

**S** **T** **A** **I** **E**

**OF THE**

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**2013**

**ENGLAND**

**IN THE BEST AREA  
FOUR TIMES  
MORE PEOPLE  
GET THE CHECKS  
THEY NEED THAN  
IN THE WORST**

**DiABETES UK**  
CARE. CONNECT. CAMPAIGN.

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## FOREWORD



Last year our State of the Nation report highlighted a major health crisis. More and more people were living with or at risk of Type 1 and Type 2 diabetes. Growing numbers of them were experiencing devastating complications, but the NHS still struggled to deliver the care and education people with diabetes need to manage their condition.

This year's report shows precious little improvement to that bleak picture – indeed, in some areas things have got worse. Diabetes continues to be a major challenge for the NHS. It is still a huge drain on resources, quality of care still depends on where you live, and the crisis is still not being taken seriously. The key problems we highlighted last year remain, and these will only worsen as the numbers involved increase.

Almost a quarter of a million people were diagnosed with diabetes last year; couple these with our estimates for undiagnosed diabetes and that means a massive 7.4 per cent of England's population live with the condition.

And yet there is still no specific health service focus on diabetes, no national plan to improve the quality of its care, to tackle rising incidence or stem the increase in complications. The quality of diabetes care across the country is patchy and risks exacerbating the already unacceptable 'postcode lottery' in standards of prevention and care.

Take the standards for diabetes care recommended by NICE. People who live in the best performing Clinical Commissioning Group (CCG) area are four times more likely to be given eight of the vital health checks recommended by NICE as compared to people living in the worst performing area. This geographical variation has a direct effect on clinical outcomes for people with diabetes.

Education, care planning and support for self management are vital to improving people with diabetes' day-to-day control of their condition and give them the best chance of living long and healthy lives. But our report shows that only 4.2 per cent of all people with diabetes are being offered education.

Almost uniquely in the NHS, the challenge is not funding. Diabetes care already takes up 10 per cent of NHS spending – much of it on treating complications. Clearly, this money would be better spent on delivering higher quality standards of care to help prevent complications in the first place.

We know what needs to happen:

- more focus on ensuring people know about diabetes and its serious consequences
- more effective programmes of risk assessment and early diagnosis
- provision and promotion of effective self-management support for people living with diabetes
- delivery of better care meeting NICE recommended essential standards

- integrated care planned around the needs of the individual and underpinned by multi disciplinary local diabetes networks to co-ordinate timely access to specialist care
- effective promotion of lifestyle change for those at risk of developing the condition.

A wealth of data is available through national diabetes audits, but we lack meaningful information about the quality of diabetes care provided by general practice. It is vital that the new NHS structures obtain and use such data to provide effective diabetes care everywhere.

We recognise and welcome that there are some improvements. Blood pressure outcomes have improved. Furthermore there have been real changes in the focus placed on foot care services, with the total number of foot checks increasing both in primary care and in hospital. Furthermore more hospitals report access to Multidisciplinary specialist foot care teams. This is really good news.

Responsibility for tackling this crisis lies with CCGs, but Government and NHS England must also play their part in making this happen. Not to do so will lead to heartache for over 3 million families, increased ill health and premature death for people with diabetes. It will also ratchet up the pressure on general practice, on acute services, and the costs that already threaten health care for all of us.

Our State of the Nation report gives clear evidence that some areas are performing better than others, and that in many CCG patches there is considerable room for improvement. Some areas can and do deliver diabetes care well. Others can too.

**Barbara Young**  
**Chief Executive**

A handwritten signature in black ink that reads "Barbara Young". The signature is written in a cursive, flowing style.

# ACTIONS NEEDED TO TACKLE THE DIABETES CHALLENGE

## Secretary of State/NHS England

- An urgent review of the wide geographic variation in achievement of the NICE recommended care processes and outcome measures and an action plan to ensure the poorest performing CCG areas are brought up at least to the standard of the median.

## Local commissioners and their providers

Local standards of care and outcomes vary widely between CCGs. This demonstrates how there can be big improvements in the delivery of the NICE nationally agreed standards. Whereas in the best performing CCG area 78 per cent of people with diabetes receive all eight of the vital checks that are measured, in the worst CCG area only 19 per cent of people with diabetes receive them. The three most important measures for how somebody's diabetes is being managed are blood glucose, blood pressure and cholesterol. The range for performance on meeting all three outcome measures is from 28 per cent in the best to 17 per cent in the poorest performing CCG.

- Each CCG to review the performance of its services in achieving the NICE recommended care processes and outcome measures and put in place an action plan for improvement of performance so that people with diabetes get the care they should. In particular, those CCGs who are below the median performance to put measures in place to raise their performance to at least to that of the median.
- Radical improvement in the provision and uptake of structured education so people with diabetes are supported to self manage.

- Radical improvement in care planning to enable people with diabetes and healthcare professionals to identify needs and agree personal goals.
- CCGs to use the good national and local diabetes audit data available to develop effective commissioning plans that deliver integrated care and drive care improvement.
- Formalising local diabetes networks that involve commissioners, primary, community, and specialist care will help to underpin the delivery of 'Best Practice for Commissioning Diabetes Services: An integrated Care Framework'.
- Improved access to available treatments including insulin pumps for both adults and children with Type 1 diabetes.
- Improvement in the skills of staff in primary care in the management of diabetes and, in particular, ensuring primary care teams are aware of the symptoms of Type 1 diabetes and ensure the referral of people with Type 1 diabetes to specialist teams for their care.

## Local Authorities

- Full implementation of the mandated Health Check programme to increase levels of risk assessment, earlier identification of Type 2 diabetes and offering of effective risk reduction interventions for those identified as high risk.

# THE STATE OF THE NATION: DIABETES IS STILL ONE OF THE BIGGEST HEALTH CHALLENGES IN THE UK

## Diabetes is growing

Every three minutes someone in the UK learns that they have diabetes. Right now there are over 3 million people in England living with the condition – 2,703,044 diagnosed and an estimated 500,000 people who have Type 2 diabetes but do not know it<sup>1</sup>. Diagnosis of diabetes increased by 38 per cent between 2001 and 2013<sup>2</sup>. Ten per cent of people with diabetes have Type 1 and 90 per cent have Type 2<sup>3</sup>.

Another seven million people could be at high risk of developing Type 2 diabetes<sup>4</sup>, and the numbers are rising dramatically every year. If current trends continue, it is estimated that by 2025, five million people in the UK will have diabetes<sup>5</sup>. By 2030, it is predicted that in some local authority areas up to 14 per cent of people will have diabetes<sup>6</sup>.

## Diabetes is serious

Without careful, continued management of the condition, a person with diabetes faces a reduced life expectancy of five to 14 years for people with Type 1<sup>7</sup> and six for Type 2<sup>8</sup>. Each year over 20,000 more people die than would have been expected<sup>9</sup>.

People with diabetes also run a greater risk of developing one or more severe health complications, which can greatly impact on their independence, quality of life and economic contribution. Many of these complications are avoidable. With good risk assessment and early diagnosis, patient education, support and good ongoing care, they need not happen.

In the UK, diabetes is the leading cause of blindness in working age people<sup>10</sup> and a major contributor to kidney failure, amputations and cardiovascular disease, including heart attack and stroke<sup>11</sup>.

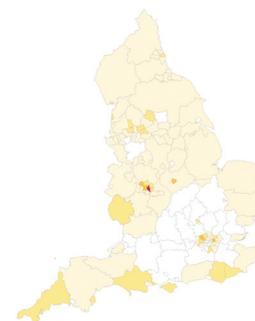
The incidence of children with diabetes being admitted with Diabetic Ketoacidosis – a potentially life-threatening complication that can lead to death if untreated – has almost doubled since 2005<sup>12</sup>.

## Increasing prevalence in England

Prevalence of diabetes expected to increase significantly

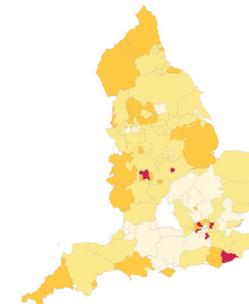
2010

Map 1: Diabetes Prevalence by PCT, 2010



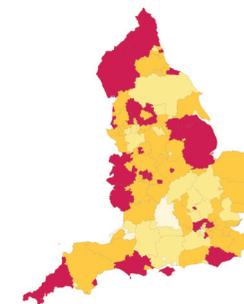
2020

Map 2: Diabetes Prevalence by PCT, 2020



2030

Map 3: Diabetes Prevalence by PCT, 2030



Produced by YPHO June 2010

Source: Office of National Statistics  
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Diabetes is responsible for over 100 amputations each week<sup>13</sup>, of which up to 80 per cent are preventable<sup>14</sup>.

Not only are the numbers of people with complications increasing as a result of the rise in people with diabetes but also the rate of complications is increasing as people live longer. The impact on the lives of people with diabetes and costs to the NHS are highly worrying.

### **Preventable complications caused by diabetes are much more expensive than good care**

UK NHS spending on diabetes was estimated at nearly £10 billion in 2010/11 – 10 per cent of the NHS budget. £1bn for Type 1 and £8.8bn for Type 2. Eighty per cent of NHS spending on diabetes goes into managing avoidable complications<sup>16</sup>. Better management of diabetes has great potential to cut costs and improve the care of people with diabetes.

**In the UK, between 2006 and 2011, there has been an increase in unnecessary complications<sup>15</sup>.**



**RETINOPATHY**



**STROKE**



**KIDNEY FAILURE**



**CARDIAC FAILURE**



**ANGINA**



**AMPUTATIONS**

# IDENTIFICATION AND PREVENTION

## Early identification – Type 1 Diabetes

Type 1 diabetes cannot be prevented. However, awareness of the signs and symptoms of Type 1 diabetes is crucial to avoid children and adults becoming acutely ill with Diabetic Ketoacidosis (DKA). This is where abnormally high blood glucose levels can lead to organ damage, coma or death. It is estimated that 25 per cent of English children and young people with Type 1 diabetes are only diagnosed after developing DKA that needs emergency treatment<sup>17</sup>.

## Symptom awareness

On World Diabetes Day November 2012, Diabetes UK launched the 4Ts: Toilet, Thirsty, Tired, Thinner to raise awareness of the four most common symptoms of Type 1 diabetes. Everyone should be aware of the 4Ts of Type 1 diabetes, remember them and know what to do if they spot them.

## Prevention and early identification – Type 2 Diabetes

NHS Health Checks can help identify the 7 million people at high risk of Type 2 diabetes be found so they can be helped to take steps to avoid getting diabetes. For the 500,000 people who have undiagnosed diabetes, these checks help them get diagnosed early so they can manage their condition without developing serious complications. At present, half of people with Type 2 diabetes already show signs of complications at diagnosis<sup>18</sup>.

In April 2013 local authorities were given a new duty to improve the health of their population. Directors of Public Health and their teams were transferred from the NHS to local government and, amongst the public health functions mandated to local authorities, was the responsibility to provide or commission health checks for the eligible population and seek continuous improvement in the percentage of the population participating in those checks<sup>19</sup>.

So that everyone is seen over five years, 20 percent of the eligible population need to be offered checks each year. PCTs offered them to 16.5 per cent in 2012-13. The annualised rate for the first quarter of the performance of local authorities was a bit lower at 15.6 per cent. More worrying is that only half of people took up the offer and received a check.

There is also considerable variation between and within regions and local authorities with the numbers of checks offered ranging from 0–14.5 per cent and take up ranging from 0–100 per cent.

## WHAT NEEDS TO BE DONE

- Local Authorities must ensure full implementation of NHS Health Checks to increase the numbers of people being offered, and taking up, the risk assessment.
- Public Health England should support local authorities in areas of low take up to reduce variation.
- NICE guidelines on referral of people at high risk to interventions which help them take action to improve their lifestyles and reduce their risk of developing Type 2 diabetes, must be implemented<sup>20</sup>.
- To help prevent diabetes, and other conditions such as cancer and heart disease, we need effective interventions that make it easier to have a healthy weight through improved town planning, regulation of food marketing and clearer labelling of food and drink.

## STANDARDS OF CARE AND OUTCOMES

The Diabetes UK 15 healthcare essentials are the 15 basic health checks and services that everyone with diabetes – whether Type 1 or Type 2 – should receive from their healthcare team. These include the nine care process checks recommended by NICE<sup>21</sup>. They are the starting point for ensuring that all people with diabetes receive high quality and effective care.

- 1. HbA1c:** Get your blood glucose levels (HbA1c) measured at least once a year.
- 2. Blood Pressure:** Have your blood pressure measured and recorded at least once a year.
- 3. Cholesterol:** Have your blood fats (cholesterol) measured every year.
- 4. Retinal Screening:** Have your eyes screened for signs of retinopathy every year.
- 5. Foot Checks:** Have your legs and feet checked – the skin, circulation and nerve supply in your legs and feet should be examined annually.
- 6. Kidney Function:** Have your kidney function monitored annually.
- 7. Weight:** Have your weight checked and your waist measured to see if you need to lose weight.
- 8. Smoking:** Get support if you are a smoker, including advice and support on how to quit.

The keys to unlocking the 15 healthcare essentials are care planning and education. Education helps people know what they need to do to manage their condition. Care planning means they work with their healthcare team to get what they need to meet agreed goals. Local diabetes networks are the foundation for co-ordinated care across the health service to meet those needs.

- 9. Care Planning:** Receive care planning to meet your individual needs.
- 10. Education:** Attend an education course to help you understand and manage your diabetes.
- 11. Paediatric Care:** Receive paediatric care if you are a child or young person.
- 12. Inpatient Care:** Receive high quality care if you are admitted to hospital.
- 13. Pregnancy Care:** Get information and specialist care if you are planning to have a baby.
- 14. Specialist Care:** See specialist diabetes healthcare professionals to help you manage your diabetes.
- 15. Emotional Support:** Get emotional and psychological support.

# TOO LITTLE TOO LATE: DIABETES CARE NEEDS TO IMPROVE

Less than a third of people with diabetes in England get the essential checks that they should have every year (excluding retinopathy) – a figure that has not greatly changed in the last few years<sup>26</sup>. The variation between areas shows potential for large-scale improvement.

## Type 1 diabetes

The 2011–12 National Diabetes Audit shows that for adults with Type 1 diabetes only 43 per cent received all care processes, excluding retinopathy screening\*. 27 per cent met their HbA1c target, 52 per cent blood pressure and 30 per cent cholesterol. Only 12 per cent met all three goals. The range of people with Type 1 diabetes receiving all of their care processes ranges from 14.9 per cent in the poorest performing CCG area to 67 per cent in the best. The range for achieving treatment outcomes varies from 5 per cent in the poorest performing area to 23 per cent in the best<sup>27</sup>. Performance is not good across the country and the wide variation shows that major improvement is possible.

## Type 2 diabetes

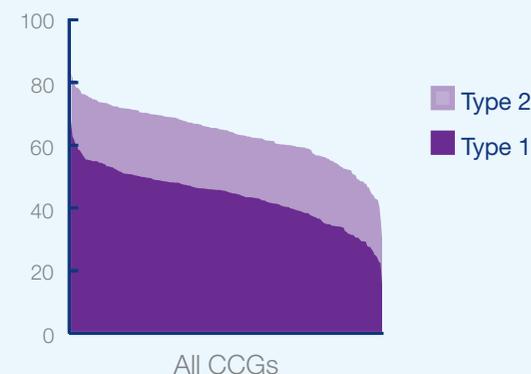
For people with Type 2, the audit found that 63 per cent of adults complete all eight care processes. 66 per cent meet their target for HbA1c, 38 per cent meet their target for blood pressure and 41 per cent reach their cholesterol target. Only 22 per cent meet all three targets for HbA1c, blood pressure and cholesterol. The range of people receiving their NICE care processes varies from 19 per cent in the poorest performing CCG to 81 per cent in the best. The range achieving treatment outcomes varies from 17 per cent in the poorest performing area to 28 per cent in the best<sup>22</sup>.

## Children and Young People with diabetes

There are around 29,000 children and young people in England & Wales with diabetes. The vast majority have Type 1 but the small number of children that develop Type 2 is increasing. There are also a small number of children who have rarer forms of diabetes<sup>23</sup>.

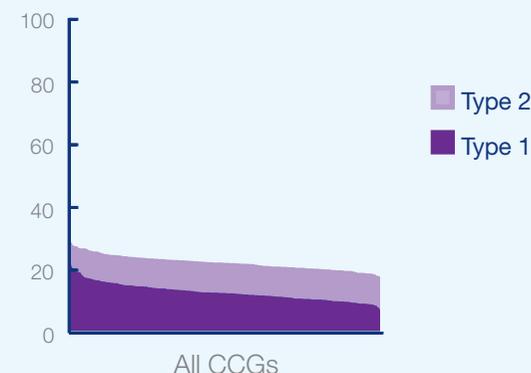
The most recent audit shows an increase in the proportion of children and young people receiving all care processes – but it is still only 5.8 per cent. Only 16 per cent of this age group achieved the recommended HbA1C target of less than 7.5 per cent<sup>24</sup>.

Variation of care processes by CCG for Type 1 and Type 2 (excluding retinopathy)



Source: National Diabetes Audit 2011-2012 (HSCIC)

Variation of treatment targets achievement by CCG for Type 1 and Type 2 (HbA1c, BP, cholesterol)



Source: National Diabetes Audit 2011-2012 (HSCIC)

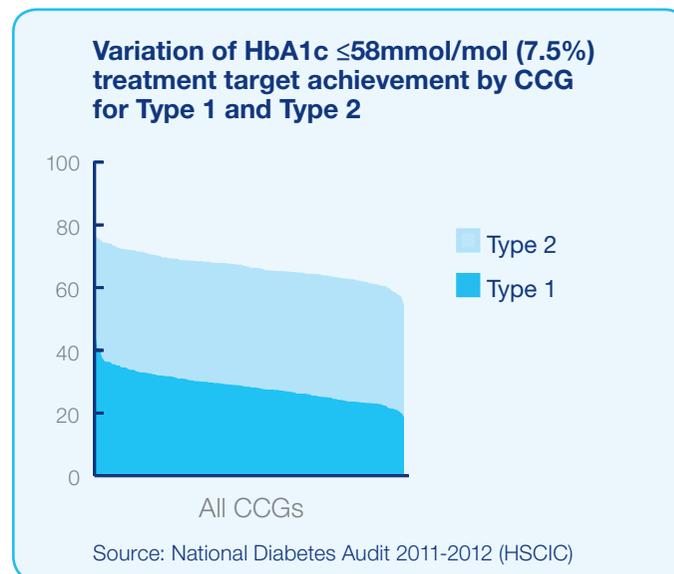
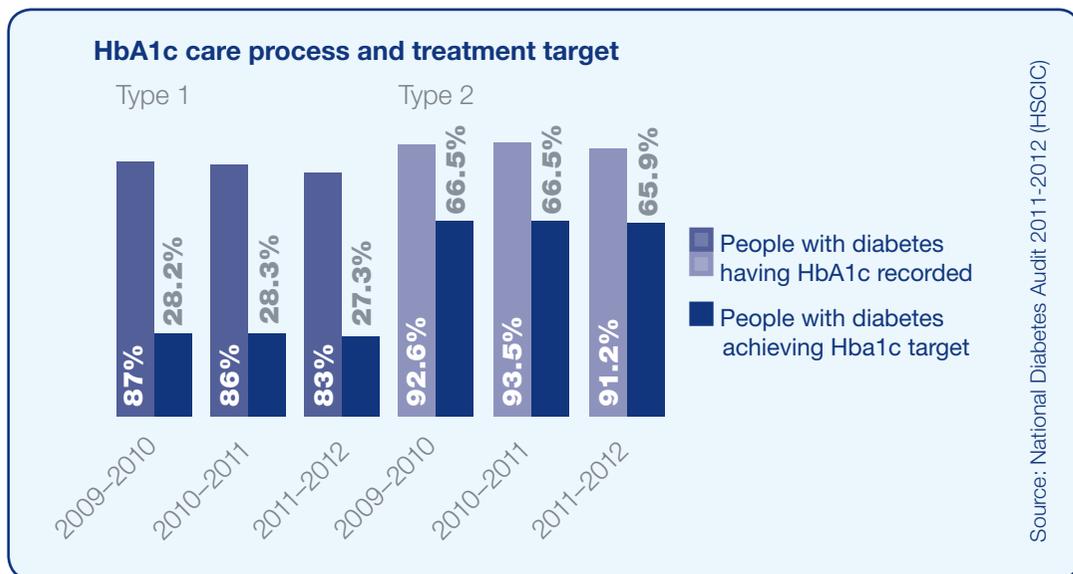
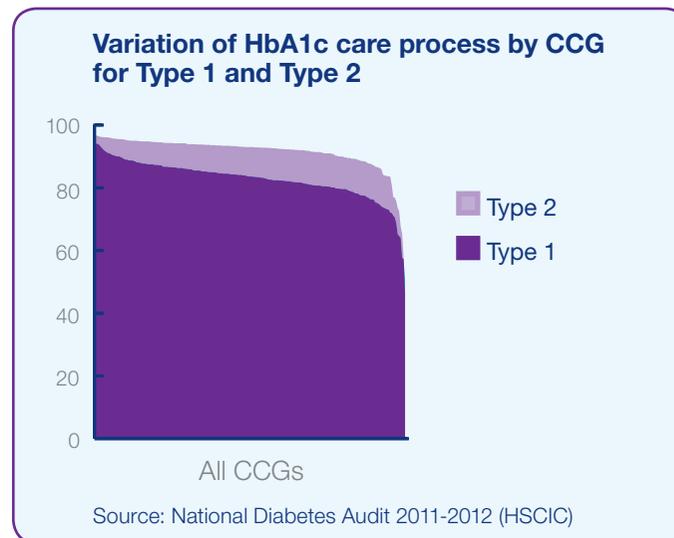
\* The National Diabetes Audit 2011/12 does not include retinopathy screening checks and data is not available currently at a local level from local retinal screening services.

# 1-3 HbA1c, BLOOD PRESSURE AND CHOLESTEROL

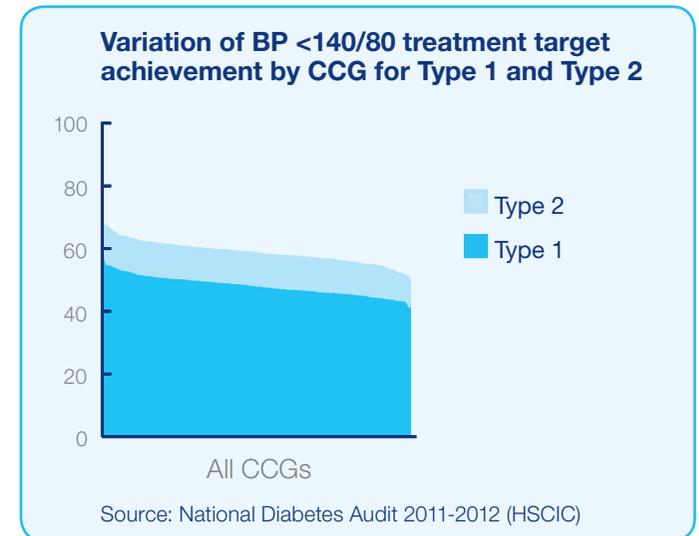
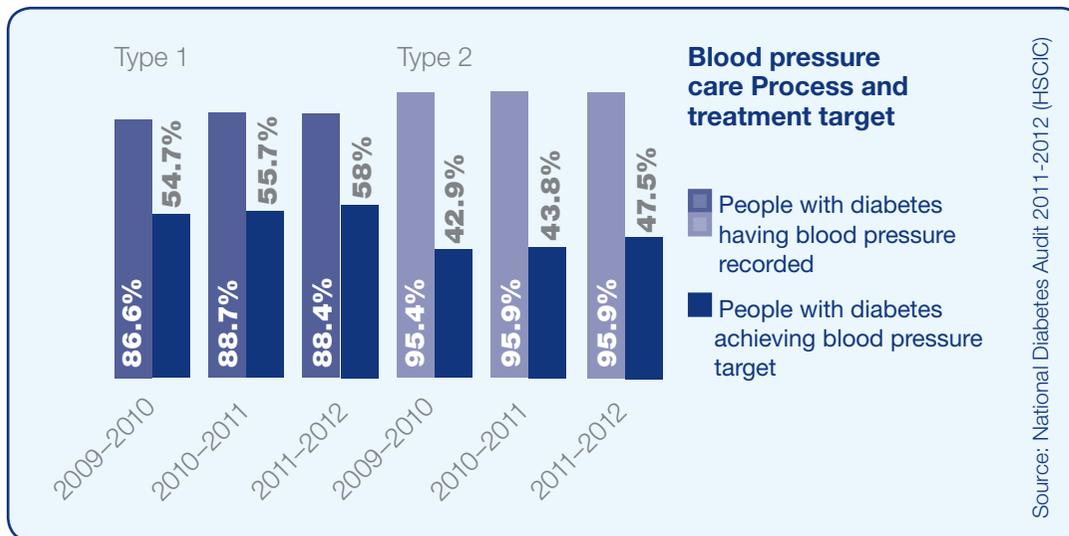
## MORE MEASURED THAN ACHIEVED

The **HbA1c** check measures a person's overall glucose control. Glucose control is essential in trying to avoid serious complications. It is the check carried out the most frequently, with over 90 per cent of people with diabetes having a regular HbA1c check. There has been a fall in both the proportion of people having the test and in those meeting the target.

People with Type 1 are much less likely to reach the recommended target. However, only around 60 per cent of people with diabetes are achieving the recommended target range for their HbA1c. Rates of achievement range from 51 percent to 72 percent in the best performing areas.



People with diabetes are already at higher risk of cardiovascular disease and poor **blood pressure** (BP) control further increases the risk of developing this complication, and particularly increases the risk of suffering a stroke. Over 90 percent of people with diabetes have their blood pressure checked but only around 50 per cent meet recommended levels. Between areas achievement varies from 42 percent to 64 percent.

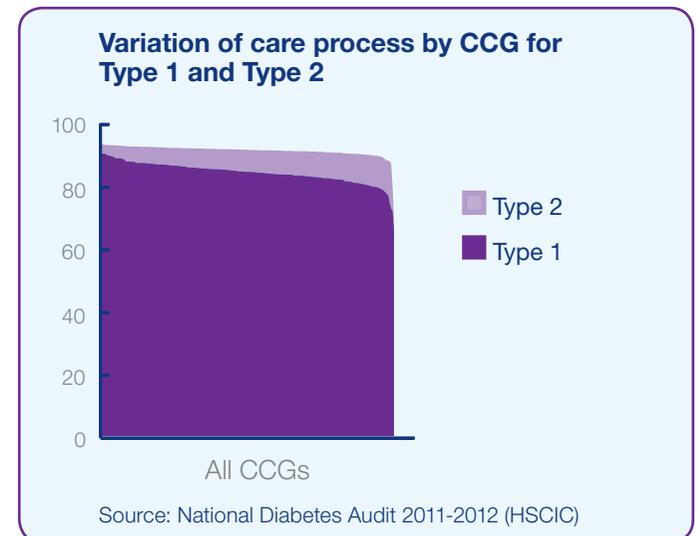


### WHAT PEOPLE SAY

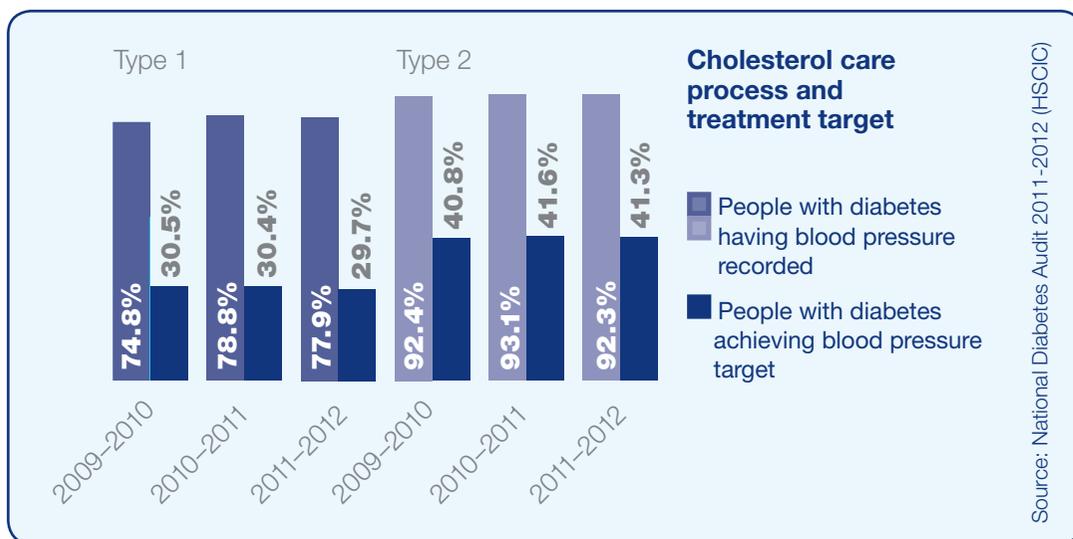
“Nurses are always giving me support towards my target of getting my Hba1c down and the doctors have done this too. I also have a physiologist who helps ... when I feel down about my diabetes as I've tried to neglect it.”

“I had much higher HbA1c results than usual. I had to instigate my own demands for further HbA1c tests after adjusting my insulin levels in an effort to correct things. Intolerable!!”

“The intermittent problem with high blood pressure causes me concern because apart from diet and tablets I'm not sure how else you can reduce BP.”

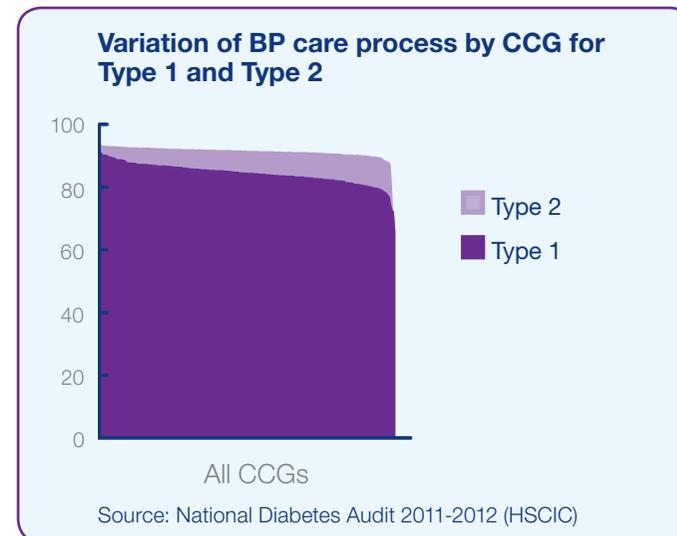
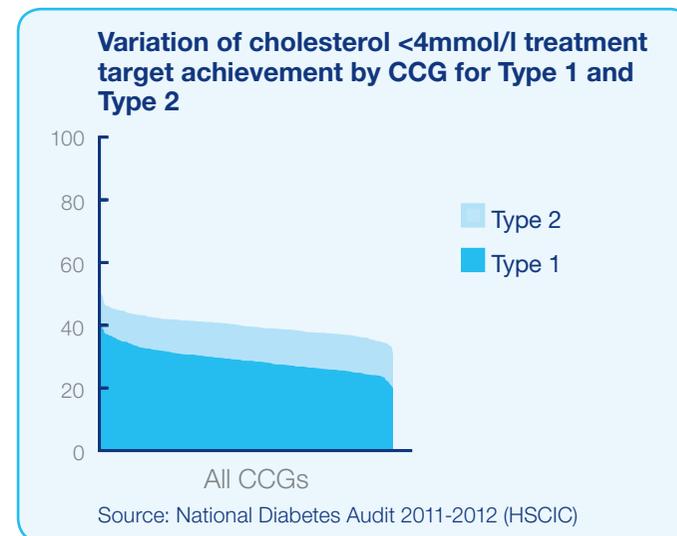


Poor **cholesterol** control also raises the risk of developing cardiovascular disease. The scope for improvement is shown by the fact that this measure is also marked by variation in measurement and achievement between areas. Overall, fewer people with Type 1 diabetes get their checks and meet the target than those with Type 2.



### WHAT NEEDS TO BE DONE

- The poorer performing CCG areas need to put systems in place so more people get these three checks and are provided with the treatment and support for people to take action on their results.
- Personalised care planning should be in place and people provided with their HbA1c, blood pressure and cholesterol results in advance of their annual review.
- The percentage of people with diabetes receiving ongoing and structured education needs to be increased dramatically so they are empowered to manage their own diabetes and understand the importance of the care processes.



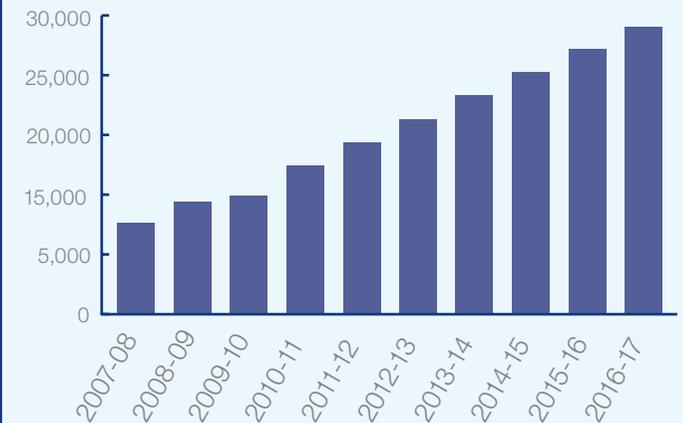
# 4 RETINAL SCREENING

**Retinopathy** is damage to the retina and is a complication that can affect anyone with diabetes. People should be offered an appointment for eye screening when their diabetes is diagnosed and once a year after that. Retinopathy is the most common cause of blindness among people of working age in the UK. It is estimated that in England every year there are 1,280 new cases of blindness caused by diabetic retinopathy. The programme estimates screening could save more than 400 people per year from sight loss in England<sup>25</sup>.

In 2011–12, the service offered screening to 98.6 per cent of people with Type 1 and Type 2 diabetes, however, uptake was only 73.9 per cent<sup>26</sup>. Data reporting the offer and uptake of retinal screening by CCGs, or retinal screening services, is not currently available to assess variation across England. In a recent RNIB survey of ophthalmology staff, 80 per cent reported that they did not have enough capacity which is causing delays in diagnosis and treatment, including retinopathy, that save eyesight<sup>27</sup>.

**THERE IS A NATIONAL DIABETEIC EYE SCREENING PROGRAMME - BUT NOT EVERYONE TAKES UP THE OFFER OF SCREENING**

**Estimated number of people with retinopathy (based on the average annual increase in NDA prevalence between 2007/08–2010/11)**



Source: QOF and NDA (various years)

## WHAT NEEDS TO BE DONE

- Much better provision of patient education and care planning can make people with diabetes more aware of the consequences of not taking up the offer of eye screening.
- Screening programmes must be convenient to access and track patients' progress to ensure they receive annual screening and have access to prompt treatment and follow-up when needed.
- Commissioners need to ensure that ophthalmology services are available to meet the demand for treatment once sight threatening retinopathy is identified.
- Screening services must have good links with local provider eye departments.
- Data is needed to assess the coverage of retinal screening delivered by retinal screening services and improve uptake nationally.

# 5 FOOT CHECKS

**PEOPLE WITH DIABETES ARE UP TO 30 TIMES MORE LIKELY TO HAVE AN AMPUTATION THAN THE GENERAL POPULATION**

Diabetes can lead to poor circulation and reduced feeling in the feet and legs, which can lead to **amputation**.

People should have their feet checked annually to assess their level of risk. But 15 per cent do not. This figure has not changed in recent years. People with diabetes are more likely to be admitted to hospital with a foot ulcer than any other complication of diabetes<sup>28</sup>.

Fewer people with Type 1 diabetes (73 per cent) are reported as receiving a foot check than those with Type 2 diabetes (87 per cent). Variation between the lowest and highest performing areas ranges from 47 per cent to 87 per cent for people with Type 1 diabetes who have had their feet checked. For Type 2 diabetes the variation is between 73 per cent in the poorest performing CCG to almost 90 per cent in the best.

## WHAT PEOPLE SAY

People with diabetes tell us that care can be good:

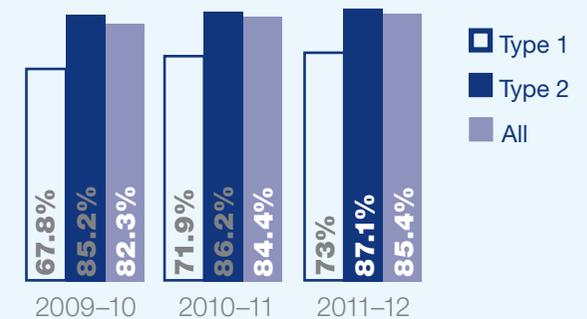
“ I have had a couple of problems, one with my left foot and one with my right leg and the care, treatment – AND FIX :- ) have been first class. ”

But we still hear very upsetting stories:

“ The discomfort in my feet has increased over the last six months but I can't seem to get anyone interested in the situation. My feet feel swollen but they are not. My blood pressure meter detects a pulse in both ankles. I am going to have to talk to a doctor about the feet. ”

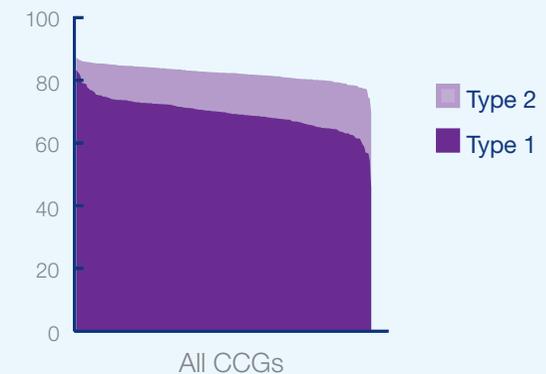
“ After having two toes removed already, my son has now developed an ulcerated big toe which they wish to amputate. I believe that this is because he has not received the support he requires. ”

**Patients receiving foot surveillance care process**



Source: QOF and NDA (various years)

**Variation of foot surveillance process by CCG for Type 1 and Type 2**



Source: National Diabetes Audit 2010-2011 and 2011-2012 (HSCIC)

Over 6,000 leg, foot or toe amputations are carried out each year on people with diabetes. This is over 100 amputations per week<sup>29</sup>.

Up to 80 per cent of these are preventable with the correct management<sup>30</sup>. Amputation rates vary widely from one area to another – in the worst area a person with diabetes is eight times more likely to have a major amputation than in the best<sup>9</sup>.

Amputations and foot ulcers have a huge impact on quality of life. Up to 80 per cent of people die within five years of having an amputation<sup>31</sup>.

If current rates continue, the amputation rate will rise from over 6,000 in 2011/12 to more than 7,000 in 2015/16 in England<sup>29</sup>. It is estimated that between £600 million and nearly £700 million is spent each year on foot ulcers and amputations, and that around 61,000 people with diabetes in England have foot ulcers at any given time<sup>32</sup>.

There is evidence that providing an integrated foot care pathway, with trained staff in foot protection services in the community and speedy access to multi disciplinary teams has been shown to reduce amputations by over 50 per cent. The teams can save over four times their cost<sup>32</sup>. Thirty per cent of hospital sites participating in the National Diabetes Inpatient Audit do not have access to a multi disciplinary specialist foot care team (MDT). This is a major improvement on the previous year when four in ten hospital sites did not have access to an MDT. But there is still considerable room for improvement.

#### Hospital sites without multi disciplinary foot care teams



Source: National Diabetes Inpatient Audit 2011-2012 (HSCIC)

#### WHAT NEEDS TO BE DONE

- All people with diabetes should have annual foot checks and be told their risk score – and understand it. They also need to know how to look after their own feet.
- Staff in primary care need better education and training so they know how to carry out foot checks, inform people about their risk status and refer appropriately.
- People in all areas should have swift access to Foot Protection or Multi Disciplinary Foot Care Teams shown to significantly reduce risk.
- Stays in hospital raise the risk of problems with the feet of people with diabetes. When they go into hospital, for whatever reason, they should have their feet checked on admission and throughout their stay.

# 6 KIDNEY FUNCTION

**KIDNEY FAILURE IS ONE OF THE MOST SEVERE AND LIFE-THREATENING COMPLICATIONS OF DIABETES**

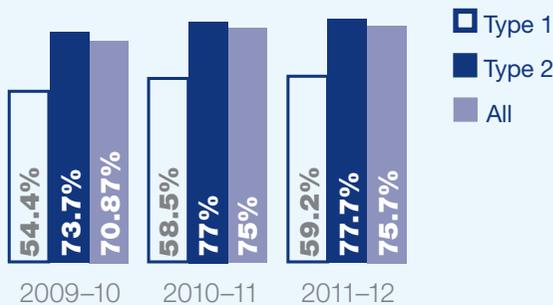
**Kidney disease** is more common in people with diabetes. It also increases the risk for cardiovascular disease. Diabetes is the most common cause of end-stage renal failure requiring renal replacement therapy (RRT), which is generally dialysis or transplantation. People whose kidney disease is so severe that it needs to be treated with RRT are two and a half times more likely to die in the following year than those without the disease<sup>33</sup>. Those who are not treated with RRT die quickly and it is the most expensive complication to treat.

The risk of kidney disease can be cut by half with intensive control of blood glucose and blood pressure. If recognised early, kidney disease in diabetes can be slowed down. Annual checks should be carried out. However, one of the two checks for kidney function, urine albumin is the least carried out care process at 76 per cent, despite a slight rise over the last few years<sup>22</sup>. Kidney disease can be reduced by a co-ordinated approach to care involving: early screening, prompt referral to specialist teams, using medications with proven effectiveness and increasing patient awareness<sup>34</sup>.

## WHAT NEEDS TO BE DONE

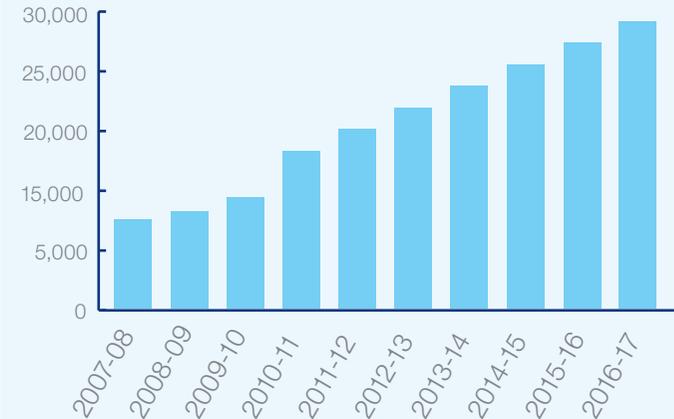
- The proportion of people with diabetes receiving kidney function tests needs to be increased in the worst performing areas.
- People with diabetes and healthcare professionals in primary care need to have better awareness of the risks and seriousness of chronic kidney disease.

**Patients receiving urine albumin care process**



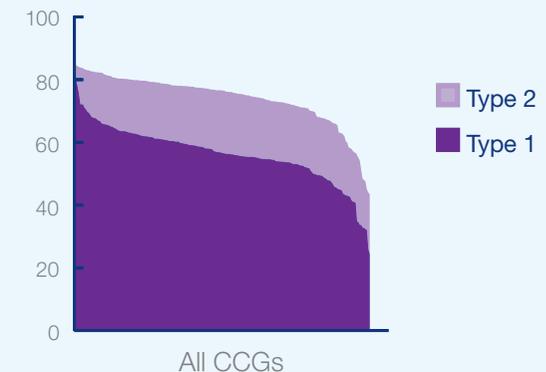
Source: National Diabetes Audit 2011-2012 (HSCIC)

**Estimated number of people with renal failure (based on the average annual increase in NDA prevalence between 2007/08-2010/11)**



Source: QOF and NDA (various years)

**Variation of urine albumin process by CCG for Type 1 and Type 2**



Source: National Diabetes Audit 2011-2012 (HSCIC)

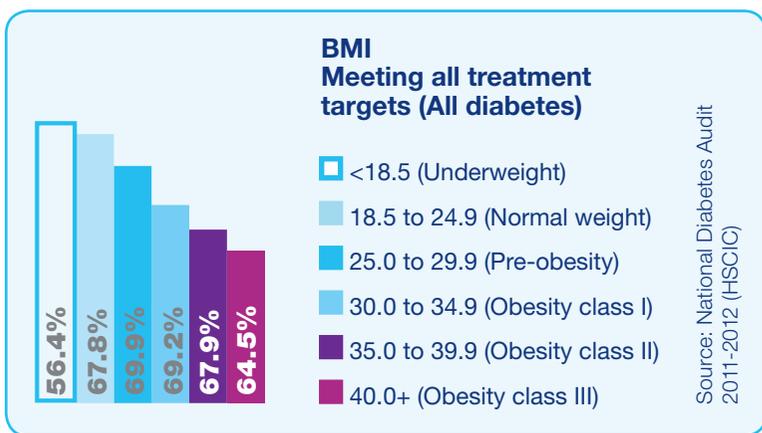
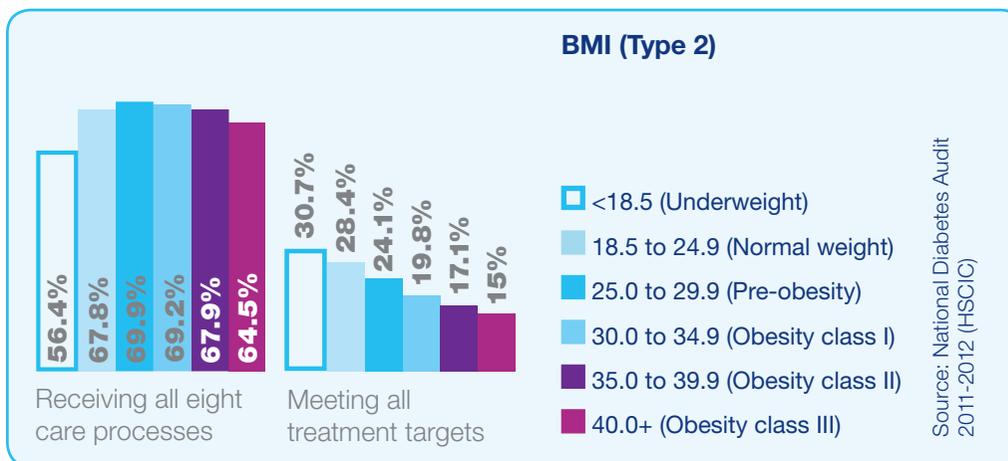
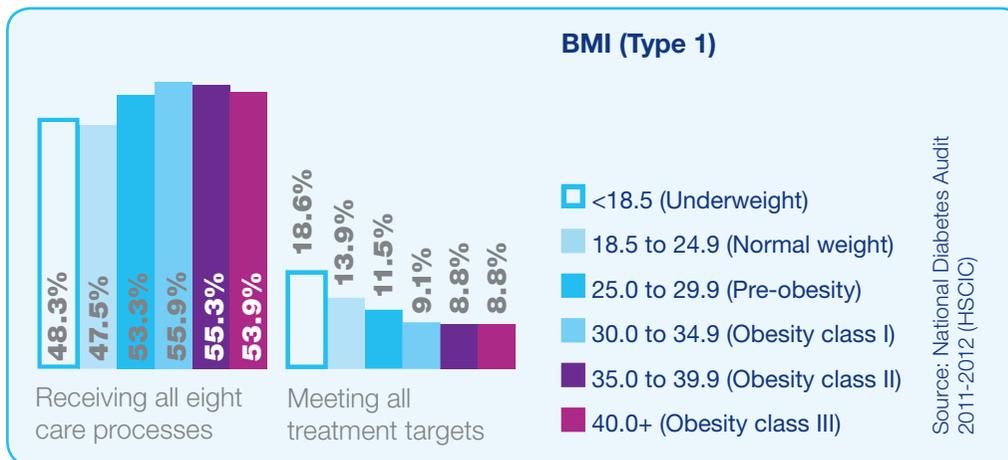
# 7 WEIGHT

## FREQUENTLY MEASURED, BUT IT IS NOT CLEAR WHAT SUPPORT PEOPLE WITH DIABETES GET TO MANAGE THEIR WEIGHT

People with diabetes should have their **weight** monitored and their waist circumference measured annually as part of their review. 90 per cent of people receive this check. Weight reduction for an overweight or obese person with Type 2 diabetes is effective in improving glycaemic control and reducing cardiovascular risk factors. Weight loss is associated with a reduction in mortality of 25 per cent<sup>35</sup>.

The majority of people with diabetes (90 per cent) are getting their BMI measured and there is less variation between CCGs in the worst and best performing areas than for the other care processes. For both types of diabetes, but particularly for Type 2, people with a lower body mass index (BMI) are more likely to meet their treatment targets than those with a higher BMI.

There is a lack of provision of specialist care to improve people's diets in England - only half of the services available are provided by specialist diabetes dietitians. There are Department of Health recommendations for the minimum level of physical activity that should be taken by adults per week (150 minutes)<sup>36</sup>. However, there is variable access to exercise schemes provided to help people become more physically active in order to manage their weight.



### WHAT NEEDS TO BE DONE

- People who require support or management to help them lose weight should be referred to a dietitian, exercise specialist or an alternative service (such as behavioural change therapy), and have access to a diabetes specialist dietitian when they need it.

# 8 SMOKING

**FREQUENTLY MEASURED, BUT THERE IS A LACK OF DATA ON WHAT HAPPENS NEXT**

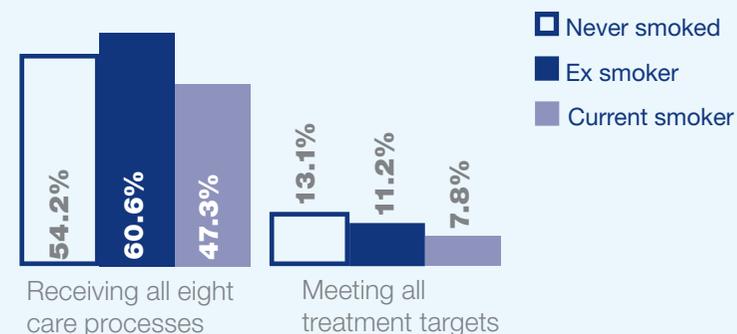
Having diabetes already puts people at increased risk of heart disease and stroke, and **smoking** further increases this risk. Current smokers are also less likely to meet their treatment targets, especially if they have Type 1. People with diabetes should receive support if they are a smoker, including advice and support on how to quit.

The National Diabetes Audit reports that 85 per cent of all people with diabetes have their smoking status recorded. 45 per cent of people with Type 1 are recorded as a current smoker, and 33 per cent of people with Type 2<sup>22</sup>. Data is not available to show what the outcome is, for example, how many people with diabetes are referred to stop smoking services.

## WHAT NEEDS TO BE DONE

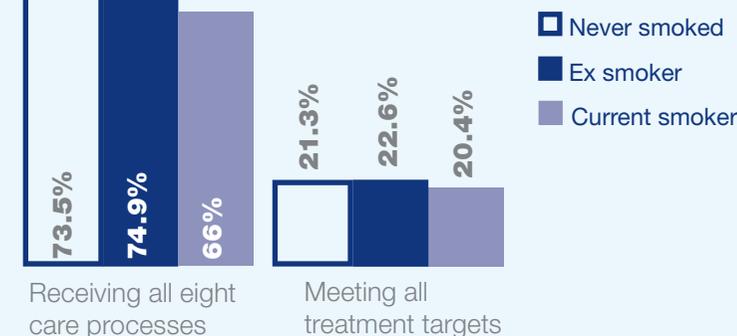
- Support to quit smoking should be given, either in the form of advice and support or through active referral into a local stop smoking programme.
- GPs should be actively encouraged to refer people into smoking cessation services.

**Smoking status (Type 1)**



Source: National Diabetes Audit 2011-2012 (HSCIC)

**Smoking status (Type 2)**



Source: National Diabetes Audit 2011-2012 (HSCIC)

# 9

## PERSONALISED CARE PLANNING

**RECOGNISED AS ESSENTIAL IN MEETING THE INDIVIDUAL NEEDS OF PEOPLE WITH DIABETES, BUT NEEDS TO BE ADOPTED MORE WIDELY AS PART OF INTEGRATED SERVICES**

**Care planning** is a process that allows people with diabetes to have active involvement in deciding, agreeing and owning how their diabetes is managed, and recognises that the person with the condition knows most about how it impacts on their life.

A yearly care plan should be agreed as a result of a discussion between the person and their diabetes healthcare team, where they discuss and identify individual needs to agree actions and goals supporting self-management. Personalised care planning helps to achieve both processes and outcomes, but feedback from people with diabetes suggests that there is a long way to go before it is routinely in place.

The results of Diabetes UK's 15 Healthcare Essentials online survey reported that only just over a third (35.5%) of people with diabetes had agreed a care plan with their healthcare professional, which had been developed by discussing their individual needs to set targets<sup>37</sup>.

The House of Care is an excellent example of how the attitudes and systems within the NHS need to change to support people with long term conditions, including diabetes, to become more engaged in their own care and self-management. The Year of Care pilot programme showed that the care planning process can improve experiences of care and enable people to make real changes in self-care behaviour; healthcare professionals reported improved knowledge and skills, and greater job satisfaction, and general practices reported better organisation and team work<sup>38</sup>.

### WHAT PEOPLE SAY

- “ It's really difficult to get an individualised care plan. I get the plan strictly by numbers without my GP listening to what I want to say. Frustrating. ”
- “ No agreed care planning takes place and certainly I am not being directed towards personally set goals. ”
- “ I receive great care and back up from my team. They look after me and this ensures that I stick to the plan we created with any back up required. ”

### WHAT NEEDS TO BE DONE

- Personalised care planning is a key component of integrated care and should be built into the development of services.
- Local services need to put in place the leadership, facilitation and training to put the 'House of Care' into practice.
- Increase awareness amongst people with diabetes about what to expect from care planning and how it can support them in their diabetes management.

# 10 EDUCATION AND SELF MANAGEMENT SUPPORT

**NICE GUIDANCE HAS BEEN IN PLACE SINCE 2003, HOWEVER COURSES ARE STILL NOT WIDELY AVAILABLE AND THE NUMBERS OF PEOPLE BEING OFFERED OR ATTENDING EDUCATION ARE ALARMINGLY LOW**

**Structured education** is a key component in enabling people to self-manage their diabetes well by giving them the skills, knowledge and motivation to take control of their diabetes. People with diabetes should be offered the opportunity to attend an education course in their local area that meets national standards<sup>39</sup>, either in a group or one-to-one. These courses are recommended by NICE and are cost effective for people with Type 2<sup>40</sup> and cost-saving in four to five years<sup>41</sup> for people with Type 1.

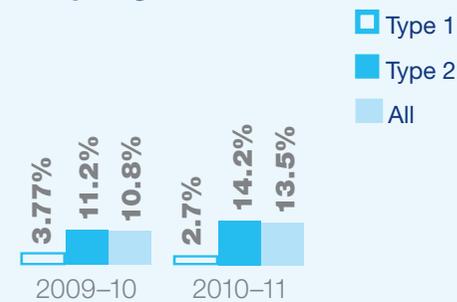
However, data from the 2011–12 National Diabetes Audit shows worryingly low levels of offers of structured education and even lower numbers attending education courses. Only 2.2 per cent of people newly diagnosed with Type 1 were reported as being offered structured education and even fewer attend. The figures reported are slightly higher for those with Type 2 diabetes.

These figures have increased slightly since last year. While some areas do better than others there is massive scope for improvement everywhere. 31 per cent of people with diabetes reported that they had never been offered structured education, even at initial diagnosis<sup>37</sup>.

## WHAT NEEDS TO BE DONE

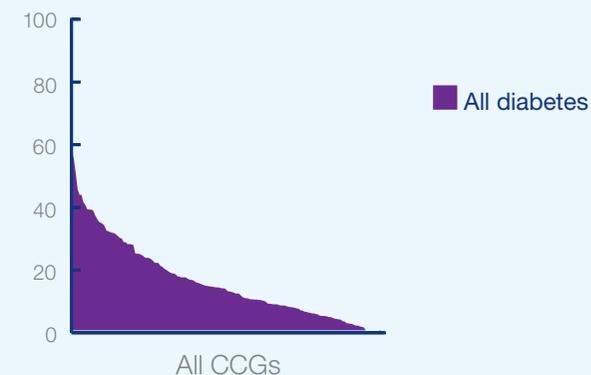
- It is not enough for people just to be offered a structured education course. The clear benefits need to be explained to encourage take-up.
- Some people with ongoing diabetes have never received any formal education, and also need to have the benefits of structured education explained to them.
- Commissioners must ensure adequate provision of education and ongoing learning and there needs to be a greater variety of ways to access different learning options.
- Better data is needed about access and uptake to properly commission for local needs.

### Structured education (offered or attended) for newly diagnosed



Source: National Diabetes Audit 2011-2012 (HSCIC)

### Percentage of structured education offered or attended to newly diagnosed patients with diabetes by CCG



Source: National Diabetes Audit 2011-2012 (HSCIC)

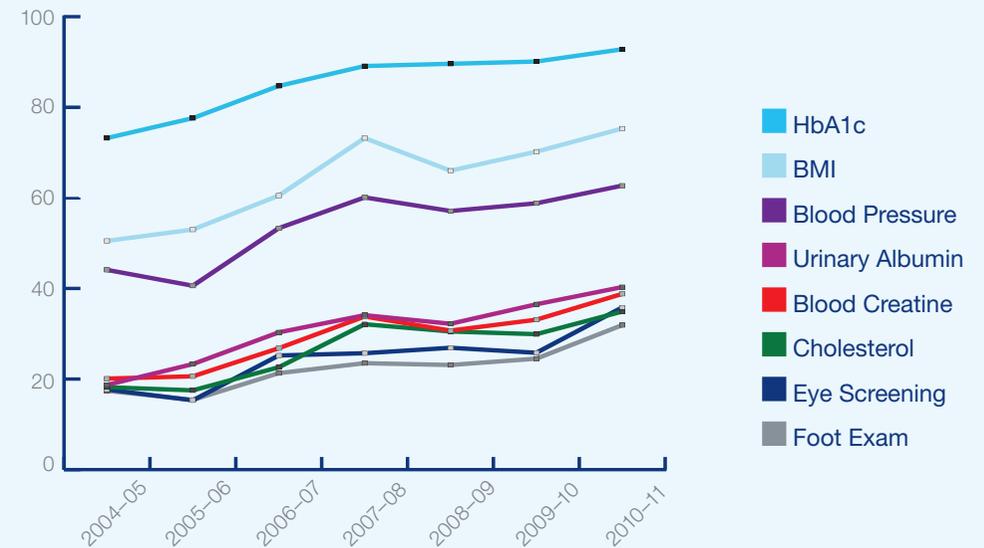
# 11 PAEDIATRIC DIABETES CARE

**THERE ARE VARIABLE OUTCOMES FOR CHILDREN AND YOUNG PEOPLE, WITH CONTINUING POOR PERFORMANCE IN BOTH DIAGNOSIS AND ONGOING MANAGEMENT**

Children and young people with diabetes should receive high quality **paediatric care**, from specialist diabetes paediatric healthcare professionals. When the time comes to leave paediatric care, they should know exactly what to expect so they have a smooth transition to adult services.

The specialist care they require is not routinely in place in all areas, putting them at high risk of developing complications later on in life. We are currently one of the worst performing countries in Europe in terms of blood glucose levels for children with diabetes<sup>42</sup>. After the age of 12, children and young people with diabetes should also receive these key checks every year: blood glucose level measurement (HbA1C); body mass index; blood pressure; urinary albumin; blood creatinine; cholesterol; retinal screening and a foot exam. In 2010–11, the proportion of children receiving all annual care checks increased, but still only 5.8 per cent received them. 84 per cent of children and young people over the age of 12 have blood glucose levels higher than recommended guidelines. The variation between paediatric diabetes units participating in the National Paediatric Diabetes Audit (NPDA) shows that the best performing areas achieved over 30 per cent of children and young people meeting the recommended level of <7.5 per cent and the worst performing unit achieved less than 5 per cent<sup>43</sup>.

**Percentage of children and young people with diabetes having key care processes carried out**



Source: Data from the National Paediatric Diabetes Audit (various years)

Diabetic ketoacidosis (DKA) is a critical, life-threatening condition caused by prolonged raised blood glucose levels that requires immediate medical attention. The most recent National Paediatric Diabetes Audit reported in 2010-11, that young people aged between 15 and 19 years had the highest incidence of DKA, followed by 10-14 year olds. Those under 10 years and over 20 had relatively lower incidence rates. 15.5 per cent of children and young people have had one episode of DKA in the last five years, and 10.4 per cent of children and young people have had two or more episodes in the last five years. The incidence of DKA amongst children diagnosed with diabetes has been increasing since 2005/6 and this is a worrying trend needing to be addressed<sup>43</sup>.

## **Insulin pumps**

An insulin pump delivers a small amount of insulin around the clock via a thin flexible tube. A recent audit shows they are used by one fifth of under 18 year olds with Type 1 diabetes, much lower than in other European countries. Key challenges for the service are the lack of staff capacity and training available to provide the time and support to meet the needs of children using insulin pumps<sup>44</sup>.

## **WHAT NEEDS TO BE DONE**

The Best Practice Tariff for Paediatric Diabetes was implemented in April 2013 and a large majority of paediatric units are meeting the tariff. This should ensure that all children, young people and their families have access to a basic level of care and services and appropriately qualified paediatric diabetes healthcare professionals, and that there is less variation across the country.

- There needs to be continued improved awareness of the signs and symptoms of diabetes, in order to reduce the 25 per cent rate of DKA at diagnosis<sup>45</sup>, including through the Diabetes UK 4Ts campaign.
- Self-management, support and education for children and young people – and their families – needs to be available and its use encouraged.
- CCGs need to commission local specialist paediatric diabetes services that meet the paediatric diabetes tariff. These resources need to be put into the paediatric diabetes teams to deliver the care, checks, and treatments that children need to improve health outcomes, including for insulin pumps.
- Support needs to be developed with schools to ensure that children can manage their diabetes and take part in all school activities.
- Effective transition services must be in place to support young people when it is time for them to transfer into adult diabetes services.

# 12 INPATIENT CARE

**PROVISION OF INPATIENT SPECIALIST SUPPORT REMAINS LOW AND THERE ARE REAL CONCERNS OVER LEVELS OF CARE**

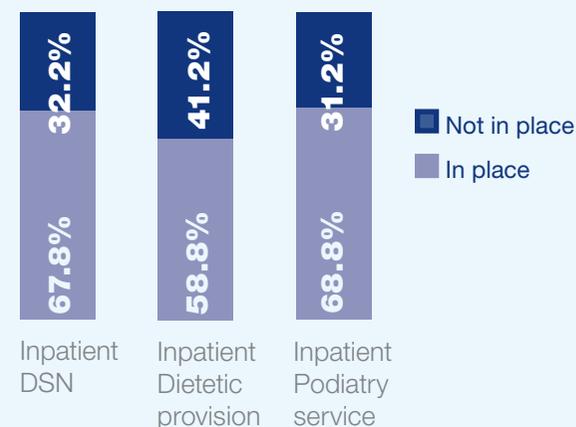
People with diabetes may go into hospital for any reason, however their diabetes should be managed with specialist diabetes input.

Being in hospital and out of normal routine or regime can affect people's diabetes management and people with diabetes tend to stay longer in hospital compared to people without diabetes. However, many hospital sites do not have access to specialist diabetes nurses and dietitians or have an inpatient podiatry service.

## **The 2012 National Diabetes Inpatient Audit (NaDIA)<sup>46</sup> data showed that:**

- 15.3 per cent – around one in seven – of inpatient beds were occupied by people with diabetes.
- More than 60 people with diabetes developed diabetic ketoacidosis (DKA) whilst in hospital.
- The majority of hospitals in the survey made medication errors, with more than a third of inpatients experiencing a medication error during the period of the study, however these medication errors are reducing.
- Only three in five inpatients who should have seen a specialist diabetes care team, actually saw one. In the same period, one in five patients experienced a mild hypo, and one in ten experienced a severe hypo.

### **Provision of inpatient diabetes support**



Source: National Diabetes Inpatient Audit 2012 (HSCIC)

## **WHAT NEEDS TO BE DONE**

- There should be diabetes inpatient specialist nurses and teams in every hospital, to deliver high-quality support and expertise to reduce length of stay and ensure delivery of safe, person-centred care. In addition, all medical staff in hospitals need a basic understanding of how to look after people with diabetes.
- Management plans should be part of the inpatient care of people with diabetes, to ensure that their diabetes is effectively managed whilst they are in hospital.
- Flagging systems should be in place so that people with diabetes are identified and their needs assessed as soon as possible after admission. Protocols should be in place to allow people to self-manage their diabetes in terms of medication (including insulin), blood testing and food.

# 13 PREGNANCY CARE

**WOMEN WITH DIABETES OR GESTATIONAL DIABETES REQUIRE SPECIALIST INPUT WHEN PREGNANT OR PLANNING A PREGNANCY. BUT THERE ARE TEAMS THAT STILL LACK PRE-PREGNANCY AND PREGNANCY PATHWAYS**

Having children is big decision for anyone. Many women who have diabetes have healthy pregnancies and healthy babies but it requires a lot of work and dedication on their part. Whether a woman has Type 1, Type 2, or gestational, which is a type of diabetes that arises during pregnancy, they should see a specialist healthcare professional at every stage.

Diabetes UK has published specific guidance and care recommendations around the management of **pre-pregnancy care and pregnancy in women with diabetes**, to ensure that they receive high quality management and support from a multi disciplinary team with expertise in diabetes and obstetric care<sup>47</sup>.

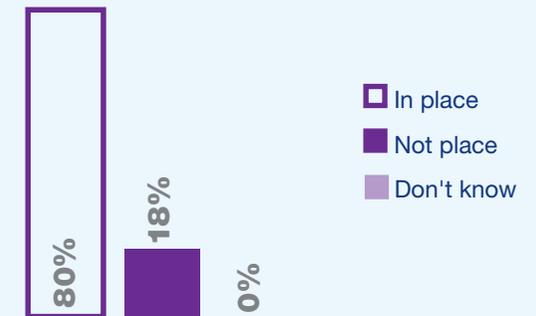
No national data is routinely collected in relation to the provision of pre-pregnancy and pregnancy services for women with diabetes. However a diabetes in pregnancy audit is currently underway in England and will publish results in August 2014.

Diabetes E is a self assessment and performance tool. Its data shows that 80 per cent of specialist provider units that took part have a pre-pregnancy pathway in place, and 86 per cent have a pregnancy pathway in place<sup>48</sup>.

## WHAT NEEDS TO BE DONE

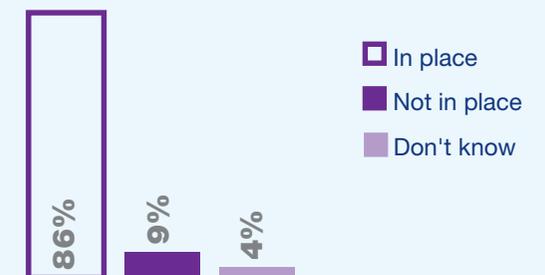
- All women with diabetes should have access to expert support and advice when planning their pregnancy.
- All women with diabetes who become pregnant should receive care from a multi disciplinary care team that assesses and supports all their needs, from conception to post-natal care.

### Pre-pregnancy pathway



Source: Diabetes E

### Pregnancy pathway



Source: Diabetes E

# 14

## SPECIALIST CARE

**ACCESS TO SPECIALIST CARE IS VITAL, HOWEVER NUMBERS OF SPECIALIST STAFF ARE NOT REACHING RECOMMENDED GUIDELINES<sup>49</sup> AND POSTS ARE BEING CUT**

Diabetes and its management is complex, and this can be made even more challenging when people with diabetes develop complications related to their diabetes, or if they are diagnosed with other conditions or illnesses. People with diabetes should see specialist diabetes healthcare professionals to help them manage their diabetes. Diabetes affects different parts of the body and people should have the opportunity to see specialist professionals such as ophthalmologists, podiatrists and dietitians.

The National Diabetes Inpatient Audit (NaDIA) showed that only around 30 per cent of people with diabetes surveyed get access to **specialist care** whilst in hospital<sup>46</sup>. Diabetes Specialist Nurse (DSN) workforce audits have shown that DSN posts are being frozen or not replaced as vacancies arise<sup>50</sup>. The Dietetic Workforce Audit has shown that the provision of specialist diabetic dietitians is below Diabetes UK's recommended minimum staffing levels<sup>51</sup>. The annual consultant workforce audit shows that the net expansion in diabetes and endocrinology at three percent is lower than the five percent expansion across all specialities<sup>52</sup>.

In the 15 Healthcare Essentials online survey 30 per cent of people who took part said they had not been referred to specialist care when needed<sup>41</sup>. Diabetes UK has also received reports of staff and posts being cut which directly impact on the provision of specialist patient care, and reduces access to specialist services.

### **Insulin pumps**

NICE guidance is a step forward in increasing the accessibility of insulin pump therapy<sup>53</sup>, however people are still experiencing difficulty in some areas in securing access to a pump and its associated support. This is due to cost, lack of specialist knowledge or even just not being able to be assessed for suitability<sup>44</sup>.

### **WHAT NEEDS TO BE DONE**

- Specialist services should be commissioned and developed with specialist input and ideally by specialist commissioning teams.
- Services specifically for people with diabetes such as pump management needs to be adequately resourced and developed to be able to meet the local level of need, and the ongoing management of people using pumps.
- All people with diabetes meeting the NICE criteria for pumps should be able to have one.
- Services must stop cutting specialist staff and roles. Diabetes UK has published core staffing recommendations for the provision of specialist diabetes care.

# 15

## EMOTIONAL AND PSYCHOLOGICAL SUPPORT

### DATA IS LACKING ON AN IMPORTANT PART OF DIABETES CARE

Being diagnosed with diabetes and living with a long-term condition can be difficult and the rate of depression is twice as high in people with diabetes than the general population<sup>54</sup>. People need to be able to talk about their issues and concerns with specialist healthcare professionals, trained in psychological care and in diabetes. They should also be able to receive timely access to these services. Depression in diabetes leads to poorer diabetes self-care and medication adherence, leading to poorer control and increased complications and healthcare costs.

The 'Diabetes E' eighth year data reports that 59 per cent of hospitals participating did not have access to emotional and psychological support services for adults at diagnosis<sup>48</sup>.

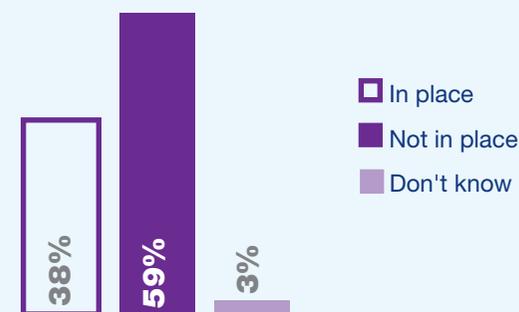
The Diabetes UK report *Minding the Gap* (2008)<sup>54</sup> found that 85 per cent of people with diabetes do not have access to specialist psychological services, and even where a service is available the waiting time to be seen frequently exceeds three months. Feedback from people with diabetes shows how much needs to change to help people cope at the times when they are struggling<sup>37</sup>.

### WHAT PEOPLE SAY

“ I appear to be on the knife edge of depression all the time, however I may be alone in experiencing this but I believe a little bit of encouragement would have helped me greatly. ”

“ No emotional support provided, offered, or identified. This would have helped with initial compliance issues as there was a period of rebellion towards the diagnosis of diabetes. ”

### Percentage of specialist provider units with emotional and psychological support available to adults



Source: Diabetes E

### WHAT NEEDS TO BE DONE

- Emotional and psychological care needs to become accepted as a routine part of diabetes management, and a key component of integrated systems of care, with the right level of skilled staff and resources.
- Specialist psychological services need to be able to provide direct clinical care with psychological therapies, and education and training for members of the diabetes multi disciplinary team.
- Expert psychological care for people with diabetes needs to be provided by professionals with specific knowledge and experience in the area of diabetes.

## ABOUT DIABETES

Diabetes is a condition where there is too much glucose in the blood because the body cannot use it properly. This happens because the pancreas does not produce any insulin, or not enough, or the insulin it does produce is unable to work properly. This is a problem because insulin is the key that unlocks the door to the body's cells so glucose can enter them. So with diabetes, the body is unable to use glucose as fuel and instead glucose builds up in the blood.

### There are two main types of diabetes

Type 1 and Type 2. They are different conditions, with different causes. The treatments can be different too. Both types are serious, lifelong conditions that can lead to devastating complications if they are not managed well. But with the right treatment and support, people with diabetes can reduce their risk of developing complications.

### Type 1 diabetes

People with Type 1 diabetes cannot produce insulin. About 10 per cent of people diagnosed with diabetes have Type 1. No one knows exactly what causes it, but it's not to do with being overweight and it isn't currently preventable. It usually affects children or young adults, starting suddenly and getting worse quickly.

### Type 2 diabetes

People with Type 2 diabetes don't produce enough insulin or the insulin they produce doesn't work properly. About 90 per cent of people diagnosed with diabetes have Type 2. They might get Type 2 diabetes because their family history, age or ethnic background puts them at increased risk. They are also more likely to get Type 2 diabetes if they are overweight. It starts gradually, usually later in life, and it can be years before they realise they have it.

There are other forms of diabetes, such as MODY (Maturity onset diabetes of the young), but these are much rarer than Type 1 and Type 2 diabetes.

So far, there is no cure for diabetes.

## 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.



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