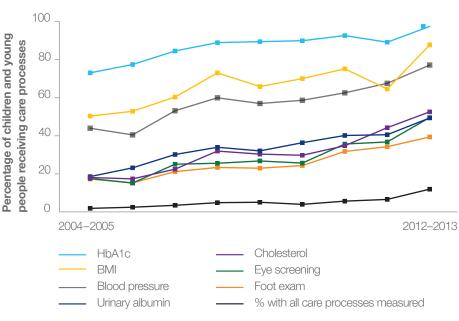
Children and young people with diabetes should have access to high-quality care from specialist paediatric healthcare professionals, and receive seven key processes of care every year⁴⁴.

Increasing numbers of young people (aged between 12 and 24) are getting each of the seven care processes. The percentage of young people having all of these important checks has almost doubled – from 6.7 per cent in 2011–2012 to 12.1 per cent in 2012–2013²⁷.

However, there is still a long way to go before the overall completion rate even matches that for adults with Type 1 diabetes (which is still relatively low). Improvements are also needed for many of the individual care processes – completion rates for eye, feet, kidney, and cholesterol testing are around or below 50 per cent.

Moreover, steps must be taken to reduce the high numbers of children and young people with unacceptable HbA1c levels.

More children are receiving key care processes, but overall completion rates are still very low



Source: National Paediatric Diabetes Audit 2012–13 (figures for England)

The best practice tariff for paediatric diabetes was introduced in 2012 as an incentive to spread best practice and reduce regional variation. From April 2014, the standards included in the tariff are mandatory for all paediatric diabetes units, and the tariff has been extended to cover inpatient care. While these are important steps, a great deal of work is still required before all children with diabetes receive the care they need.

More than a quarter of children and young people with diabetes have unacceptable blood glucose levels, and only 12 per cent receive all of the recommended health checks – these poor standards of care cannot continue²⁷

Supporting children with diabetes at school

It is now a legal requirement for schools to provide support to children with Type 1 diabetes, and other medical conditions⁴⁵. This includes putting in place a health care plan for each child, ensuring they can take part in all school activities, and having a medical conditions policy.

Providing children with the support they need to participate in all aspects of school life requires a coordinated effort. Local authorities and clinical commissioning groups need to ensure there is appropriate training for school staff about looking after children with diabetes, and guidance from clinicians about preparing a health care plan.

Effective transition to adult services

Around a quarter of admissions for DKA are in the 16 to 25 age group⁴³. Diabetes control often deteriorates during adolescence, and young people are particularly vulnerable when their care is transferred from child to adult diabetes services. This is also a time when life-long health behaviours are developed.

Transition needs to be well coordinated, and should not occur until a young person has sufficient clinical understanding about managing their condition to get the most out of adult diabetes services. If this does not happen, there is a risk they will disengage from these services, leading to poor diabetes control and long-term complications.

Over 90 per cent of the variation in HbA1c (across regional diabetes networks and PDUs) is unaccounted for. This suggests that much of the variation is due to differences in service provision and delivery which needs addressing.

National Paediatric Diabetes Audit 2012–13

- Paediatric Diabetes Units need to improve provision of each of the seven care processes, and reduce the numbers of children and young people with high HbA1c levels. This should include:
 - setting targets for improvement and implementing action plans to achieve them
 - making effective use of networking and peer review programmes.
- Local authorities and the Department for Education need to ensure all schools are aware of their new legal duties and what these mean in practice. Ofsted inspections should check school compliance.
- All young people need access to a smooth and effective transition process from child to adult diabetes services, which:
 - is age appropriate and centred around the individual
 - involves a well-coordinated multidisciplinary approach, including adult and paediatric teams.

12 Inpatient care

People with diabetes need to receive specialist care and support when they are in hospital, regardless of the reason for their admission. This is essential to ensure their diabetes is well managed, to minimise the risk of complications arising, and to prevent patient harm.

Evidence suggests specialist diabetes inpatient teams save three times their cost. They reduce prescribing errors and improve patient outcomes, leading to fewer expensive complications in hospital and a shorter stay⁴⁶.

It is also vital that all hospital staff who are involved in caring for people with diabetes are skilled and competent to deliver that care. Otherwise, patients may be at risk of acute or long-term complications.

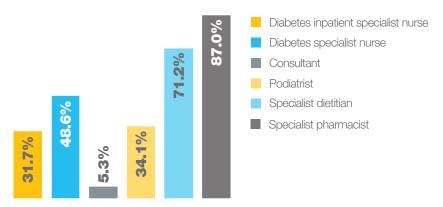
The 2013 National Diabetes Inpatient Audit showed that, while there have been some improvements in diabetes care:

- 37 per cent of inpatient drug charts had at least one diabetes medication error, 22 per cent had at least one prescription error, and 22 per cent had at least one medication management error
- 22 per cent of inpatients had one or more hypoglycaemic episodes
- only 35 per cent of inpatients with diabetes were seen by a member of the diabetes team
- almost one-third of sites did not have a diabetes inpatient specialist nurse, and a similar proportion did not have a multidisciplinary foot care team.

In addition, nearly a quarter of inpatients who responded to the patient experience questionnaire said they would have liked more involvement in the planning of their diabetes treatment. Some respondents found it difficult to self-manage their condition during their stay because they were unable to test their blood glucose levels, or were not provided with the right type of food.

Many inpatients do not receive specialist diabetes care, and suffer complications while in hospital

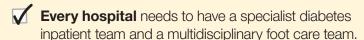
Many hospitals do not have diabetes specialists to care for inpatients with diabetes



Percentage of sites participating in audit where no staff time was available specifically for the care of people with diabetes

Source: National Diabetes Audit 2012-13 (figures for England and Wales)

What needs to happen now?



Patients with diabetes should be supported to self-manage their diabetes while in hospital.

All healthcare professionals working in hospitals should be competent in diabetes care. To help achieve this, Health Education England should encourage CCGs to include competency assessment within contract specifications.

13 Pregnancy care

The first pregnancy in diabetes audit has highlighted serious concerns about the care given to women with diabetes

While women with diabetes can have healthy pregnancies and healthy babies, they face an increased risk of complications and adverse outcomes – including stillbirth, miscarriage, neonatal death, and congenital anomalies.

Women with diabetes who are pregnant or planning a pregnancy need care and support from multidisciplinary teams with expertise in diabetes and obstetrics. Their pregnancies need to be well managed, including prior to conception where possible.

In 2014, the first national pregnancy in diabetes audit reported on data collected from 1,700 pregnancies and 128 participating organisations. Nearly half of the women included had Type 2 diabetes. The audit provided a wealth of useful information, but raised concerns about the care given to women with diabetes⁴⁷.

Good glucose control before and during pregnancy can greatly reduce the risk of complications. However, the audit showed that, in early pregnancy:

- only 5 per cent of women with Type 1 diabetes, and 18.5 per cent of women with Type 2 diabetes, achieved the target blood glucose levels
- 11 per cent of women with Type 1 diabetes, and 9 per cent with Type 2, had blood glucose measurements at the level at which NICE guidelines recommend pregnancy is avoided.

Some of the medicines used to treat diabetes must not be taken during pregnancy. Despite this, one in 10 women with Type 2 diabetes became pregnant while taking a potentially hazardous glucose-lowering medication.

First contact with a specialist antenatal diabetes team should happen as early as possible. While more than half (51.2 per cent) of women with Type 1 diabetes had their first contact with this team prior to eight weeks gestation, only just over one-third (36.6 per cent) of women with Type 2 had their first contact with the team in this timeframe.

Other points of concern included:

- · rates of stillbirths and neonatal deaths remain high
- 30 per cent of babies required intensive or specialist neonatal care.

The audit confirmed the growing proportion of pregnancies in women with Type 2 diabetes – who tend to be older, from socially deprived and ethnic minority groups, and to have had diabetes for a relatively short time. These women are less likely to be under the care of specialist services than women with Type 1 diabetes. The report notes that these factors present challenges to those preparing and delivering pregnancy preparation support, meaning a multi-sector approach will be needed.

What needs to happen now?



Every diabetes and maternity service needs to take action to improve care for women with diabetes prior to and throughout pregnancy, including:

- implementing initiatives to improve glucose control, use of higher-dose folic acid, and preparation for pregnancy
- incorporating information about pregnancy into patient education programmes and other learning opportunities
- screening for complications (which can get worse during pregnancy)
- considering the impact on services of women who develop diabetes during pregnancy and need more intense support.

5 Specialist care

Better access to diabetes specialists, and integrated models of care, can improve patient outcomes and save the NHS money

People with diabetes need access to a range of healthcare professionals and services, to help them manage their condition and to treat complications.

Integrated pathways of care across primary, community and specialist care are the ideal way of ensuring people with diabetes get the support and treatment they need in the right place, and at the right time, in a coordinated manner. In an integrated model of care, local health services are configured in a way that focuses on the patient's perspective, needs and circumstances. This can deliver value for both the individual and the health system.

Diabetes specialist nurses (DSNs) are integral to achieving good patient care and outcomes. They play an important role in preventing expensive and debilitating complications, supporting people with complex needs, and helping people to self-manage their diabetes. In primary care, their specialist expertise can reduce hospital admissions; in hospitals, their skills can help to reduce prescribing errors and length of stay⁴⁶.

Evidence suggests diabetes specialist nurses are a key part of highquality, cost-effective care. Despite this, and the fact that the incidence of diabetes is increasing, DSN numbers are stagnating, posts are being frozen, and skill levels are still under threat48.

In the 2013 National Diabetes Inpatient Audit, 31 per cent of sites said they had no diabetes inpatient specialist nurses. Moreover, 71 per cent of sites had no specialist dietitian time for inpatient care for people with diabetes, and 34 per cent had no podiatrists³⁵.

What needs to happen now?



Commissioners and providers across primary, community and specialist care should work together to design and commission integrated care pathways to ensure people with diabetes get the specialist support they need. This involves:

- assessing local need
- reviewing local workforce capacity and competency
- defining and agreeing the local model of care and the local pathways to deliver all the services needed to meet the diabetes service specification
- ensuring the key enablers of integrated diabetes care are in place. These are integrated IT, aligned finances and responsibility, collaborative care planning, clinical engagement, and clinical governance.



Commissioners and providers need to recognise the importance of diabetes specialist nurses when designing cost-effective diabetes services, and ensure:

- people living with diabetes have access to appropriately skilled and qualified nurses in all care settings
- recommended minimum staffing levels are maintained (at least five DSNs per 250,000 people, and one diabetes inpatient specialist nurse per 300 beds⁴⁹).



All hospitals should employ specialist diabetes staff, including nurses, dietitians, and podiatrists.

Emotional and psychological support

Diabetes is a complex condition, which can be challenging to manage on a daily basis. Effective self-management is critical, but requires personal motivation.

People with diabetes have a significantly higher risk of depression, anxiety, and eating disorders than the general population⁵⁰. This can limit their ability to self-manage their condition and reduce medication adherence – leading to poorer diabetes control and a greater likelihood of complications.

Access to emotional support and specialist treatment can reduce psychological distress and improve outcomes for people with diabetes⁵¹. Information and education programmes can also help to reduce anxiety related to managing diabetes, and equip people with tools to cope with their condition.

Despite this, there continue to be significant gaps in the provision of psychological support and care for people with diabetes. **Around three-quarters of adults and children do not have access to psychological services, and have not received emotional support when needed**⁵². As noted earlier, attendance at diabetes education programmes is relatively rare, even among people with recent diagnoses.

The emotional and psychological support offered to newly diagnosed patients is woeful. I have met a number of people who because of this lack of support have gone on to develop real emotional and psychological issues.

Response to the Diabetes UK 15 Healthcare Essentials online survey

Depression is twice as common in people with diabetes than in the general population, yet few people have access to the support they need

What needs to happen now?

Emotional support and psychological care need to be a routine part of diabetes management – for children and adults – with services delivered as part of integrated models of care. To achieve this:

- Commissioners and providers should work together to design and implement integrated diabetes services in their area, which cover the full spectrum of mental and physical healthcare
- CCGs should commission specialists in psychological care and diabetes, and ensure these form part of multidisciplinary diabetes teams and paediatric diabetes services
- **GPs** should consider the emotional and psychological needs of patients with diabetes as part of personalised care planning
- CCGs need to ensure relevant learning and peer support opportunities are available, using data to identify local needs and inform the commissioning process.

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