

STATE OF THE NATION 2016

Time to take control of diabetes



England

DiABETES UK

About Diabetes UK

We are the UK's leading diabetes charity that cares for, connects with and campaigns on behalf of every person affected by or at risk of diabetes. We provide care, support and information to help people with diabetes manage their condition. We campaign for better care and treatment for everyone with diabetes to make sure they can live a long and healthy life. And our researchers are leading the way in understanding diabetes.

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Foreword



Diabetes is the fastest-growing health threat facing our nation. Over three million people are living with diabetes in England. If their condition is well managed they can live long, fulfilling lives.

However, in early 2016 the Public Accounts Committee found: “an unduly unhealthy picture of the state of diabetes services in England”. There are significant variations in care for people with diabetes. Too often people with diabetes are not receiving the support they need to help them manage their condition and reduce their risk of devastating and costly complications.

“ The costs of diabetes to the NHS will continue to rise. In order to control these costs, the Department and NHS must take significant action to improve prevention and treatment for diabetes patients in the next couple of years. ”

Public Accounts Committee, January 2016

The case for change is ever clearer. During 2015 and 2016, we welcomed several national diabetes audit reports covering care processes and treatment targets, inpatients, children and young people, pregnancy and, for the first time, the National Diabetes Foot Care Audit (NDFA). These audits show that a staggering one in six people occupying a hospital bed now has diabetes. Amputation rates vary widely from place to place. It is the exception rather than the rule if young people receive all of their key checks.

Commissioners must act now to take control of diabetes services in their areas. Whilst there have been some improvements, unacceptably wide variations in care and treatment outcomes remain. The luck of where you live, what type of diabetes you have or your age can determine the quality of your care. There are key targets for managing diabetes in terms of blood glucose, cholesterol and blood pressure. Two out of five people with Type 2 diabetes meet them – but fewer than one in five people with Type 1 diabetes do.

In some areas, thousands of people with diabetes have attended education courses that give them the confidence and skills to take control of their condition. They can be life changing. So it is galling that in most places these courses have reached a small fraction of the thousands who will benefit.

But there is hope. Diabetes is at the top of the health agenda now more than ever. Our task is to translate this into rapid action that addresses the devastating crisis around this condition. Over the past year there has been rapid progress in setting up the NHS Diabetes Prevention Programme. Diabetes is one of six clinical priorities in the new system for scrutinising and supporting local NHS performance – the CCG Improvement and Assessment Framework.

More than ever, we know what needs to happen to provide good diabetes services. And we are working with NHS England to develop new ways of helping the NHS improve the quality of local diabetes systems based on the outstanding practice that exists in the NHS.

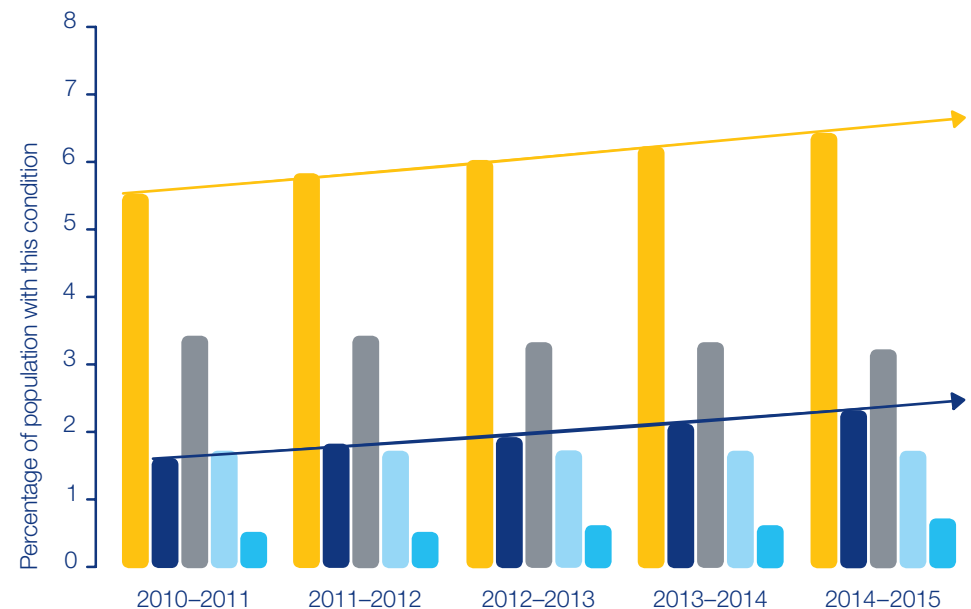
Diabetes is a crisis for the health of the nation. But if we work together we can realise our vision of a world where diabetes can do no harm.

Chris Askew
Chief Executive

Time to take control: Diabetes in England 2016

- Five million people in England are at high risk of developing Type 2 diabetes¹.
- If current trends persist, one in three people will be obese by 2034 and one in ten will develop Type 2 diabetes¹.
- It is currently estimated that the NHS spends about £10 billion on diabetes every year. This is 10 per cent of the NHS budget².
- The total cost (direct care and indirect costs) associated with diabetes in the UK currently stands at £23.7 billion. This figure is predicted to rise to £39.8 billion by 2035/2036².

The prevalence of diabetes is nearly three times higher than the prevalence of all cancers combined



- Diabetes
- Cancer
- Coronary Heart Disease
- Stroke and mini stroke
- Dementia
- ▶ Future diabetes projection
- ▶ Future cancer projection

Source: Quality and Outcomes Framework, Health and Social Care Information Centre (2010-2015)

15 Healthcare Essentials for everyone with diabetes

Everyone with diabetes needs to receive vital care and services, regardless of their age, ethnicity, where they live and whether they have Type 1 or Type 2 diabetes. Diabetes UK's 15 Healthcare Essentials set out the care that all people with diabetes should expect to receive from their healthcare team. They include the nine care process checks recommended by NICE and provide a starting point for ensuring everyone gets high quality and effective care. Care planning enables people to make the most of the 15 Healthcare Essentials and involves collaborative working between people with diabetes and their healthcare teams to develop and achieve individual goals.

1 Get your blood glucose levels measured

You should have your blood glucose levels measured and reviewed at least once a year. An HbA1c blood test measures your overall blood glucose control over the previous three months and helps you and your diabetes healthcare team set your own target.

This long-term picture is different from home blood glucose monitoring (self-monitoring) your blood glucose levels, which indicates your blood glucose level at the time of the test. Not everyone needs to self-monitor, but if you do you should have access to test strips and the equipment you need.

2 Have your blood pressure measured

Your blood pressure should be measured and recorded at least once a year, and you should agree a personal target that is right for you.

3 Have your blood fats measured

You should have your blood fats (such as cholesterol and triglycerides) measured every year. Like blood glucose levels and blood pressure, you should have your own targets that are realistic and achievable.

Working towards and reaching your targets for blood glucose, blood pressure and blood fats is an important part of managing your diabetes and should be reviewed at least once a year as part of your check-up. Your healthcare team is there to offer advice and support to help you reach your targets and reduce your risk of developing long-term complications.

4 Have your eyes screened for signs of retinopathy

Your eyes should be screened for signs of retinopathy every year by your local diabetic eye screening service.

5 Have your feet and legs checked

The skin, circulation and nerve supply of your feet and legs should be examined by a healthcare professional at least once a year. You should be told if you are at risk of foot problems, how serious they are and if you need to be referred to a specialist podiatrist or foot clinic.

6 Have your kidney function monitored

You should have two tests to measure your kidney function every year: a urine test for protein (a sign of possible kidney problems) and a blood test to measure kidney function.

7 Get individual, ongoing dietary advice

You should receive ongoing dietary advice from a healthcare professional with appropriate expertise in nutrition and be referred to a dietitian for tailored advice if necessary. You should have the opportunity to check your weight and get the support and information you need to manage your weight.

8 Get emotional and psychological support

Diabetes can be hard, whether you've just been diagnosed or have lived with the condition for years. It's important that you are able to talk about your issues and concerns with specialist healthcare professionals, so that they can support and advise you.

9 Be offered a group education course in your local area

You should be offered a diabetes education course when you are diagnosed, or as part of a yearly refresher, to help you understand and manage your diabetes. If you are unable or don't wish to attend a group course, you should be offered a suitable alternative.

10 See specialist diabetes healthcare professionals to help you manage your diabetes

Diabetes affects different parts of the body and you should be referred to specialist professionals when needed, such as a diabetes specialist nurse, dietitian, ophthalmologist, pharmacist or podiatrist.

11 Get a free flu vaccination

You should get a flu vaccination every year from your GP. People with diabetes are at greater risk of severe illness, such as pneumonia, if they get flu. You should also be given a personal care plan telling you what steps to take if you are ill.

12 Receive high-quality care if admitted to hospital

If you have to stay in hospital, you should still receive high-quality diabetes care from specialist healthcare professionals, whether you have been admitted due to your diabetes or not.

13 Have the opportunity to talk about any sexual problems

Diabetes increases the risk of sexual dysfunction in both men and women. You should have the opportunity to talk to your healthcare team about any sexual problems you may be experiencing, or concerns you may have. You should be assessed and given support and education and be referred to an appropriate service if necessary.

14 If you smoke, get support and advice on how to quit

Diabetes increases your risk of heart disease and stroke, and smoking further increases this risk. If you smoke, you should be given the support and advice you need to help you quit.

15 Get information and specialist care if you are planning to have a baby

Your diabetes control has to be a lot tighter and monitored very closely before and during pregnancy. You should expect support from specialist healthcare professionals at every stage from preconception to post-natal care.

1 Blood glucose

A substantial number of people with diabetes have exceptionally high-risk glucose levels

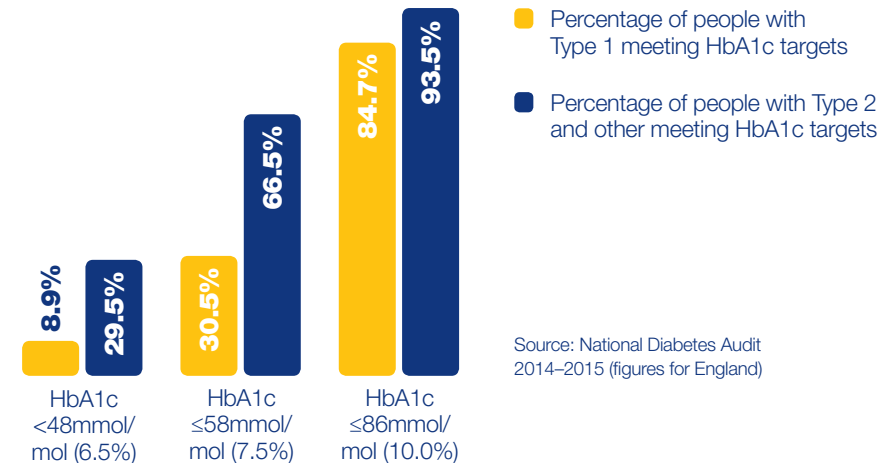
Blood glucose control is essential to avoid serious complications. As a result, NICE recommends an annual HbA1c check to measure a person's overall blood glucose control. In addition, many people with diabetes self-monitor their blood glucose to avoid both hypoglycaemia and hyperglycaemia.

People with Type 1 diabetes are much less likely to receive the HbA1c check – only 84 per cent – compared with 95 per cent of people with Type 2 and other diabetes³. This situation has improved slightly from 80 per cent in 2012–2013, but it is yet to match the figures from 2010–2011, where the proportion of people with Type 1 diabetes receiving this check was 86 per cent⁴.

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

- a substantial proportion of people, especially those with Type 1 diabetes, still have exceptionally high glucose levels – 15 per cent of Type 1 and 6 per cent of Type 2 patients have HbA1c equal to or above 86mmol/mol³
- people with Type 1 diabetes are much less likely to reach recommended targets than people with Type 2 diabetes. In 2014–2015, only 31 per cent of people with Type 1 diabetes met this target compared to 67 per cent of those with Type 2 diabetes³
- there is also wider local variation in treatment outcomes for people with Type 1 diabetes. For the treatment target of equal to or below 86mmol/mol for those with Type 1 diabetes there was a range of 29 percentage points between the highest and lowest-performing CCGs. For those with Type 2 diabetes, this range was 12 percentage points³.

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



Source: National Diabetes Audit 2014–2015 (figures for England)

Insulin pumps

In order to effectively self-manage their condition, people with Type 1 diabetes also need to have access to insulin pump therapy (continuous subcutaneous insulin infusion therapy) and a specialist pump team, if they meet NICE criteria⁵.

The first audit from the National Diabetes Audit on insulin pump therapy, published in 2016, suggests that the uptake of pumps has increased over the last three years, though this should be interpreted with caution as response rates were low⁶. The audit found that people with Type 1 diabetes on an insulin pump are more likely to achieve all three NICE treatment targets of HbA1c, blood pressure and cholesterol. Pumps may be helping people with diabetes to better control their long-term blood sugar levels. People with Type 1 diabetes should be supported to take up insulin pump therapy if they and their doctor agree this would be beneficial.

Self-monitoring of blood glucose

In addition to monitoring long-term levels of blood glucose using the HbA1c test, many people need to self-monitor their blood glucose levels. This is usually done with a finger prick blood test using a blood glucose meter that indicates the blood glucose level at the time of the test. For many people with diabetes self-monitoring is necessary to manage their diabetes well. Not everyone needs to self-monitor, but if they do they should have access to test strips and the meter they need.

NICE recommends that all adults with Type 1 diabetes should routinely self-monitor their blood glucose levels and test themselves at least four times a day, including before each meal and before bed⁷. Frequent drivers and those who take regular exercise, or who are at high risk of hypos, will need to test up to ten times a day.

For adults with Type 2 diabetes, NICE recommends that self-monitoring of blood glucose levels should be offered to individuals treated with insulin, where there is evidence of hypoglycaemic episodes, if the person is on oral medication that may increase their risk of hypoglycaemia while driving or operating machinery or they are pregnant or planning to be pregnant.

A recent survey of over 1,000 people found that 27 per cent have, in the past 12 months, been refused a prescription for blood glucose test strips or have had the number of test strips on their prescription restricted⁸. Of these, over half (52 per cent) have Type 1 diabetes. Budget constraints or “excessive testing” were the most frequent reasons given for these refusals and restrictions.

People with diabetes found these restrictions stressful and had to make difficult decisions about when to test or not. As a result many had bought or considered buying test strips from pharmacies or online.

In addition, 66 per cent of respondents were given no choice of blood glucose meter. Of these, one in four (25 per cent) were not happy with the meter provided. For instance, the meter was too large to easily move around or didn't upload the data to a computer.

“ I feel stressed because of the fear of not having enough test strips to meet legal requirements to test my blood glucose levels before driving. ”

“ I am constantly worried we'll run out. I get cross with my daughter if she wastes a strip by dropping it or not producing enough blood. ”

“ It makes living with diabetes feel like a real chore and that people are going against me when I'm trying to do my best to improve my health. ”

2 Blood pressure

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 diabetes⁹.

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 2 and other diabetes¹⁰.

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 specifies recommended treatment targets.

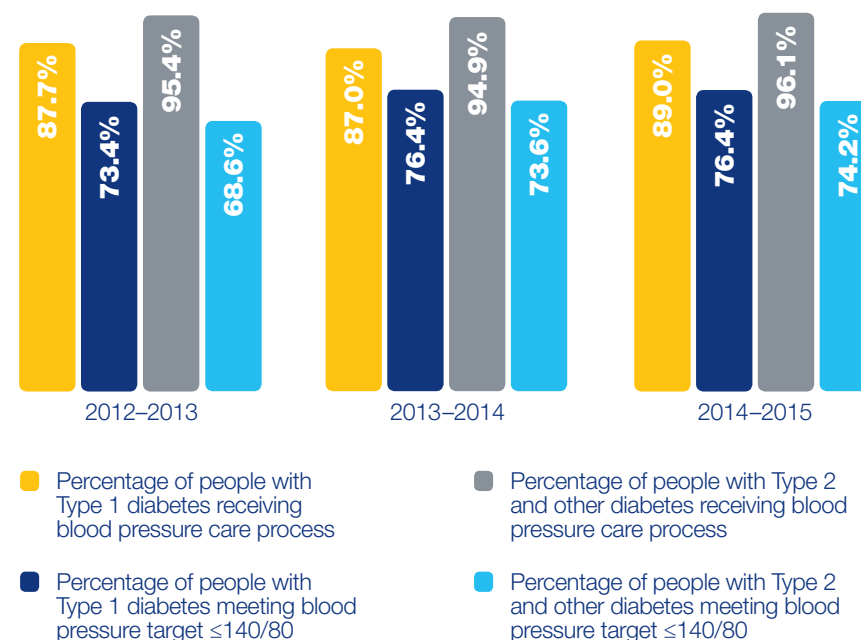
In 2014–2015, 89 per cent of people with Type 1 diabetes and 96 per cent of those with Type 2 and other diabetes had their blood pressure checked – a similar figure to previous years³. However, only 76 per cent of all people with Type 1 diabetes and 74 per cent of people with Type 2 and other diabetes met the recommended treatment target. While this represents a slight improvement from 2012–2013⁴, it still means that one in four people with diabetes are not meeting the treatment target for blood pressure.

Unlike the targets for HbA1c and cholesterol, people with Type 2 diabetes were less likely to meet the treatment target for blood pressure³. There was also a considerable variation in blood pressure target achievement rates by CCG, for patients with all types of diabetes. The range between the best and worst CCGs for people with Type 1 diabetes was greater than 36 percentage points with the highest performing achieving 95 per cent and the lowest performing achieving 59 per cent. For Type 2 and other diabetes the range was 23 percentage points with the highest performing CCG achieving 87 per cent and the lowest 64 per cent³.

For local data, see the Diabetes Watch online tool:
diabeteswatch.diabetes.org.uk

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

People with Type 2 and other diabetes are more likely to get their blood pressure checked than people with Type 1, but less likely to meet recommended targets



Source: National Diabetes Audit 2014–2015 (figures for England and Wales)

3 Cholesterol

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

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

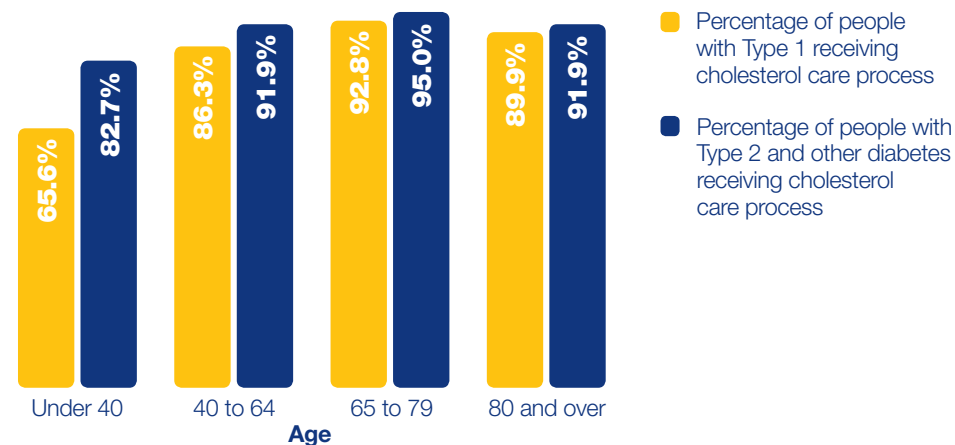
In 2014–2015, 93 per cent of people with Type 2 and other diabetes received a cholesterol check, but only 79 per cent of people with Type 1 had this essential check³.

Younger people were less likely to have their cholesterol checked than those aged over 40. This check was carried out in only 66 per cent of people with Type 1 in the under 40 age group and 83 per cent of those with Type 2 in that age group³.

Twenty-nine per cent of people with Type 1 and 22 per cent of people with Type 2 and other diabetes did not meet the cholesterol treatment target of <5mmol/L, and 70 per cent with Type 1 and 58 per cent with Type 2 and other diabetes failed to meet the tougher target of <4mmol/L³.

As with treatment targets for HbA1c and blood pressure, there were large variations in achievement rates across CCGs³.

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



Source: National Diabetes Audit 2014–2015 (figures for England and Wales)

All three NICE-recommended treatment targets

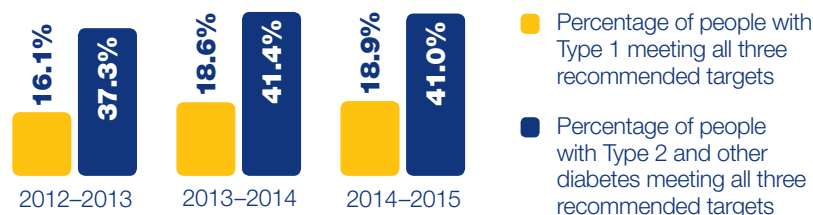
Achievement of all three NICE-recommended treatment targets

Achievement of the three NICE-recommended treatment targets has improved slightly for those with both Type 1 and Type 2 diabetes since the last report, but progress now appears to have stalled. Adults with Type 1 diabetes are less than half as likely to achieve all three treatment targets than adults with Type 2. For years 2012–2013, 2013–2014 and 2014–2015 the percentages were 37 per cent, 41 per cent and 41 per cent respectively for those with Type 2 and other diabetes and 16 per cent and 19 per cent (for 2013–2014 and 2014–2015) respectively for those with Type 1 diabetes^{3,4}.

There were large variations in rates across CCGs for achieving the treatment targets for HbA1c, cholesterol and blood pressure³.

This indicates there is considerable scope for improvement across all areas.

People with Type 1 diabetes are less likely to meet recommended treatment targets compared to people with Type 2 and other diabetes



Source: National Diabetes Audit 2014–2015 (figures for England and Wales)

For local data, see the Diabetes Watch online tool:
diabeteswatch.diabetes.org.uk

What needs to happen now?

- **Healthcare professionals** should collaborate with people who have diabetes through the care planning process to develop and achieve their individual goals, agreeing targets for blood glucose, blood pressure and blood fats. These should be reviewed at least once a year for everyone with diabetes as this is crucial for optimum diabetes management.
- **People with diabetes** should be supported to eat a healthy diet and maintain a healthy weight.
- **People with diabetes who smoke** should be given help to quit.
- **Insulin pump therapy** should be offered to all those who could benefit and who meet NICE guidance.
- **CCGs** should have an improvement plan to tackle local variation in treatment outcomes for all people with diabetes and ensure that particular attention is given to addressing treatment target outcomes for people with Type 1 diabetes as they are at greater risk of short and long-term diabetes-related complications.
- **CCGs** should put plans in place to ensure that all people with diabetes have the skills and confidence to manage their condition by 2020.
- **NHS England** should work with local areas to increase the proportion of people accessing structured education to 50 per cent by 2020.

4 Eye screening

Many people with diabetes are not having their eyes checked regularly and services for treating eye disease are fragmented

People with diabetes are at higher risk of developing retinopathy which, if left undetected and untreated, can lead to blindness. It is important that they are screened for signs of retinopathy every year by a local diabetic eye screening service.

Diabetic retinopathy occurs in 40 per cent of people with Type 1 diabetes and in 20 per cent of people with Type 2 diabetes¹¹. Retinopathy is the most common cause of preventable sight loss among people of working age in the UK and accounts for around 7 per cent of people who are registered blind¹². On average 1,280 new cases of blindness caused by diabetic retinopathy are reported each year in England alone, while a further 4,200 people per annum are thought to be at risk of retinopathy-related vision loss¹³.

Diabetic eye disease can affect anyone with diabetes but increases with age. Keeping blood glucose, blood pressure and cholesterol levels under control can help to reduce the risk of developing retinopathy. People with diabetes also have an increased risk of developing glaucoma and cataracts.

Regular screening can ensure problems are identified and treated as early as possible. Research shows that if retinopathy is identified early and treated appropriately, blindness can be prevented in 90 per cent of those at risk¹².

Currently all people with diabetes aged 12 and over should be offered annual screening appointments by the National Diabetic Eye Screening Programme (NDESP). In 2014–2015, uptake of appointments was 83 per cent in England¹⁴. However, there are variations across the country – in the best-performing eye screening programmes, uptake was more than 92 per cent; in the worst, it was less than 72 per cent¹⁴. 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.

However, even when people with diabetes do receive their annual eye screening, follow-up care and treatment can be variable and inconsistent, with many of those most at risk of diabetic retinopathy coming from harder-to-reach groups¹⁵. In addition, services are fragmented and there is a need for good local referral pathways from screening into ophthalmology to ensure early treatment.

What needs to happen now?

- **Eye screening services** should ensure that everyone with diabetes can access screening. This may mean offering appointments in evenings and weekends and in locations that are easily accessible.
- **GPs and opticians** should raise awareness amongst people with diabetes of the need to take up their retinal screening appointment and ensure that people understand that this is in addition to an eye health check or sight test.
- **Commissioners** should ensure that there is a clear referral pathway from screening to treatment for those identified as being at high risk of sight threatening diabetic retinopathy and that all services required to deliver this are commissioned.

5 Foot checks and diabetes footcare

Every week over 135 leg, foot or toe amputations are carried out on people with diabetes, but around 80 per cent of these could be prevented

If diabetes is poorly managed, it can lead to nerve damage, poor circulation and reduced feeling in the feet and legs. This can lead to serious foot problems, such as ulcers, and may result in amputation. The number of diabetes-related amputations and foot ulcers is increasing and is very costly to the NHS and local health economies.

There are over 7,000 diabetes-related amputations (leg, foot or toe) every year in England. Foot ulcers and amputations cost £1 in every £150 spent in NHS, but CCGs could reduce this by reorganising care to prevent amputations and shorten hospital stays¹⁶.

Experts estimate that four out of five amputations could be prevented as 80 per cent are preceded by foot ulcers, which are largely avoidable. Evidence shows that foot ulcers and amputations can be avoided through improved awareness among people with diabetes about footcare and their risk status and by providing access to good-quality structured care¹⁷.

Diabetic foot disease is the most common cause of diabetes-related hospital admission¹⁸ and foot ulcers and amputations impact hugely on quality of life for people with diabetes. In addition, up to 80 per cent of people die within five years of having an amputation¹⁹.

Everyone with diabetes is at risk of developing foot ulcers which can lead to amputations, but most at risk are people who have lived with diabetes for a long time. A recent audit found ulcers were more likely in people with Type 1 diabetes, especially smokers, and older men²⁰.

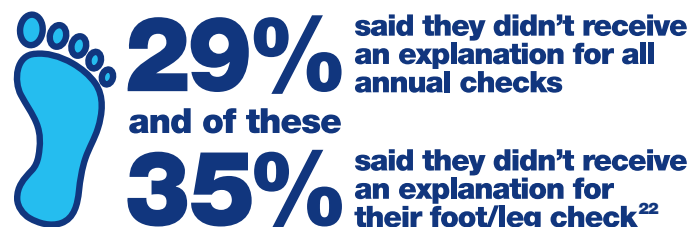
The footcare pathway

The risk of amputation can be reduced by having in place an integrated footcare pathway. Everyone with diabetes, over the age of 12, should have a quality annual foot check and, if at increased risk, referred for specialist assessment by community foot protection services¹⁷. People should also have rapid access to multidisciplinary specialist footcare teams (MDT) when they have an ulcer or other acute foot problem¹⁷. Recent evidence shows that the longer the delay before being seen by the MDT, the more likely foot ulcers will be severe and slow to heal²⁰.

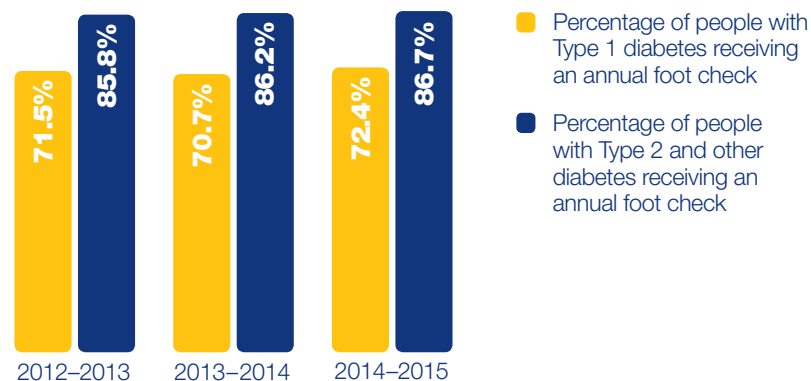
Guidance on preventing foot ulcers and amputations is not consistently implemented²⁰. There is still considerable variation in outcomes and processes across the diabetes footcare pathway from foot checks delivered in primary care, and the quality of the checks, to major and minor amputation rates.

Annual foot checks

The annual foot check is critical to ensure that people with diabetes are in the right place on the footcare pathway. This can be conducted by the GP surgery. People with diabetes should be told their risk of foot problems and how to care for their feet to prevent these. Despite this, over a quarter (27 per cent) of people with Type 1 diabetes and 13 per cent of people with Type 2 and other diabetes did not receive an annual foot check in 2014–2015³. These figures have hardly changed over recent years, and there is significant variation between GP practices and between CCG areas. The variation between CCGs is even greater for people with Type 1 diabetes where there are 34 percentage points between the best and worst performing areas.



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



Source: National Diabetes Audit 2014–2015 (figures for England and Wales)

Foot checks do not consistently meet NICE guidance standards. People with diabetes do not always get information about how to look after their feet, their risk and where to go if they have a problem²¹, and less than 60 per cent of CCGs can confidently say that there is training provided locally for those performing foot checks²⁰.

Footcare for people with diabetes in hospital

People with diabetes who have reduced sensation in their feet are at higher risk of developing a foot ulcer when in hospital. These risks can be reduced if their feet are examined during admission and action taken to prevent ulcers. However, the 2015 inpatient audit showed that less than a third (29 per cent) of people with diabetes had their feet checked within 24 hours of admission¹⁸. In addition, there is wide variation across hospitals.

For local data, see the Diabetes Watch online tool:
diabeteswatch.diabetes.org.uk

It is vital that people with foot infections or ulcers are urgently seen by a member of the MDT, but almost one third (31%) of hospitals are without such a team and only 58 per cent of people with new or deteriorating foot disease were seen within 24 hours of referral¹⁸.

Foot disease increases length of stay and is expensive¹⁶, so having a system to ensure foot risk is assessed and that people are referred appropriately whilst in hospital and on discharge makes good financial sense.

What needs to happen now?

- **Commissioners and providers** should ensure best practice guidance is implemented and local footcare pathways and outcomes are regularly reviewed, including by ensuring participation in the National Diabetes Foot Care Audit.
- **All CCGs** should commission a diabetes footcare pathway across all settings, including inpatient care, emergency care and general practice to ensure timely referral from primary care through to the MDT. The relationship between the foot protection service and the MDT should be clearly defined.
- **All inpatients** with diabetes should receive foot checks, foot protection and access to specialist footcare, if required, during admission and on discharge.
- **A root cause analysis** should be conducted for all major amputations.
- **CCGs and providers** should participate in foot networks to share learning.

6 Kidney Function

People with diabetes are at increased risk of kidney disease, which 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 2¹⁰.

Keeping blood glucose levels and blood pressure well controlled can greatly reduce the risk of kidney disease developing. In the very early stages of kidney disease there are usually no symptoms, so testing kidney function is essential for picking up problems early when they can often be successfully treated. NICE recommends that people with diabetes take two tests to measure their kidney function every year: a urine test for protein – which is a sign of possible kidney problems – and a blood test to measure kidney function. It is important that both tests are conducted.

In 2014–2015 the blood test was measured in 81 per cent of people with Type 1 and in 95 per cent of people with Type 2 and other diabetes, but the measurement of the urine test was the lowest of all of the NICE-recommended care processes³. Recorded rates for completion of this test were particularly low in people with Type 1 diabetes (56 per cent) and in people aged under 40³.

In addition, a survey of people with diabetes showed that people were least likely to get an explanation for the urine and blood tests for kidney function. Of the three in ten people (29 per cent) who did not receive an explanation about their tests, nearly half (46 per cent) did not get an explanation about the kidney function tests²².

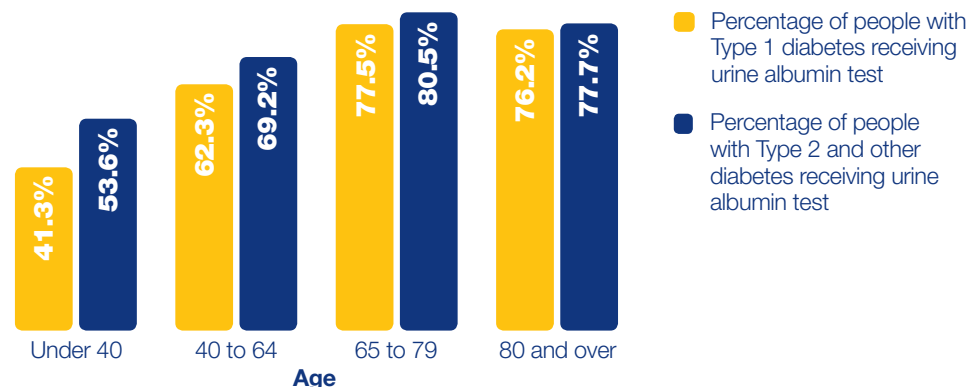
Charges for kidney checks

Another recent survey taken by nearly 300 people with diabetes revealed that, despite it being free on the NHS, 8 per cent of respondents were charged money for sample bottles whilst receiving this crucial kidney health check. In 65 per cent of these cases, people were not provided with an explanation as to why they were being required to pay for their kidney check²³.

For local data, see the Diabetes Watch online tool:
diabeteswatch.diabetes.org.uk

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

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



Source: National Diabetes Audit 2014–2015 (figures for England and Wales)

What needs to happen now?

- **People with diabetes and their healthcare teams** need to understand why urine albumin tests are important and understand and address why they are not happening.
- **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.
- **People with diabetes** should never be made to pay for their kidney checks, and any charges being placed on them must be withdrawn.

7 Individual dietary advice

It is important for everyone with diabetes to follow a healthy diet. They should get individual, ongoing dietary advice from a healthcare professional with appropriate expertise in nutrition and be referred to a dietitian for tailored advice if necessary²⁴. People with diabetes should also have the opportunity to check their weight and get the support and information they need to manage their weight.

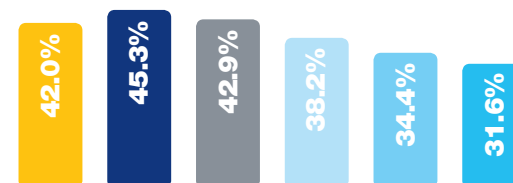
In 2014–2015, 83 per cent of people with Type 2 and other diabetes had their BMI recorded and 85 per cent of those included in the audit were classed as overweight or obese³. In addition, 75 per cent of people with Type 1 diabetes had their BMI recorded and 60 per cent of people with Type 1 in the audit were classed as overweight or obese³. People who were obese were least likely to meet all the treatment targets for blood glucose (HbA1c), blood pressure and cholesterol³. Not meeting treatment targets puts them at an increased risk of developing complications like cardiovascular disease (heart disease and stroke).

People with diabetes should have access to interventions to support weight management, but these are not always made available. The provision of 'tier 3 services' for weight management in England is variable and absent in many areas²⁵. It is not clear whether people with diabetes are getting support to help them manage their weight.

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

People with diabetes should have support to follow a healthy diet and manage their weight

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



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



Source: National Diabetes Audit 2014–2015 (figures for England and Wales)

What needs to happen now?

- **GPs and other healthcare professionals** should identify people with diabetes who need weight management support, 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 factors that influence weight) and evaluate the effectiveness of these programmes.

8 Emotional and psychological support

At least four in ten people with diabetes experience emotional and psychological problems, yet few access the support they need

Diabetes is a relentless, challenging and progressive condition. People with diabetes must cope with the constant demands of self-management and the threat of serious complications. Not surprisingly, the impact on emotional and psychological wellbeing can be profound.

People with diabetes commonly experience emotional or psychological problems, such as depression, emotional distress and eating disorders. Depression is twice as common in people with diabetes as in the general population, and around 40 per cent of people with diabetes experience poor psychological wellbeing, often directly related to the demands of living with diabetes²⁶.

Depression among people with diabetes reduces their ability and motivation to self-manage, leading to poorer quality of life and a greater likelihood of complications and early death. It also drives up NHS costs. **Physical healthcare costs are 50 per cent higher for people with Type 2 diabetes with poor mental health than those without mental health problems – costing the NHS an extra £1.8 billion every year²⁷.**

Access to integrated psychological support for people with diabetes can reduce psychological distress, improve outcomes and reduce healthcare costs²⁵.

Yet less than a quarter of people with diabetes have access to appropriate emotional and psychological support²⁸. All too often physical and mental health services are fragmented and fail to address people's mental health needs in the context of their diabetes management (and vice versa).

The psychological and emotional wellbeing of people with diabetes of all ages must be integral to diabetes care and delivered through good care planning and referral to specialist psychological services when required.

What needs to happen now?

- **NHS England** should drive system-wide integration of physical and mental health and increase access to evidence-based psychological therapies.
- **Health Education England** should develop and deliver a comprehensive workforce strategy to ensure that the right staff with the right skills are available to meet the emotional and psychological needs of people living with diabetes.
- **Commissioners and service providers** should work together to ensure emotional and psychological support for people with diabetes is embedded in each step of the diabetes care pathway – including through care planning, peer support and timely access to Improving Access to Psychological Therapies (IAPT) with specific diabetes care pathways.
- **Commissioners and service providers** should ensure that healthcare professionals working in diabetes, in primary and specialist care, have access to psychological expertise – both for referral and to provide support and training for the diabetes team.
- **Healthcare professionals** need to consider emotional and psychological support part of the remit of the whole diabetes team and ensure they have adequate training to identify psychological problems in people with diabetes. They should deliver proactive support as part of ongoing care, including through the care planning process and linking to peer support.

9 Diabetes self-management education

Diabetes education supports people to take control of their health, but only a small minority access courses

People with diabetes only spend around three hours with a healthcare professional every year. For the remaining 8,757 hours they must manage this complex condition themselves²⁹. Diabetes education equips people with the knowledge and skills they need to manage their condition well. As a result, diabetes self-management education improves health outcomes reduces the onset of devastating complications and is cost effective or even cost saving³⁰.

Structured education courses for people with Type 1 and Type 2 diabetes are recommended by NICE³¹. **Yet in 2014–2015, only 2 per cent of people newly diagnosed with Type 1 diabetes and 6 per cent of people newly diagnosed with Type 2 diabetes were recorded as attending structured education³.** While there may be some under-recording of data, local intelligence suggests that attendance remains far too low.

This is despite a large increase in the number of people recorded as being offered a course, following the inclusion of diabetes education in the GP incentive scheme (Quality and Outcomes Framework). In 2014–2015, 76 per cent of people newly diagnosed with diabetes were offered structured education, up from 16 per cent in 2012–2013³. Worryingly, only a third of people newly diagnosed with Type 1 diabetes were recorded as being offered education, compared with 79 per cent of people newly diagnosed with Type 2.

OVER TWO THIRDS OF PEOPLE DON'T FULLY UNDERSTAND THEIR DIABETES³³



Low uptake of diabetes education suggests that courses are not being commissioned or marketed well in many areas. While referral rates have increased, some referrals may be a tick box exercise with little explanation of the benefits of attending. For some, the venues and times make it difficult to attend. For others, the waiting list is too long or the term 'structured education' is off-putting.

Data obtained by Diabetes UK under the Freedom of Information Act shows that many CCGs are not commissioning diabetes education effectively. In 2015, **over a quarter of CCGs told us that they do not commission education courses for adults with Type 1 diabetes. Moreover, over half of CCGs did not know how many people are going on some or all of their courses³²,** indicating a lack of basic monitoring to drive improvement.

Yet experience from areas that have achieved a step change in diabetes education suggests that simple measures can improve uptake, such as:

- improving the quality of the referral, by engaging and informing healthcare professionals about the benefits of diabetes education
- holding courses at a range of times and venues
- marketing courses effectively and allowing people to self-refer
- offering tailored courses to meet local needs
- using an electronic referral form and appointing a dedicated administrator
- offering a menu of education options – so that people who can't or won't attend structured education courses have other ways to learn (with structured education still promoted on an ongoing basis).

The Department of Health has estimated that the DAFNE structured education course for people with Type 1 diabetes could **save the NHS £48 million per year nationally, or £93,133 per 100,000 of the population, if it is made available to everyone in the UK with Type 1 diabetes**³⁴

“ Going on the course took the worry away. It reduced my HbA1C. It reduced my cholesterol. I lost three stone in weight. My blood pressure came down and is perfectly normal for my age. Now I understand the condition. ”

Malcolm, living with Type 2 diabetes

What needs to happen now?

National decision makers should work with local areas to drive delivery of these calls to action in order to achieve a radical improvement in diabetes education and self-management.

Healthcare professionals should:

- promote the benefits of diabetes education courses to their patients
- find out what courses are available locally, be familiar with referral pathways and consider attending a taster session.

CCGs should:

- put plans in place to ensure that all people with diabetes have the skills and confidence to manage their condition by 2020
- commission or provide a menu of education options for people with diabetes, including:
 - accessible structured education courses, meeting NICE criteria, for all adults with Type 1 and Type 2 diabetes
 - other learning options appropriate for the local population.
- ensure that at least half of all people newly diagnosed with diabetes attend a structured education course within a year
- reach those who may have missed out in the past – so that at least half of people with diabetes receive structured education over the next five years.

10 Access to diabetes specialists

Better access to specialist care can improve patient outcomes and save the NHS money

Everyone with diabetes needs access to a range of healthcare professionals to help them manage their condition and treat complications. People need access to physicians, nurses, podiatrists, dietitians and clinical psychologists with specialist knowledge of diabetes.

These specialist skills should be available as part of an integrated model of care across primary, community and specialist services so people with diabetes get the specialist diabetes support and treatment they need in the right place, and at the right time, in a coordinated manner. Local care pathways and models for ensuring access to appropriately skilled professionals will vary from area to area, but the increasing focus on 24 hours, 7 days a week care means that all localities will need to review staffing and skill mix.

Access to specialist diabetes teams in hospital

It is most important to ensure that any service reconfiguration does not restrict timely access for people with diabetes to specialist skills when they need this. In inpatient settings, this will include people who are admitted with diabetes complications, those who develop complications whilst in hospital and people being newly diagnosed with diabetes in hospital. Studies have shown that access to specialist diabetes teams reduces the average length of an inpatient stay by three days³⁵.

Most people with Type 1 diabetes need input from the specialist team whilst in hospital whatever the reason for their admission. The latest diabetes inpatient audit found that whilst 57 per cent of diabetes consultants' working time was spent on the care of people with diabetes, with nearly a third of their time being spent on outpatients, only 12 per cent of consultants' total working time was spent on inpatient care for people with diabetes¹⁸. The number of inpatients requiring referral to the specialist diabetes team has increased, but only two thirds (68 per cent) of these were seen by a member of the team. Whilst levels of referrals have increased, there has been no significant increase in staffing levels in diabetes teams¹⁸.

The audit found that nearly one in ten (9 per cent) of hospital sites did not have any consultant time for diabetes inpatient care and almost one third (31 per cent) of sites have no diabetes inpatient specialist nurse (DISN) available. Nearly three quarters (71 per cent) of sites have no specialist inpatient dietetic staff time for people with diabetes and over a quarter (26 per cent) of sites have no specialist inpatient podiatrist¹⁸.

Access to specialists in the community

In community and outpatient settings, access to specialists will be required in diabetes clinics and multidisciplinary diabetes foot clinics as part of the foot protection service. Anecdotal evidence suggests that diabetologists have been called away from outpatient clinics to undertake general inpatient care.

Access to specialists for people with Type 1 Diabetes

The needs of adults with Type 1 diabetes differ from those with Type 2. People with Type 1 diabetes are fully dependent on insulin and are usually diagnosed at a younger age. They are at increased risk of developing complications, due to their longer exposure to the condition, and they have a greater need for specialist input because there can be serious consequences if things go wrong. A multidisciplinary specialist diabetes team should, therefore, coordinate support for adults with Type 1 diabetes.

The role of diabetes specialists in supporting other healthcare professionals

Everyone with diabetes benefits from the key role specialist diabetes team have in supporting and skilling up local healthcare professionals, including primary care teams. This includes specialist advice and training from the specialist team to support management of complications, the introduction and use of new treatments and the delivery of quality foot risk assessments and other care processes.

Diabetes specialist nurses

Diabetes specialist nurses (DSNs) are integral to achieving good, cost effective, 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 stay³⁶. Despite this, and the fact that the prevalence of diabetes is increasing, DSN numbers are stagnating, posts are being frozen and downgraded and skill levels are still under threat.

In a recent survey of 425 DSNs³⁷, three in ten (32 per cent) nurses due to retire within five years said that when they retired they thought their post would be downgraded. Over a quarter (28 per cent of respondents) reported that DSN posts had recently been cut in their hospital or team, and nearly a third (31 per cent) said that posts had been left unfilled. As a result, the majority of respondents (77 per cent) said that they had concerns about patient care and/or safety. Perhaps unsurprisingly, almost a fifth of DSNs said they are planning to leave the profession in the foreseeable future.

“ I am unable to provide the intensive support to patients that I would like. With more people being diagnosed with diabetes and more complex medication choices available, I feel that our service should not have to be affected by budget cuts. ”

Diabetes Specialist Nurse

What needs to happen now?

- **Commissioners and providers across primary, community and specialist care** should work together to design and commission integrated models of care with pathways to ensure people with diabetes can access the specialist support they need. This will include assessing local need, reviewing local workforce capacity and competency and defining and agreeing the local model of care and pathways.
- **Commissioners and providers** should ensure all hospitals employ specialist diabetes staff, including nurses, dietitians, podiatrists and clinical psychologists working in multidisciplinary teams led by diabetologists.
- **Commissioners and providers** should ensure the key enablers of integrated diabetes care are in place: integrated IT, aligned finances and responsibility, collaborative care planning, clinical engagement and clinical governance.
- **Commissioners and providers** should ensure people living with diabetes have access to appropriately skilled and qualified diabetes specialist nurses in all care settings; minimum staffing levels should be at least five DSNs per 250,000 population and at least one diabetes inpatient specialist nurse per 300 beds³⁸.
- **Health Education England** should work with stakeholders to support a national nursing career framework and clear postgraduate pathways to ensure registered nurses have the skills necessary to support people with diabetes.

11 Flu vaccinations

People with diabetes are at greater risk of severe illness, such as pneumonia, if they get flu. They should be given a flu vaccination every year from their GP and a personal care plan advising them of steps to take if they are ill.

Influenza is a highly contagious viral infection, and people with diabetes are more at risk of the complications that arise from it. The greatest risk is a severe loss of diabetes control, resulting in coma from either diabetic ketoacidosis or hyperosmolar hyperglycaemic state, both of which can be fatal if left untreated. Pneumococcal pneumonia is another potentially fatal consequence of flu infection in people with diabetes.

Vaccinations against infectious diseases are amongst the safest and most reliable means of health protection available. Yet in 2015 one in five people with diabetes did not receive their annual flu vaccination, putting them at risk of severe illness or even death³⁹.



People with diabetes are more at risk of complications from influenza and pneumonia, but one in five do not receive annual vaccinations

What needs to happen now?

- **All people with diabetes**, over the age of six months, including those who are pregnant, should be offered a free vaccination by their GP against influenza each year regardless of age or type of diabetes management.
- **All people with diabetes**, if treated with medication and over two years old, should be offered a free vaccination to protect against pneumococcal pneumonia by their GP each year.
- **All people with diabetes** should be provided with a personal care plan telling them to make sure they get their vaccinations and what steps to take if they catch the flu.

12 Inpatient care

People with diabetes who are admitted to hospital should receive high-quality diabetes care from healthcare professionals who are appropriately trained to care for people with diabetes, and they should have access to a specialist team if required.

People with diabetes are twice as likely to be admitted to hospital compared to people without diabetes⁴⁰. In the general population about one in 16 people has diabetes⁴¹, but when it comes to hospital inpatients, one in six people (17 per cent) occupying hospital beds has diabetes¹⁸. In some sites this is nearing 40 per cent (one in three inpatients)¹⁸. This increase reflects the ageing population and the increasing prevalence of diabetes in the community and demonstrates the need for adequate levels of diabetes staff in hospitals.

It 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. In the 2015 National Diabetes Inpatient Audit (NaDIA), only two in three (65 per cent) people with diabetes thought that all the staff looking after them knew enough about diabetes¹⁸.

Diabetes-related harm in hospital

An unacceptable number of inpatients suffer diabetes complications whilst in hospital. In 2015 the inpatient audit¹⁸ showed that:

- 38 per cent of inpatient drug charts had at least one diabetes medication error, 22 per cent had at least one prescription error and 24 per cent had at least one medication management error – all either worse or not improved from 2013
- 20 per cent of inpatients had one or more minor hypoglycaemic episodes, and ten per cent had at least one severe hypoglycaemic episode – a significant deterioration since 2013. In addition, 23 per cent of inpatients experienced insulin errors.

One in six people in hospital have diabetes, but one in three hospitals has no diabetes specialist nurse and an unacceptable number of inpatients experience diabetes-related harm whilst in hospital

Access to a diabetes specialist team

Only two thirds (68 per cent) of inpatients requiring referrals to the specialist diabetes team were seen by a member of the team¹⁸. Whilst most hospitals reported that levels of referrals and patient contacts have increased, there has been no corresponding significant increase in staffing levels in diabetes teams².

The audit¹⁸ also found that nearly one in ten (9 per cent) hospital sites did not have any consultant time for diabetes inpatient care. Almost one third (31 per cent) of sites have no diabetes inpatient specialist nurse available, with no increase from the numbers in 2010. Nearly three quarters (71 per cent) of sites had no specialist inpatient dietetic staff time for people with diabetes and over a quarter (26 per cent) of sites have no specialist inpatient podiatrist. The latter is an improvement on previous years, but still needs to improve considerably as a substantial proportion (9 per cent) of inpatients with diabetes are admitted with active diabetic foot disease which is the most common reason for someone to have a diabetes-related admission¹⁸.

Almost one third of hospital sites do not have a multi-disciplinary footcare team (31 per cent), and four out of ten inpatients admitted with active foot disease were not seen by a member of the multi-disciplinary diabetic footcare team within the first 24 hours of their hospital stay¹⁸.

Patient experience of hospital care

Less than 60 per cent of inpatients with diabetes who responded to the patient experience questionnaire said they were able to take control of their diabetes care whilst they were in hospital and 14 per cent of inpatients stated that they were not able to test their own blood glucose levels but would have liked to¹⁸. Nine per cent of inpatients taking insulin for their diabetes reported that they were not permitted to self-administer insulin while in hospital, but would have liked to do so¹⁸.

Overall inpatient satisfaction has reduced since the previous audit, with 34 per cent of patients reporting the hospital sometimes, rarely or never provided the right choice of food to manage their diabetes¹⁸.

“ I had a spell in hospital and the timing of my medication was altered. As a result I had two really nasty hypos. I have complete understanding of my diabetes needs but they wouldn't listen. ”

“ I had a fall and broke my hip which was replaced in hospital. The surgery went well but the diabetic care during my stay was very poor. ”

From Diabetes UK panel survey²²

What needs to happen now?

Commissioners should:

- ensure through their contracts that all healthcare professionals working in hospitals are competent in diabetes care.
- ensure that hospitals have a specialist multidisciplinary footcare team that is compliant with NICE guidelines on diabetes footcare.

Hospitals should:

- have a diabetes inpatient specialist team to respond to referrals and provide support and training to generalist staff. Staffing levels should be reviewed by providers to ensure that people with diabetes can access specialist diabetes care when and where needed as seven day working is rolled out.
- monitor and review patient safety standards to implement improvements working across all parts of the hospital. This should include recording cases of diabetes-related severe harms on the corporate risk register and sharing evidence of any systems that have successfully reduced the incidence of these.
- ensure that everyone with diabetes receives foot checks, foot protection and access to specialist footcare if required during admission and on discharge from hospital.
- ensure that their nutrition policies meet the needs of the one in six of their patients who has diabetes.
- ensure that people with diabetes are enabled and supported to self-manage their diabetes where appropriate while in hospital.

13 Sexual problems

People with diabetes should have the opportunity to talk about any sexual problems they might be experiencing

Diabetes increases the risk of sexual dysfunction in both men and women and can be caused by physical, emotional and lifestyle factors, or by medication. Sexual dysfunction is more common in men and women with diabetes because poorly controlled diabetes can damage the blood vessels and the nervous system, causing reduced blood flow and loss of sensation in sexual organs⁴².

Erectile dysfunction (ED) is the most common type of sexual problem in men with diabetes. Women with diabetes are also at increased risk of experiencing sexual difficulties and diabetes-related sexual problems such as vaginal dryness, low desire, fungal and bacterial infections. Treatments are available, but people often do not discuss the problem with their doctor and so do not have the opportunity to discuss treatment.

Sexual health problems have been shown to increase depression amongst men and women with diabetes⁴³, and sexual function is more closely linked with depression than any other diabetes complication in men and women⁴⁴.

Early detection of ED is vital to decrease a man's risk of future cardiovascular events and help stop the progression of ED. Currently only 15 to 20 per cent of men are asked about ED⁴⁵. Testosterone deficiency can affect up to 50 per cent of men with Type 2 diabetes, and there is a strong association between low testosterone and mortality and morbidity. National guidelines recommend mandatory testing of testosterone levels in all men with ED⁴⁶.

Some medication used in the treatment of diabetes and associated conditions can cause ED as a side effect. Healthcare professionals should explore if it is possible to change or modify medications to treatment that is less likely to impact on ED.

NICE recommends that men with diabetes are given the opportunity to discuss erectile dysfunction as part of their regular review⁴⁷

What needs to happen now?

- **Everyone with diabetes** should be given the opportunity to talk about any sexual problems they may be experiencing. They should be assessed and given support and education and referred to an appropriate service if necessary.
- **Men with diabetes** should be informed of their risk of developing ED and supported by their healthcare team to make lifestyle choices to help prevent the development of ED.
- **GPs and other healthcare professionals** should be mindful that early detection of ED is an opportunity to reduce the risk of future cardiovascular events and halt the progression of ED.
- **GPs and other healthcare professionals** need to be skilled in delivering effective consultations, including talking about sexual problems related to diabetes.
- **Audit mechanisms** (such as QOF) should be used to ensure that people are being given the opportunity to discuss sexual problems.

14 Smoking

Stopping smoking is one of the best things a person with diabetes can do to improve their health – they should be given the support and advice they need to help them quit

Diabetes increases the risk of heart disease and stroke, and smoking further increases this risk. People with diabetes can halve their risk of suffering the complications of diabetes if they stop smoking⁴⁸. People with diabetes should have their smoking status recorded.

The proportion of people with diabetes who had their smoking status recorded in 2014–2015 drifted down by a couple of percentage points for both Type 1 and Type 2 and other diabetes³. (For Type 1 it has fallen from 81 per cent in 2009–2010 to 78 per cent in 2014–2015. For Type 2 it has gone from 88 per cent in 2009–2010 to 85 per cent).

We do not know how many people with diabetes who smoke are then referred to stop smoking services, but we do know that smoking cessation budgets have been cut in four in ten councils, compared to only one in twenty councils that have increased them⁴⁹.

Progress is being made in reducing youth smoking, most recently through the very welcome transition to standardised packaging that began in May 2016⁵⁰. But there is an urgent need for more resources to encourage people to stop smoking. In addition, a tobacco industry levy could lead to major benefits for many people with diabetes by generating revenue to reverse cuts to stop smoking services.

What needs to happen now?

- **People with diabetes** should be asked whether or not they smoke and if they do, they should be referred to stop smoking services.
- **Diabetes UK** supports the Smokefree Action Coalition⁵¹ in its call for a levy on tobacco companies to pay for a £500 million fund to support tobacco control programmes⁵².

15 Pregnancy care

Pregnant women with diabetes are at increased risk of complications compared to women who do not have 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.

Up to 5 per cent of the 700,000 women who give birth each year have diabetes. This is either pre-existing diabetes or gestational diabetes, which develops in pregnancy⁵³. The incidence of both types of diabetes in pregnancy is growing due to higher rates of obesity in the general population and more pregnancies in older women⁵³.

Women with diabetes who are planning a pregnancy should be prescribed 5mg/day of folic acid from at least three months before conception. They should have an appointment with their joint diabetes and antenatal care team within a week of their pregnancy being confirmed. Pregnant women should be supported to self-monitor their blood glucose levels.

If women are diagnosed with gestational diabetes, they should be seen by members of the joint diabetes and antenatal care team within a week of diagnosis. After giving birth, they should have an annual blood glucose test.

In 2015, the second National Pregnancy in Diabetes Audit reported on data collected from 2,553 pregnancies in women with diabetes⁵⁴. Nearly half of the women had Type 2 diabetes.

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

- only 15 per cent of women with Type 1 diabetes and 36 per cent of women with Type 2 diabetes achieved the target blood glucose levels
- Over one in ten (12 per cent) of women with Type 1 diabetes and 8 per cent with Type 2 had blood glucose measurements at levels which NICE guidelines strongly advise that a pregnancy is avoided.

Some of the medicines used to treat diabetes must not be taken during pregnancy. Despite this, 9 per cent of the women with Type 2 diabetes who became pregnant were taking such medication at the time.

First contact with a specialist antenatal diabetes team should happen as early as possible. While 52 per cent of women with Type 1 diabetes had their first contact with this team prior to eight weeks gestation, only 37 per cent of women with Type 2 diabetes had their first contact with the team in this timeframe.

Other points of concern include the fact that rates of stillbirths and neonatal deaths remain high, and that a third of babies born to women with diabetes required intensive or specialist neonatal care.

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
- considering the impact on services of women who develop diabetes during pregnancy and need more intense support.

Children and young people

Around one in four children and young people with diabetes reach the NICE target for blood glucose levels⁵⁵. A similar number receive all of the recommended health checks⁵⁵. However, these figures have shown considerable progress in the last few years.

Diagnosis

Around 96 per cent of the 27,682 children and young people in England and Wales with diabetes have Type 1⁵³. 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: 16 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 death⁵⁶. It is crucial, therefore, that the signs and symptoms of Type 1 diabetes are identified quickly.

**TYPE 1
DIABETES:**

Make the grade



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 should receive seven key processes of care every year⁵⁷.

Increasing numbers of young people aged between 12 and 24 are receiving all seven care processes. The percentage of young people having all of these important checks has risen from 16 per cent in 2013–2014 to 25 per cent in 2014–2015⁵³. However, substantial variation persists between Paediatric Diabetes Units, with the proportion of young people aged between 12 and 24 receiving all care processes ranging from 0 per cent to over 90 per cent⁵⁵.

There is still a long way to go before the overall completion rate matches that for adults with Type 1 diabetes, which is still relatively low. Improvements are also needed for many of the individual care processes: indeed, completion rates for eye, feet, kidney and cholesterol testing are all between 52 and 65 per cent⁵³.

Moreover, it is imperative that steps are taken to reduce the high numbers of children and young people with unacceptably high HbA1c levels and the variation in care experienced by children in different parts of the country.

This means continuing to invest in the approach that has started to make improvement: a national tariff that only pays for good quality care; 100 per cent participation in clinical audit and a nation-wide programme of peer review for quality improvement.

Supporting children with diabetes at school

It has been a legal requirement for schools to provide support to children with Type 1 diabetes since September 2014⁵⁸. Schools are required to have a medical conditions policy for the school and an individual healthcare plan for each child with Type 1 diabetes. The policy and plan should ensure that children with Type 1 diabetes are able to participate in all school activities.

Providing children with the support they need to participate in all aspects of school life requires a coordinated effort. CCGs need to ensure there is guidance from clinicians about preparing a healthcare plan. Ofsted needs to use its regulatory tools to enforce this legal duty and ensure that schools abide by it. The Department for Education needs to raise awareness amongst schools of their legal duties, and academy chains should take reasonable steps to ensure that their schools are compliant.

Effective transition to adult services

Around a quarter of admissions for DKA are in the 15 to 24 age group⁵⁶. 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.

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. Transition involves a well coordinated, multidisciplinary approach, including adult and paediatric teams⁵⁹. It should not occur until a young person has sufficient understanding about managing their condition to get the most out of adult diabetes services. If this does not happen, there is a risk that they will disengage from these services, leading to poor diabetes control and long-term complications.

What needs to happen now?

- **GPs, schools and parents** need to be aware of the symptoms of Type 1 diabetes.
- **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.
- **Paediatric Diabetes Units** should make effective use of networking and peer review programmes, as it has been demonstrated that these aid improvement.
- **The Department for Education** needs to ensure all schools are aware of their new legal duties on supporting children with diabetes in schools and what these mean in practice. The Department should encourage Ofsted to incorporate into their inspection regime the need for schools to be compliant with the new duties.
- **CCGs** should use the new NHS England transition service specification to ensure that they are commissioning an effective transition process.
- **Adult and paediatric diabetes teams** should work together to develop a smooth and effective transition process for all young people with diabetes.

Preventing Type 2 diabetes

Whilst Type 1 diabetes cannot be prevented, a significant proportion of Type 2 diabetes can be prevented and the increase in diabetes prevalence we are seeing is largely due to the rise in Type 2 diabetes.

Obesity is the most significant risk factor for developing Type 2 diabetes, accounting for 80–85 per cent of the overall risk of developing the condition⁶⁰. A large waist circumference is also a key risk factor. This is of particular concern as almost two in every three adults in the UK are either overweight or obese⁶¹, placing them at increased risk of developing the condition – 11.9 million people in UK are at increased risk due to having an increased waist size or because they are overweight or obese⁶². It is estimated that five million people in England already have non-diabetic hyperglycaemia (higher than normal blood glucose levels), putting them at high risk of Type 2 diabetes⁶³.

**NEARLY
TWO
IN EVERY
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IN THE UK ARE
OVERWEIGHT
OR OBESE**

Diabetes UK, in partnership with NHS England and Public Health England, have developed the Healthier You: NHS Diabetes Prevention Programme

Increasing individuals' awareness and understanding of their risk of developing Type 2 diabetes

Public awareness and understanding of the seriousness of Type 2 diabetes remains low. Giving people an understanding of their risk is an important first step to taking action on modifiable risk factors, and identifying people currently at high risk of Type 2 diabetes is important in order to give them access to support to lower their risk.

The NHS Health Check Programme commissioned by local authorities and delivered in partnership with CCGs is a key way of identifying people who are at high risk of developing Type 2 diabetes. While many Local Authorities are successfully meeting the Public Health England target to offer the NHS Health Check to 20 per cent of the eligible population each year, the uptake is far below the goal of 75 per cent⁶⁴. In fact, currently only 49 per cent of people that were offered an NHS Health Check go on to receive one. Variation in both offer and uptake is very wide across local authorities⁶⁴ and there is much good practice to be shared⁶⁵.

Supporting people to act on their risk through access to interventions for people at high risk

Diabetes UK, in partnership with NHS England and Public Health England, have developed the Healthier You: NHS Diabetes Prevention Programme (NHS DPP) to deliver an evidence-based behavioural intervention, at scale, to help people with non-diabetic hyperglycaemia reduce their risk. Evidence has shown that programmes like the NHS DPP significantly lower risk and are shown to prevent or delay the onset of Type 2 diabetes, which is cost effective in terms of reducing numbers developing Type 2 and subsequently complications⁶⁶. In 2016–2017, 20,000 people are due to go through the programme, rising to 100,000 by 2019/2020.

Population-level change that will help people reduce their risk of developing Type 2 diabetes

Many people are working hard to improve their health, but we know that making healthy choices is not always easy. That is why we want to see supportive environments, regardless of where we live, work and socialise, where people can lead healthy lives without difficulty.

Diabetes UK is calling for a coordinated plan to tackle obesity in the general population. This will require action across a number of areas, including efforts by individuals, government, the food and drinks industry, employers and the voluntary sector. We are working in partnership with the Obesity Health Alliance to call for action to reduce obesity. In particular, Diabetes UK is calling for action across the whole population, including the use of legislation where necessary, to:

- make products healthier by reducing levels of saturated fat, sugar and salt (reformulation)
- encourage healthy choices in the retail environment (through labelling and pricing)
- strengthen marketing restrictions on junk foods to children
- increase physical activity levels
- improve the food provided in the public sector.

What needs to happen now?

- **CCGs and local authorities** should ensure they are identifying people at high risk of Type 2 diabetes through NHS Health Checks, Diabetes UK Know Your Risk tool, practice registers and community outreach focusing on people most at risk, for instance people from BAME backgrounds.
- **GPs** should keep registers of people identified as high risk (with non-diabetic hyperglycaemia).
- **NHS England** should ensure that the NHS DPP is fully rolled out as set out in the Department of Health Mandate to NHS England.
- **The Government** should implement a robust strategy to tackle obesity in society.

References

- 1 Public Health England (2015). *NHS Diabetes Prevention Programme (NHS DPP) Non-diabetic hyperglycaemia*. Produced by: National Cardiovascular Intelligence Network (NCVIN)
- 2 Hex, N et al (2012). Estimating the current and future costs of Type 1 and Type 2 diabetes in the United Kingdom, including direct health costs and indirect societal and productivity costs. *Diabetic Medicine*. 29 (7); 855–862
- 3 Health and Social Care Information Centre (2016). *National Diabetes Audit – 2014–2015: Report 1, Care Processes and Treatment Targets*
- 4 Health and Social Care Information Centre (2014). *National Diabetes Audit – 2012–13: Report 1, Care Processes and Treatment Targets*
- 5 National Institute for Health and Care Excellence (NICE) (2008). *Continuous subcutaneous insulin infusion for the treatment of diabetes mellitus*. <https://www.nice.org.uk/guidance/ta151?unlid=4242176082015112322750>
- 6 Health and Social Care Information Centre (2016). *National Diabetes Insulin Pump Audit Report, 2013–2015*
- 7 National Institute for Health and Care Excellence (NICE) (2015). *Type 1 diabetes in adults: diagnosis and management*. <https://www.nice.org.uk/guidance/ng17?unlid=711968536201631133540>
- 8 Diabetes UK Test Strips Survey (2016). Publication forthcoming
- 9 Emerging Risk Factors Collaboration (2010). Diabetes mellitus, fasting blood glucose concentration, and risk of vascular disease: a collaborative meta-analysis of 102 prospective studies. *Lancet* 375 (9733); 2215–2222
- 10 Morrish NJ, Wang SL, Stevens LK, et al (2001). Mortality and causes of death in the WHO multinational study of vascular disease in diabetes. *Diabetologia* 44 (2); 14–21
- 11 Royal National Institute of Blind People. *Understanding eye conditions related to diabetes*. <http://www.rnib.org.uk/eye-health-eye-conditions-z-eye-conditions/understanding-eye-conditions-related-diabetes>
- 12 Leamon, S. (2014). *Number of adults and children certified with sight impairment and severe sight impairment in England and Wales: April 2011–March 2012*. RNIB and Moorfields Hospital NHS Foundation Trust; Liew, G et al. (2014) *A comparison of the causes of blindness certifications in England and Wales in working age adults (16–64 years), 1999–2000 with 2009–2010*. *BMJ Open* 2014;4:e004015 doi:10.1136/bmjopen-2013-004015
- 13 Public Health England (2016). *NHS Diabetic Eye Screening Programme: Information for health professionals*
- 14 Public Health England (2016). *NHS screening programmes: KPI reports 2014–2015*
- 15 Royal National Institute of Blind People (2012). *Preventing Avoidable Sight Loss – A Public Health Challenge*
- 16 Marion Kerr (2012). *Footcare for people with diabetes: the economic case for change*. <https://www.diabetes.org.uk/Documents/nhs-diabetes/footcare/footcare-for-people-with-diabetes.pdf>
- 17 National Institute for Health and Care Excellence (NICE) (2015). *NG19: Diabetic foot problems: prevention and management*. <https://www.nice.org.uk/guidance/ng19?unlid=283062410201621619507>
- 18 Health and Social Care Information Centre (June 2016). *National Diabetes Inpatient Audit 2015 – National Report*
- 19 Singh, N et al (2005). *Preventing foot ulcers in patients with diabetes*. *Journal of the American Medical Association* January 12 (293); 217–28
- 20 Health and Social Care Information Centre (2016). *National Diabetes Foot Care Audit Report 2014–2015 England and Wales*
- 21 Diabetes UK (2015). *15 Health Care Essentials survey*. Information on request
- 22 Diabetes UK (2016). *Spring Panel*. Base=686, fieldwork conducted April–June 2016. Information on request
- 23 Diabetes UK (2015). *Kidney Checks Survey*. Information on request
- 24 National Institute for Health and Care Excellence (NICE) (2011). *Quality Standard: Diabetes in Adults*. <https://www.nice.org.uk/guidance/qs6>
- 25 NHS England (2014). *Joined up clinical pathways for obesity: Report of the working group*. <https://www.england.nhs.uk/wp-content/uploads/2014/03/owg-join-clinc-path.pdf>

- 26** Diabetes UK & NHS Diabetes (2010). *Emotional and Psychological Support and Care in Diabetes*. https://www.diabetes.org.uk/About_us/What-we-say/Diagnosis-ongoing-management-monitoring/Emotional-and-Psychological-Support-and-Care-in-Diabetes/
- 27** Mental Health Taskforce (2016). *The Five Year Forward View for Mental Health: A report from the independent Mental Health Taskforce to the NHS in England*
- 28** Diabetes UK (2008). *Minding the gap. The provision of psychological support and care for people with diabetes in the UK*. Diabetes UK (2015). *15 Healthcare Essentials online survey*. Baseline: 3000 responses
- 29** Department of Health (2007). *Working together for better diabetes care. Clinical case for change: Report by Sue Roberts, National Director for Diabetes*
- 30** The evidence base is summarised in: Diabetes UK (2015), *Diabetes education: the big missed opportunity in diabetes care*
- 31** National Institute for Health and Care Excellence (NICE) (2015). NG17: *Type 1 diabetes in adults: diagnosis and management*; National Institute for Health and Care Excellence (NICE) (2015). NG28: *Type 2 diabetes in adults: management*; NICE (2015). NG18: *Diabetes (Type 1 and Type 2) in children and young people: diagnosis and management*
- 32** FOI request submitted by Diabetes UK in June 2015. Responses were received between 17 June and 25 October 2015. 208 of 209 CCGs responded
- 33** Diabetes UK (2015). *Diabetes and Me survey 2015*
- 34** Department of Health (2009, updated 2013). *Quality and Productivity: Proven Case Study. Improving the quality of care for people with Type 1 diabetes: dose adjustment for normal eating (DAFNE)*
- 35** Kerr, M (2011). *Inpatient Care for People with Diabetes – the Economic Case for Change*
- 36** Courtenay M, Carey N, James J, et al (2007). An evaluation of a specialist nurse prescriber on diabetes inpatient service delivery. *Practical Diabetes International* 24 (2); 69–74
- 37** Diabetes UK (2016). *Specialist Nurses survey*. Publication forthcoming
- 38** Diabetes UK (2010). *Commissioning Specialist Diabetes Services for Adults with Diabetes: A Diabetes UK Task and Finish Group Report*
- 39** Health and Social Care Information Centre (2015). *Quality and Outcomes Framework (QOF) for April 2014–March 2015, England*
- 40** Sampson MJ, Doxio N, Ferguson B et al (2007). Total and excess bed occupancy by age, speciality and insulin use for nearly one million diabetes patients discharged from all English acute hospitals. *Diabetes Research and Clinical Practice* 77 (1); 92–98
- 41** *1 in 16 based on ONS population data for 2014 (64.6million) with total diabetes population of 4 million from QOF and AHPO modelling*
- 42** Feldman HA, Goldstein I, Hatzichristou DG, et al (1994). Impotence and its medical and psychosocial correlates: results of the Massachusetts Male Aging Study. *Journal of Urology* 151 (1); 54–61. Giugliano F, Maiorino M, Bellastella G, et al (2010). Determinants of erectile dysfunction in patients with Type 2 diabetes. *International Journal of Impotence Research* 22 (3); 204–209. Enzlin P, Rosen R, Wiegand M, et al (2009). Sexual dysfunction in women with Type 1 diabetes: long-term findings from the DCCT/ EDIC study cohort. *Diabetes Care* 32 (5); 780–785. Abu Ali RM, Al Hajeri RM, Khader YS et al (2008). Sexual dysfunction in Jordanian diabetic clinic women. *Diabetes Care* 31 (8); 1580–1581. Esposito K, Maiorino MI, Bellastella G et al (2010). Determinants of female sexual dysfunction in Type 2 diabetes. *International Journal of Impotence Research* 22 (3); 179–184
- 43** Roy T, Lloyd CE (2012). Epidemiology of depression and diabetes: a systematic review. *Journal of Affective Disorders* October (142); 8–21
- 44** de Groot M, Anderson R, Freedman KE et al (2001). The prevalence of co-morbid depression in adults with diabetes: a meta-analysis. *Diabetes Care* (724); 1069–1078
- 45** Hackett G, Cole N, Bhartia M et al (2014). The response to testosterone undecanoate in men with Type 2 diabetes is dependent on achieving threshold serum levels (the BLAST study). *International Journal of Clinical Practice* 68 (2); 203–215

- 46** British Society for Sexual Medicine (2013). *Guidelines on the management of erectile dysfunction*. http://www.bssm.org.uk/downloads/BSSM_ED_Management_Guidelines_2013.pdf
- 47** National Institute for Health and Care Excellence (NICE). *NG17 Type 1 diabetes in adults: diagnosis and management*. National Institute for Health and Care Excellence (NICE). CG28. *Type 2 diabetes in adults: management*
- 48** Diabetes UK. *Help with giving up smoking*. https://www.diabetes.org.uk/Guide-to-diabetes/Living_with_diabetes/Help-with-giving-up-smoking/ Accessed April 2016
- 49** Anderson, W & Cheeseman, H (2016). *A survey of tobacco control leads in local authorities in England: January 2016*. ASH and Cancer Research UK. <http://www.ash.org.uk/localtoolkit/docs/AnnualTCreport16.pdf>
- 50** Action on Smoking and Health (2016). *Media advisory: Standardised "plain" packaging starts 20th May 2016*. <http://www.ash.org.uk/media-room/press-releases/:media-advisory-standardised-plain-packaging-starts-20th-may-2016>
- 51** Smokefree Action Coalition. *About Smokefree Action Coalition*. <http://www.smokefreeaction.org.uk/about.html#members>
- 52** Cancer Research UK. *Big tobacco, cough up*. <https://www.cancerresearchuk.org/support-us/campaign-for-us/make-the-tobacco-industry-pay-help-us-save-stop-smoking-services?t=wmtjzv3e>
- 53** The National Institute for Health and Care Excellence (NICE) (2015). *Diabetes in pregnancy: management from preconception to the postnatal period*
- 54** Health and Social Care Information Centre (2015). *National Pregnancy in Diabetes Audit Report 2014*
- 55** Royal College of Paediatrics and Child Health (2016). *National Paediatric Diabetes Audit Report 2014–2015, Part 1: Care processes and outcomes*
- 56** Royal College of Paediatrics and Child Health (2014). *National Paediatric Diabetes Audit report 2011–2012, Part 2: Hospital admissions and complications*
- 57** These are seven of the nine annual checks that NICE recommends should be received by adults with diabetes. They are recommended from the age of 12. Only the HbA1c check is recommended in younger children
- 58** Children and Families Act (2014). Section 100, Supporting pupils at school with medical conditions. <http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted>
- 59** NHS England. *Children and young people's diabetes transition specification*. <https://www.england.nhs.uk/resources/resources-for-ccgs/out-frwrk/dom-2/cyp-diabetes/>
- 60** Hauner H. *Obesity and diabetes*, in Holt RIG, Cockram CS, Flyvbjerg A et al (ed.) *Textbook of diabetes* 4th edition. (Oxford: Wiley-Blackwell, 2010)
- 61** Institute for Health Metrics and Evaluation (IHME). *Prevalence of obesity and overweight by year among people 20 years and older*. https://docs.google.com/spreadsheets/d/1jfUSFvuyMnrD69W4H5DWJBS4PDfjsTK3Yv-_ouM4oQ/edit?pli=1#gid=2097889834
- 62** Based on the latest 2014 dataset for the UK population (Office for National Statistics. Population Estimates for UK, England and Wales, Scotland and Northern Ireland – Mid-2014): 25,183,266 adult men and 26,504,311 adult women are recorded. 22% of the men is 5,540,319 and 24% of the women is 6,361,035 – which is a total of 11,901,354
- 63** National Cardiovascular Intelligence Network (NCVIN) (2015). *NHS Diabetes Prevention Programme (NHS DPP) Non-diabetic hyperglycaemia*
- 64** NHS England. *NHS Health Check Data*. http://www.healthcheck.nhs.uk/commissioners_and_providers/data/
- 65** Diabetes UK. *NHS Health Checks and Diabetes*. <https://www.diabetes.org.uk/Professionals/Resources/shared-practice/Health-checks/>
- 66** Public Health England (2015). *A systematic review and meta-analysis assessing the effectiveness of pragmatic lifestyle interventions for the prevention of Type 2 diabetes mellitus in routine practice*. <https://www.gov.uk/government/publications/diabetes-prevention-programmes-evidence-review>

DiABETES UK

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*Calls may be recorded for quality and training purposes.
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