STATE OF THE NATION 2012

ENGLAND

DIABETES UK
CARE. CONNECT. CAMPAIGN.

CONTENTS

FOREWORD

The challenge of diabetes has been recognised since 2001, when the **National Service Framework for Diabetes**[1] set out a vision for diabetes services in England to be delivered by 2013. **We are now at 2012 and this vision is far from being achieved.**

There have been some demonstrable improvements in services since the start of the delivery plan in 2003, with some good practice and effective interventions in place in some areas of the country. However, services are geographically very variable and there are still significant numbers of people with diabetes who do not have access to the agreed essential standards of care.

The challenge

Between 2006 and 2011 the number of people diagnosed with diabetes in England has increased by 25 per cent, from 1.9 million to 2.5 million[2]. It's estimated that up to 850,000 people have diabetes but don't know it. There has also been a huge growth in complication rates during this time. Diabetes is now the biggest single cause of amputation, stroke, blindness, and end stage kidney failure. Diabetes is big, is growing out of control, and current spending accounts for around 10 per cent of the National Health Service (NHS) budget[3].

What's the solution?

- Increased levels of awareness of the signs and symptoms of diabetes and its serious consequences.
- Programmes of risk assessment and early diagnosis, to ensure that people aren't living for years with undiagnosed diabetes.
- Effective education for all people with diabetes, so ensuring they can effectively manage their condition.
- All people with diabetes to receive the agreed essential care standards to reduce complications, costs and premature death.
- Investment of the almost £10 billion currently spent on diabetes care more wisely to deliver the above and save money and heartache.

We are in a state of crisis. Ministers and the NHS need to recognise this, to prioritise prevention of diabetes and its complications. An implementation plan is urgently needed to deliver the *National Institute for Health and Clinical Excellence (NICE)* Quality standards and the *National Standard Framework (NSF)* Outcomes, for the sake of society, the NHS, the tax payer and above all for people with diabetes and those at risk of developing diabetes

Barbara Young

Barbara Young, Chief Executive

EXECUTIVE SUMMARY

DIABETES IS BIG, IT IS GROWING, IT IS SERIOUS AND IT IS EXPENSIVE. BUT, IT IS FIXABLE after 10 years of knowing what to do, the time for action is NOW

Published in 2001, ***The National Service Framework for Diabetes*** contains nine standards for the provision of high quality diabetes services in what it recognised as a growing area of need. The nine standards cover:

1. **Prevention of Type 2 diabetes**
2. **Identification of people with diabetes**
3. **Empowering people with diabetes**
4. **Clinical care of adults with diabetes**
5. **Clinical care of children and young people with diabetes**
6. **Management of diabetic emergencies**
7. **Care of people with diabetes during admission to hospital**
8. **Diabetes and pregnancy**
9. **Detection and management of long-term complications.**

Since 2001, the issues around diabetes prevention and management have not been successfully tackled, meaning that diabetes continues to increase, along with its associated complications and costs

There are 2.9 million people in the UK[4] diagnosed with diabetes, and if trends continue, this number will rise to 5 million people by 2025[5].

Figures from 2009 to 2010 show the prevalence of diabetes as nearly four times higher than the prevalence of all cancers combined.

In 2011, NHS spending on diabetes was almost £10 billion, or £1 million per hour[6]. 80 per cent of NHS spending on diabetes goes in to managing potentially preventable complications.

Diabetes is associated with around 24,000 excess deaths each year[7]. Half of all deaths from diabetes result from cardiovascular disease, including heart attack and stroke.

The NHS Health Checks programme is a key way of identifying people with and at risk of Type 2 diabetes, yet in 2011 only half of the NHS Health Checks expected to be offered in 2011–12 have been offered and a number of primary care trusts (PCTs) in England have not carried out any NHS Health Checks[8].

There is huge variation in ongoing care for people who have diabetes; the number of people who received all nine of their annual checks in 2010 ranged from 6 per cent to 69 per cent[9]. For children the figures are even worse, with 96 per cent of children not receiving all the yearly checks that they need[10]. This variability leads to poor service delivery, and has a negative effect on the clinical outcomes for people with diabetes, putting them at greater risk of developing complications, lowering their quality of life and requiring expensive specialist care.

Diabetes UK is calling for:

- **A National Implementation Plan for Diabetes, to deliver in practice the outcomes of the National Service Framework and the NICE Quality Standards in the context of the new NHS**
- **the full implementation of NHS Health Checks to increase levels of risk assessment and earlier identification of diabetes**
- **increased awareness of the signs and symptoms of Type 1 diabetes to reduce cases of diabetes ketoacidosis (DKA) at diagnosis**
- **access to education for all people diagnosed with diabetes**
- **delivery of nationally agreed standards of care, including the 9 Key Care Processes and other services as outlined in the Diabetes UK 15 Healthcare Essentials, to reduce variability and to reduce complications**
- **monitoring of diabetes care and outcomes within the NHS Outcomes Framework and the Commissioning Outcomes Framework**
- **better commissioning to implement the outcomes of the National Service Framework and the NICE Quality Standards to support team working and integrated care, through local delivery networks.**

THE RISING TIDE OF DIABETES – THE CHALLENGE FOR ENGLAND

Diabetes is big, and it's growing

Every three minutes someone in the UK learns that they have diabetes[11]. Right now there are 2.5 million people in England living with the condition, and estimates suggest a further 850,000 people in the UK have diabetes but are either unaware, or have no confirmed diagnosis[12].

Another 7 million people could be at high risk of developing diabetes, and the numbers are rising dramatically every year. If current trends continue by 2025, it is estimated that, **5 million** people in the UK will have diabetes.

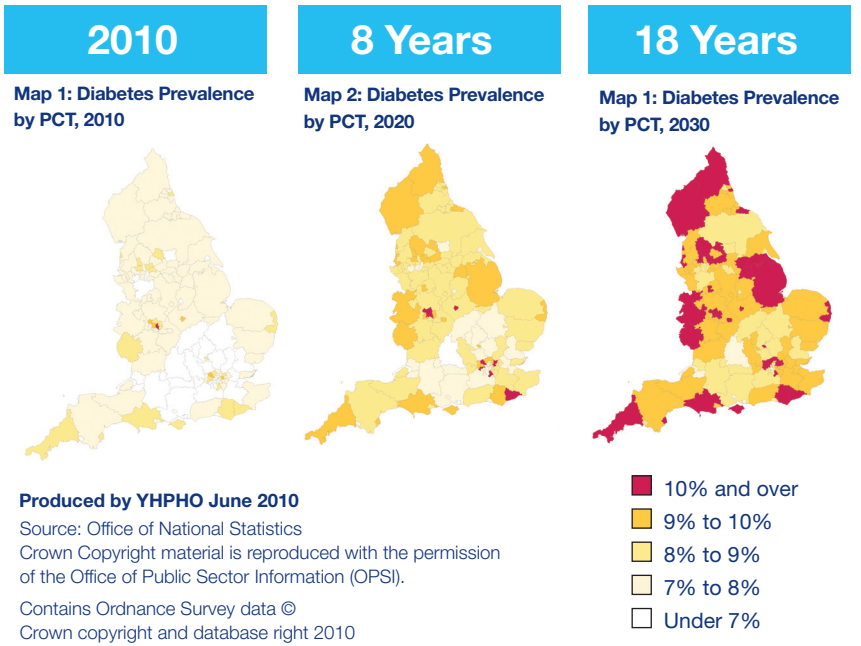
10 per cent of people have Type 1 diabetes, and 90 per cent have Type 2 diabetes[13].

Type 1 diabetes develops if the body cannot produce any insulin. It usually appears before the age of 40, especially in childhood. It is the less common of the two types of diabetes. It cannot be prevented and it is not known why exactly it develops. Type 1 diabetes is treated by daily insulin doses by injections or via an insulin pump

Type 2 diabetes develops when the body can still make some insulin, but not enough, or when the insulin that is produced does not work properly (known as insulin resistance). Type 2 diabetes is treated with a healthy diet and increased physical activity. In addition, tablets and/or insulin can be required.

Increasing prevalence in England

Prevalence of diabetes expected to increase significantly



Produced by YHPHO June 2010

Source: Office of National Statistics

Diabetes is expensive

The rapidly growing scale of the condition is alarming, as are the associated care and treatment costs. NHS spending on diabetes was almost £10 billion in 2011, or £1 million per hour, which is 10 per cent of the NHS budget. 80 per cent of NHS spending on diabetes goes into managing avoidable complications. People with diabetes account for around 19 per cent of hospital inpatients at any one time, and have a three day longer stay on average than people without diabetes. Most of Type 2 diabetes costs are due to hospitalisation[14].

Diabetes is serious

Without careful, continued management of the condition, a person with diabetes faces a reduced life expectancy of between 6 to 20 years[15].

Each year, the condition is associated with 75,000 deaths; this is 24,000 more deaths than would be expected in this group[16]. 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.

In the UK diabetes is the leading cause of blindness in working age people[17,18], and a main contributor to kidney failure, amputations and cardiovascular disease, including heart attack and stroke[19].

One in five children who have Type 1 diabetes will be at increased risk of developing diabetic ketoacidosis (DKA)[20], a critical, life-threatening condition that requires immediate medical attention.

Many of these complications are avoidable with good risk assessment and early diagnosis, patient education, support and good ongoing services. Estimates show that of more than 100 amputations carried out each week from diabetes complications[21], up to 80 per cent are preventable[22].

Cancer, stroke and heart disease have been targeted by national programmes to raise awareness and drive improvement. Diabetes has not.

Between 2006 and 2010, there has been an increase in unnecessary complications[23].

Retinopathy	increased by	118 per cent
Stroke	increased by	87 per cent
Kidney failure	increased by	56 per cent
Cardiac failure	increased by	43 per cent
Angina	increased by	33 per cent
Amputations	increased by	26 per cent

If NDA figures are reflected across the country among people with diabetes, then the number of people with these complications has increased at the above rates.

Many of these complications **need not happen**.

PREVENTION AND EARLY IDENTIFICATION – TYPE 2 DIABETES

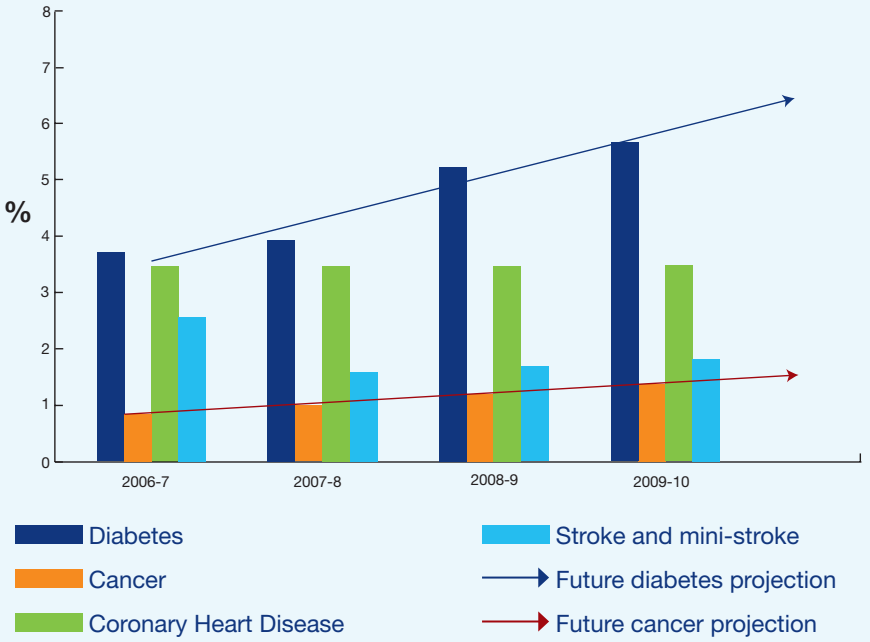
The UK is facing a huge increase in the number of people with Type 2 diabetes. Since 2006 the number of people diagnosed with diabetes in England has increased from 1.9 million to 2.5 million[24]. By 2025 it is estimated that five million people will have diabetes[25], most of which will be Type 2 diabetes.

The prevalence of diabetes is nearly four times higher than the prevalence of all cancers combined and is still rising[26]. If we are to curb this growing health crisis and reduce deaths from diabetes and its complications, awareness, early identification and prevention of diabetes must be prioritised.

About 850,000 people with Type 2 diabetes remain undiagnosed and may present with advanced retinopathy, neuropathy or arterial disease. On average, currently only 75 per cent of the expected cases of diabetes are detected in PCTs in England and the gap between actual and expected rates is closing at a very slow rate[27].

- By the time they are diagnosed 50 per cent of people with Type 2 diabetes show signs of complications[28].
- Up to 7 million people are at high risk of developing Type 2 diabetes[29].

Prevalence of diabetes was nearly 4 times higher than prevalence of all cancers combined (Figures 2006/10)



NHS Health Checks in England – current performance

NICE draft guidance recommends a two-stage strategy to assess risk for all people over 25, using a risk assessment tool followed by confirmation blood test if people are at high risk[30]. The NHS Vascular Screening Health Checks programme was implemented from April 2009 for people aged 40–74 years, to target 15 million eligible people, to be offered a check every five years[31].

By the end of December 2011 only half of the expected checks for the year 2011/12 had been offered[32]:

- this compares poorly to other screening systems such as that for cervical cancer, which has an uptake rate of 78 per cent, and breast cancer, which has an uptake rate of 77 per cent
- a number of PCTs in England have not carried out any NHS Health Checks.

We want to see:

- **public awareness campaigns to communicate the seriousness of diabetes and its complications, risk factors of Type 2 diabetes, the importance of NHS checks and healthy living so that people can reduce their risk**
- **the Department of Health ensure that local authorities commission a fully funded Health Checks Programme and follow-up action including risk assessment, tests for those at risk and intensive lifestyle interventions for those identified as high risk**
- **the NICE Public Health Draft Guidance on Preventing Type 2 diabetes: risk identification and interventions for individuals at high risk, fully implemented**
- **effective signposting of those at high risk to organisations providing information and advice to support people to adopt healthier lifestyles and to reduce their risk of developing Type 2 diabetes.**

EARLY IDENTIFICATION – TYPE 1 DIABETES

Type 1 diabetes cannot be prevented. However, awareness of the signs and symptoms of diabetes, and early identification are also crucial to ensure that both children and adults who develop it do not become acutely ill with Diabetic Ketoacidosis (DKA), where abnormally high blood glucose levels can lead to coma or death, and a raised blood glucose level can lead to the early stages of organ damage if not treated quickly and brought under control. Data from the National Paediatric Diabetes Audit shows that for 25 per cent of children and young people diagnosed with Type 1 diabetes in England, this is through developing DKA and requiring emergency treatment.

TOO LITTLE, TOO LATE, TOO VARIABLE – THE SCANDAL OF STANDARDS OF CARE

Standards of care

Every person with diabetes is supposed to receive a planned programme of nationally recommended checks each year. This should be part of personalised care planning that enables them and their healthcare professionals to jointly agree actions for managing their diabetes, and to meet their individual needs. Derived from both the NSF and NICE guidance on diabetes there are 9 Key Care Processes[33]:

1. Blood glucose level measurement
2. Blood pressure measurement
3. Cholesterol level measurement
4. Retinal screening
5. Foot and leg check
6. Kidney function testing (urine)
7. Kidney function testing (blood)
8. Weight check
9. Smoking status check.

Two-thirds of adults with Type 1 diabetes, and half of people with Type 2 diabetes fail to get the annual tests and investigations that are recommended in the national standards[34].

For children, the figures are worse. In England, 96 per cent of children don't receive all of the annual routine health checks that they should. Across paediatric specialist units, the percentage of children and young people having episodes of DKA varies from 0 to 30 per cent[35].

As well as receiving all of these checks, healthcare professionals need to ensure that action is taken on the outcomes of the checks to ensure that peoples' diabetes is being managed effectively, and that they are being supported to self-manage. The treatment that people receive varies greatly, depending on where they live, in a massive 'postcode lottery' of care.

In 2010 the number of people receiving all nine recommended tests and investigations ranged from 6 per cent to approximately 69 per cent[36], depending on where they lived.

Outcomes of care

In terms of *key outcomes*, there is also variability. If we take blood glucose measurement (HbA1c), Blood pressure measurement and cholesterol measurement, which over 90 per cent of people with diabetes have *checked* annually, the outcome data available shows that people achieving the recommended HbA1c measurement ranges from only 50 per cent to 72 per cent (average for England 63 per cent); for blood pressure this is 41–61 per cent (average for England 51 per cent); for cholesterol this is 31–49 per cent (average for England 40 per cent)[37].

A new analysis of National Diabetes Audit data by Diabetes UK reveals that half of people with the condition are not meeting their blood pressure target, meaning that more than 1.4 million of the 2.9 million people with diabetes have high blood pressure, in contrast to just 30 per cent of the general population estimated to have high blood pressure. Most people with diabetes (91 per cent) are getting their annual blood pressure check. However, once people with high blood pressure have been identified, not enough is being done to help them bring it under control, increasing their risk of diabetes-related complications such as heart disease, kidney failure and stroke.

Complications cannot be prevented, identified or managed if they are not even checked. These huge variations in the provision of care have to end.

If people got the care that standards say they should, their outcomes would be better and less variable.

	Percentage of people with diabetes in England (by PCT)					
	Receiving ALL 9 Key Care Processes	Receiving retinal screening	Receiving kidney functions checks (Urinary Albumin)	Achieving recommended glucose level outcomes	Achieving recommended blood pressure outcomes	Achieving recommended cholesterol outcomes
Maximum	68.7%	91.4%	86.2%	72.3%	61.2%	48.7%
Minimum	6.4%	52.9%	13.4%	50.2%	41.1%	31.2%
England average	**49.8%**	**76.9%**	**70.4%**	**63.3%**	**50.6%**	**40.3%**

	Prevalence of complications (by PCT)			Identification of people with diabetes (by PCT)	
	Diabetic retinopathy	Major amputations	Kidney failure	Actual cases diagnosed as a percentage of the estimated number of people with diabetes	Percentage of eligible people that receive a NHS Health Check at December 2011
Maximum	3.1%	0.2%	1.0%	98.5%	22.1%
Minimum	0.0%	0.0%	0.1%	49.9%	0.0%
England average	**0.5%**	**0.1%**	**0.4%**	**76.6%**	**5.4%**

DIABETES UK'S 15 HEALTHCARE ESSENTIALS

As well as the 9 Key Care Processes, there are other key services and support that people with diabetes should have access to. Diabetes UK has picked out these other standards of good care and aligned them with the 9 Key Care Processes to produce our **15 Healthcare Essentials**[38].

One of the purposes of developing these essentials has been to enable both people with diabetes and healthcare professionals to know what care people with diabetes should expect. Ensuring that people have the key care processes carried out and that they know what to receive is one of the ways of improving the associated outcomes and their diabetes management. Since their launch in September 2011, we estimate that the Diabetes UK **15 Healthcare Essentials** have been seen by over 1 million people with diabetes across the UK. Around 8,000 people have also responded to an online survey to tell us whether they have received all of the key processes or been offered the other key services in the last year, and given us details of their experiences.

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**

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**

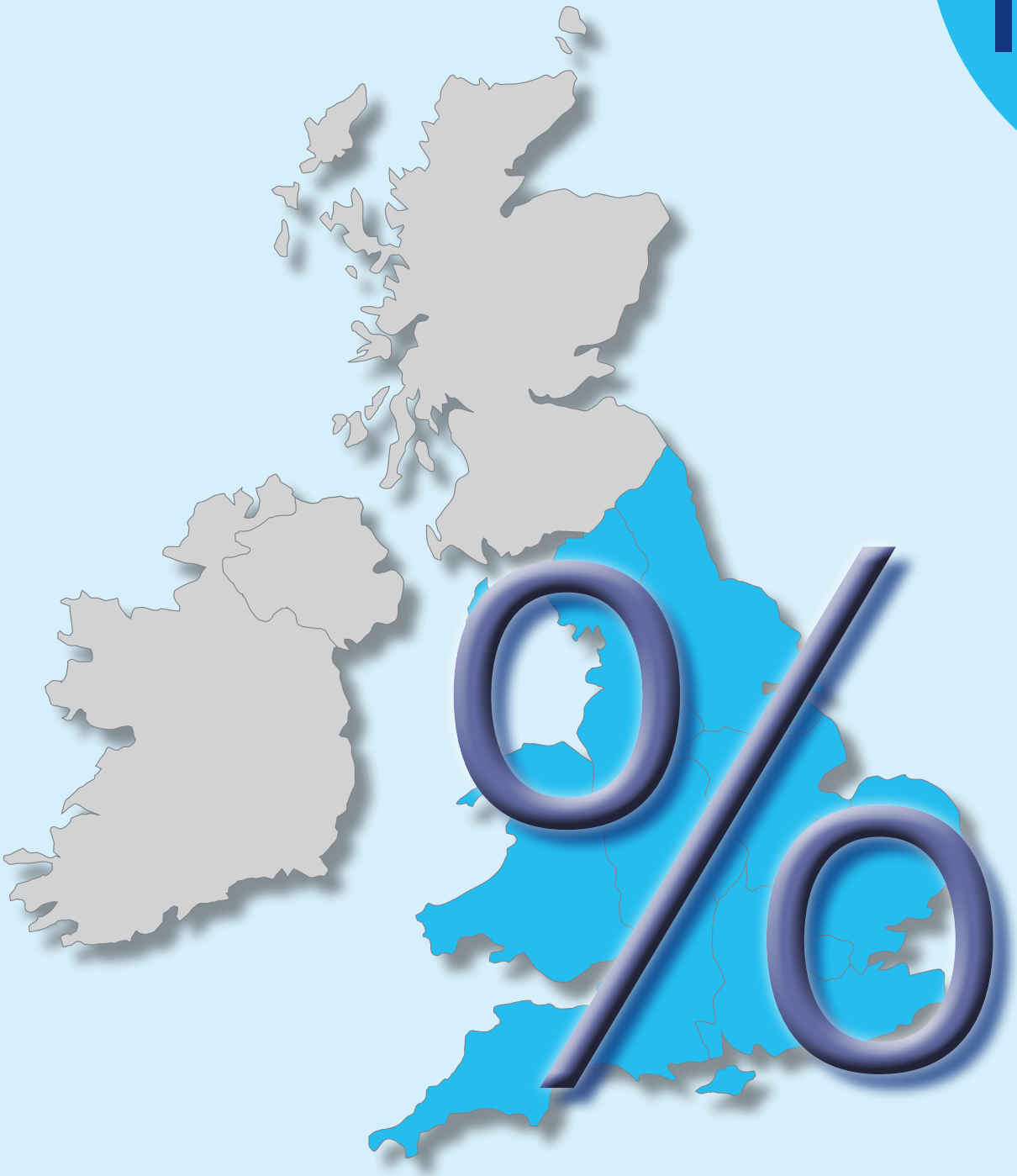
13 **PREGNANCY CARE GET INFORMATION AND SPECIALIST CARE IF YOU ARE PLANNING TO HAVE A BABY**

14 **SPECIALIST CARE SEE SPECIALIST DIABETES HEALTHCARE PROFESSIONALS TO HELP YOU MANAGE YOUR DIABETES**

15 **EMOTIONAL SUPPORT GET EMOTIONAL AND PSYCHOLOGICAL SUPPORT**

The following sections focus specifically on each of the **15 Healthcare Essentials**, to assess how well they are being delivered and acted upon.

THE PICTURE IN ENGLAND

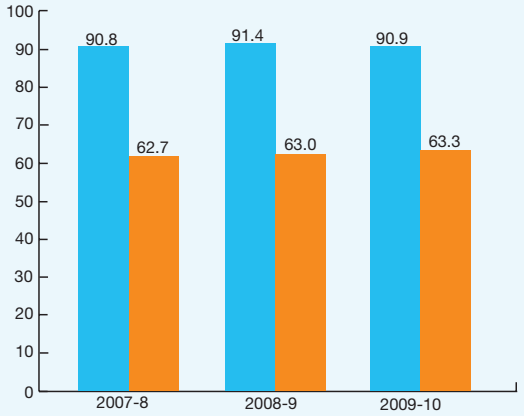


1-3 HbA1c, BLOOD PRESSURE AND CHOLESTEROL

FREQUENTLY MEASURED, BUT LOW OUTCOME ACHIEVEMENT

Regular **HbA1c** checks will only contribute to effective diabetes management only if it is part of a comprehensive system of care where people receive all of the key care processes.

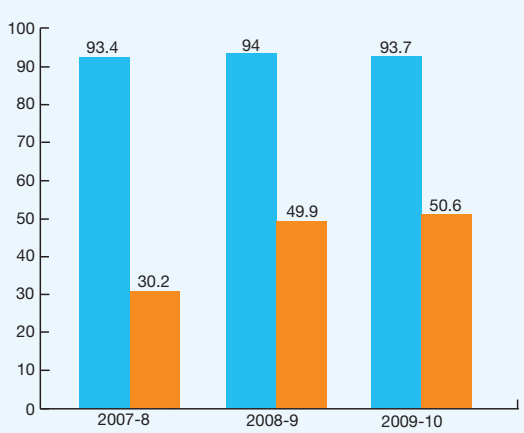
HbA1c check is carried out the most frequently, with over 90 per cent of people with diabetes having a regular HbA1c check. HOWEVER, only around 60 per cent of people with diabetes are achieving the recommended target range for their HbA1c.



Source: National Diabetes Audit 2009-10

Poor **blood pressure (BP)** control puts people at significant risk of developing heart disease, and particularly increases the risk of suffering a stroke.

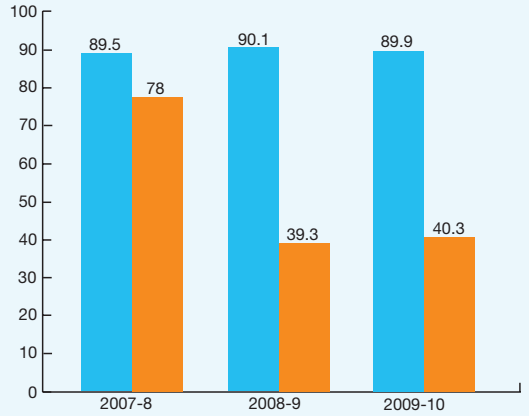
Over 90 per cent of people with diabetes have it checked. However, the figure for people in England *achieving* their target BP is only around 50 per cent.



Source: National Diabetes Audit 2009-10

Poor **cholesterol** control also raises the risk of developing cardiovascular disease, and increases risk of heart attack and stroke.

Over 90 per cent of people with diabetes have it checked. However, the percentage of people in the UK *achieving* their target cholesterol is only around 40 per cent in England.



Source: National Diabetes Audit 2009-10

WHAT NEEDS TO BE DONE

- **personalised care planning should be in place, and support to self-manage should include providing people with their HbA1c, blood pressure and cholesterol results prior to their annual review**
- **involving people in the management of their own care is essential to enabling them to successfully achieve healthy HbA1c, blood pressure and cholesterol levels.**

"I would like to have copies of my test and examination results. This would really help me to control my diabetes"

Person with diabetes

4 RETINAL SCREENING

THE NATIONAL SCREENING PROGRAMME IS AN EXAMPLE OF A CENTRALLY TARGETED DRIVE, BUT SCREENING IS STILL NOT CARRIED OUT EVERYWHERE

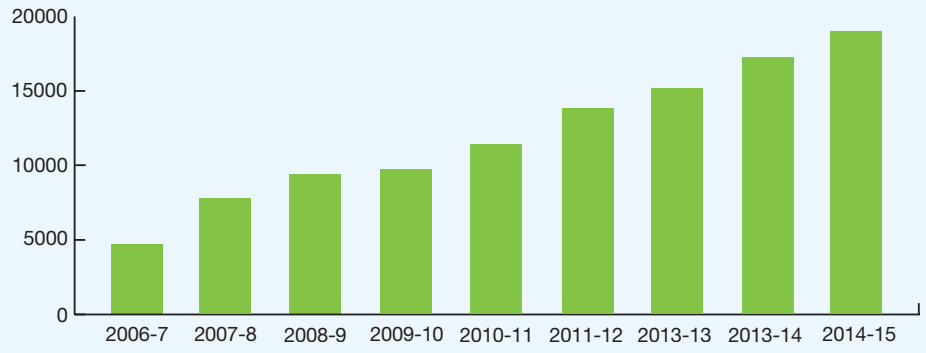
Retinopathy (damage to the retina or seeing part of the eye) is a complication that can affect anyone with diabetes. People should be offered an appointment for eye screening when their diabetes is diagnosed and once a year after that.

Retinopathy is the most common cause of blindness among people of working age in the UK. Whilst the process of retinal screening being carried out has increased, prevalence of retinopathy shows a slight increase in England.

It is estimated that in England every year 4,200 people are at risk of blindness caused by diabetic retinopathy and there are 1,280 new cases of blindness caused by diabetic retinopathy.

In 2010–11, the service identified 2.47 million people with diabetes. 91 per cent of these were offered screening, but only 79 per cent of those offered were screened. Diabetes UK has some concern over the accuracy of these figures[39].

Estimated number of people with diabetes and retinopathy (based on the average annual increase in NDA prevalence between 2006/7–2009/10)



Source: National Diabetes Audit 2009-10 and QOF diabetes prevalence data

WHAT NEEDS TO BE DONE

- **retinal screening must be carried out at least once a year as part of a person's annual review**
- **screening programmes must track patients' progress to ensure they receive annual screening and access to prompt treatment and follow-up when needed. Screening services must have good links with local provider eye departments.**

"There is a creeping delay over annual screening. It has now crept up to 17–18 months"

Person with diabetes

5 FOOT CHECKS

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

Diabetes may lead to **poor circulation and reduced feeling in the feet and legs**. People with diabetes are more likely to be admitted to hospital with a foot ulcer than any other complication of diabetes. For the current rate of more than 125 amputations carried out per week, up to **80 per cent of these are potentially preventable** if people receive the correct management.

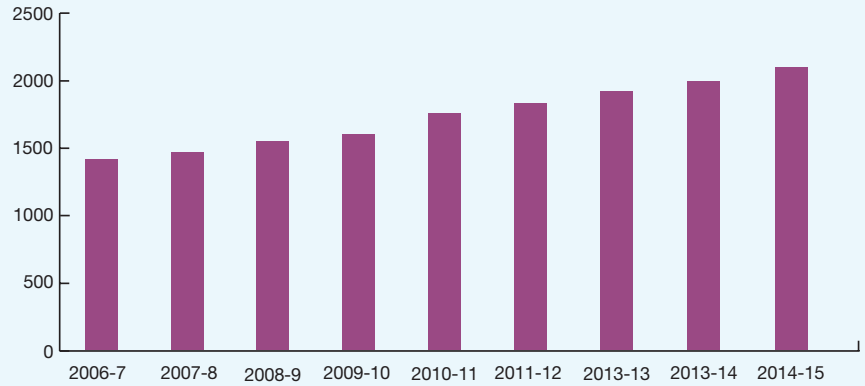
If current rates continue, the amputation rate will rise from over 6000 in 2009/10 to more than 7000 in 2014/15 in England[40].

It is estimated that between £600 million and nearly £700 million is spent each year on foot ulcers and amputations[41].

It is estimated that around 61,000 people with diabetes in England have foot ulcers at any given time[42].

People with diabetes who have an amputation or foot ulcer have a relative increased likelihood of death within five years of up to 80 per cent, which is greater than colon cancer (49 per cent), prostate cancer (20 per cent) or breast cancer (17 per cent)[43].

Number of people with diabetes with one or more major amputations



Source: National Diabetes Audit 2009-10 and QOF diabetes prevalence data

WHAT NEEDS TO BE DONE

- **all people with diabetes should have annual foot checks, be told and understand their risk score, know how to look after their own feet**
- **people in all areas should have swift access to Foot Protection or Multi-disciplinary Foot Care Teams, which have been shown to significantly reduce levels of risk**
- **people with diabetes who go into hospital, for whatever reason, should have their feet checked on admission and throughout their stay**
- **healthcare professionals need a greater understanding of the importance of diabetes footcare.**

"I lost my leg and it was because of my diabetes… no one warned me. By the time I knew, it was too late."

Person with diabetes

6 KIDNEY FUNCTION

KIDNEY FAILURE IS ONE OF THE MOST SEVERE AND LIFE THREATENING COMPLICATIONS OF DIABETES, YET IN 2009–10 ONLY 70 PER CENT OF PEOPLE HAD THEIR KIDNEY FUNCTION TESTED AS PART OF THEIR ANNUAL CHECKS

Kidney disease is more common in people with diabetes and people with high blood pressure. At annual review checks should be carried out to look at how well the kidneys are working.

People with renal failure require extremely specialist, expensive care and management.

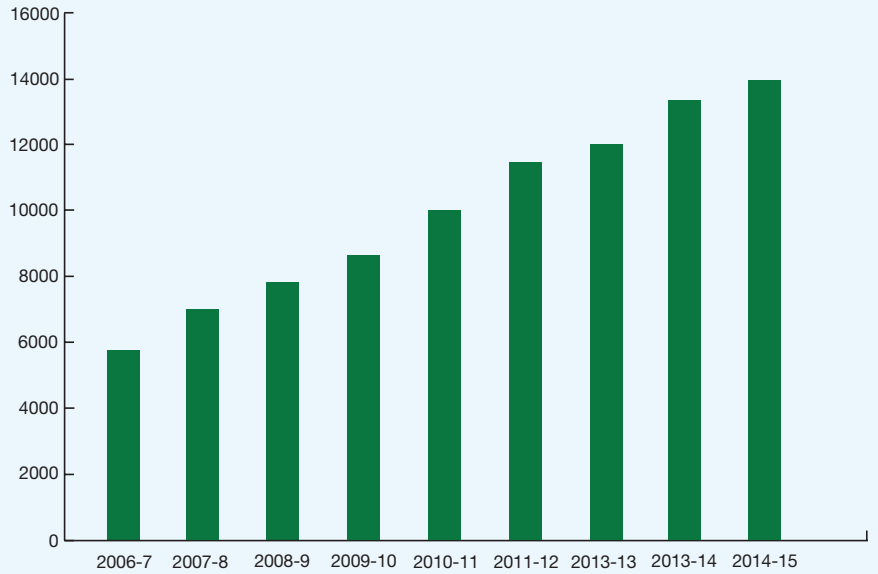
While more people have received testing of their kidney function, prevalence of renal failure has also increased.

Rates of kidney failure in people with diabetes have reached record levels in England (Diabetes UK). The rates among those people registered in the National Diabetes Audit (NDA) were higher in 2009–10 than in any year since the NDA began recording them in 2003.

The rate of kidney failure is 31 per cent higher than in 2006-07.

Diabetes UK's 15 Healthcare Essentials online survey found that 22 per cent of people had not, or were not aware that they had received a blood or urine test to monitor their kidney function[44].

Estimated number of people with diabetes with renal failure (based on the average annual increase in NDA prevalence between 2006/7–2009/10)



Source: National Diabetes Audit 2009-10 and QOF diabetes prevalence data

WHAT NEEDS TO BE DONE

- **regular kidney functions tests must be carried out at least once a year as part of the key care processes and annual review**
- **as well as testing, more needs to be done to improve the outcomes of kidney function testing as part of the care planning review, to ensure that people maintain healthy kidney function levels.**

7 WEIGHT

FREQUENTLY MEASURED, BUT LACKING DATA ON WHAT HAPPENS NEXT

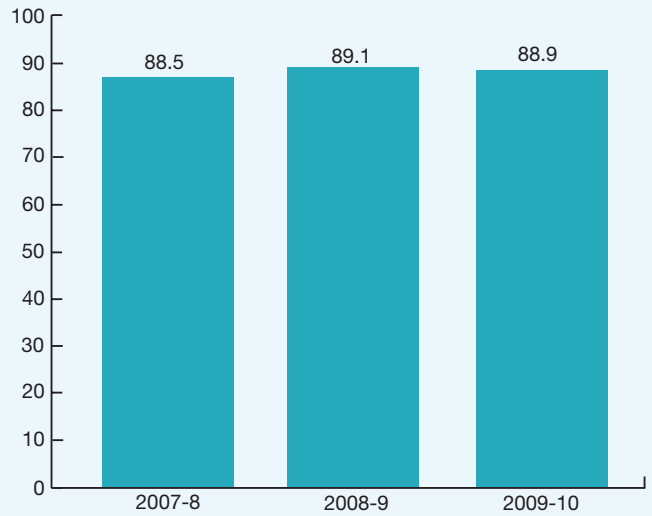
People with diabetes should have their weight monitored and their waist circumference measured annually as part of their review. Weight reduction for the overweight or obese person with Type 2 diabetes is effective in improving glycaemic control and reducing cardiovascular risk factors. Weight loss is associated with a reduction in mortality of 25 per cent[45].

The National Diabetes Audit Data for 2009/10 shows that around 89 per cent of people with diabetes had a weight check carried out, but many people are not getting adequate support to take action on weight reduction.

There is inequity in the provision of specialist dietetic care in England, with only half of the services available being 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)[46]. However, there is variable access to exercise schemes provided to help people become more physically active in order to mange their weight.

National average % of people with diabetes having measurements and assessment of weight



Source: National Diabetes Audit 2009-10

WHAT NEEDS TO BE DONE

- **monitoring of weight should be carried out and recorded at least once a year**
- **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.**

"Care from my GP and practice nurse has been excellent, but I have not seen a dietitian since my diagnosis"

Person with diabetes

8 SMOKING

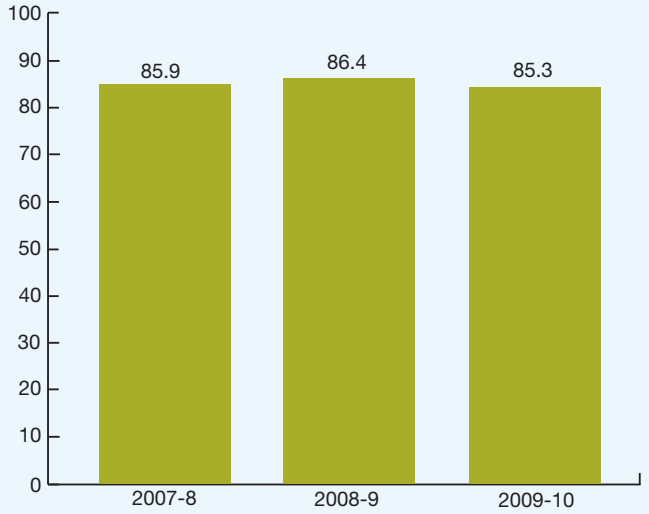
FREQUENTLY MEASURED, BUT LACKING DATA ON WHAT HAPPENS NEXT

Having diabetes already puts people at increased risk of heart disease and stroke, and smoking further increases this risk. People with diabetes should receive support if they are a smoker, including advice and support on how to quit.

In England, the national average of smoking status being recorded is around 85 per cent.

Data is not available to show what the outcome is, eg how many people with diabetes are then offered support to quit smoking, rates of referral to stop smoking services etc.

National average % of people with diabetes having smoking status recorded



Source: National Diabetes Audit 2009-10

WHAT NEEDS TO BE DONE

- **monitoring of smoking status should be carried out and recorded at least once a year**
- **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.**

9 CARE PLANNING

RECOGNISED AS ESSENTIAL IN MEETING THE INDIVIDUAL NEEDS OF PEOPLE WITH DIABETES TO ACHIEVE PROCESSES AND OUTCOMES, BUT RARELY HAPPENS EFFECTIVELY

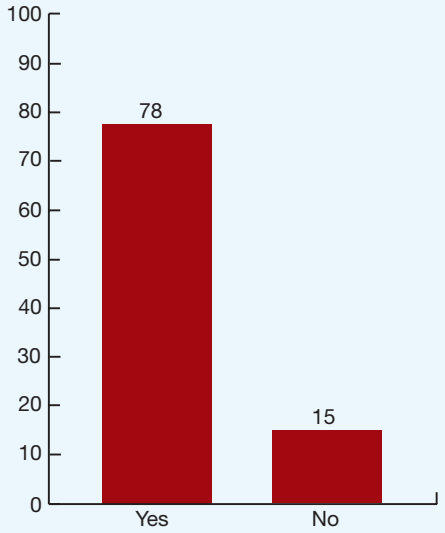
People should receive care planning to meet their individual needs and support their self-management – they live with diabetes every day and should have a say in every aspect of their care.

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 agree individual needs and set targets. Personalised care planning helps to achieve both processes and outcomes.

In the Year of Care Programme Evaluation[47] people reported an improved experience of care and real changes in self-care behaviour; professionals reported improved knowledge and skills, and greater job satisfaction, and practices reported better organisation and team work.

The data from Diabetes E PCT survey in England shows that a high percentage of both PCTs and providers state that personal care plans are required for people with diabetes, or should be developed[48]. However, only a third of people had an individual care plan to meet their needs, and where it was offered, it was not given the time it needed or felt like a form filling exercise.

% of PCTs requiring that all people with diabetes have personalised care plans



Source: DiabetesE

WHAT NEEDS TO BE DONE

- **personalised care planning should be undertaken on a regular basis so that people with diabetes can work with their healthcare professional to identify their personal healthcare needs.**

10 EDUCATION AND SELF-MANAGEMENT SUPPORT

THERE HAS BEEN NICE GUIDANCE SINCE 2003, BUT COURSES ARE STILL NOT WIDELY IN PLACE AND NOT ROUTINELY OFFERED TO THOSE NEWLY DIAGNOSED OR WITH ONGOING DIABETES

Structured Education is a key component in enabling people to self-manage their diabetes well. NICE guidance[49] was devised in order to standardise the way education courses are developed and run.

People with diabetes should be offered the opportunity to attend an education course that meets national standards, to help them manage and understand their diabetes. This should either be in group or one-to-one, and available in their local area.

There is no data routinely collected at national levels to indicate performance against the provision and uptake of education for people with diabetes.

There is very little data on how many people with diabetes are actually offered and undertake education courses. Diabetes UK's 2009 Member Survey[50] reported that only 36 per cent of people had attended a course to help them manage their diabetes since diagnosis.

WHAT NEEDS TO BE DONE

- **people newly diagnosed with diabetes should be offered an education course to help them to manage their diabetes soon after diagnosis**
- **some people with ongoing diabetes have never received any formal education, and should be offered education tailored to the management of ongoing diabetes**
- **service developers must ensure that the provision of education is prioritised, planned as a long-term activity and that it is sufficiently resourced to meet the needs of the local population**
- **access to and uptake of structured education for diabetes should be built into the Quality Outcomes Framework.**

11 PAEDIATRIC DIABETES CARE

VARIABLE OUTCOMES FOR CHILDREN WITH DIABETES AND SOME OF THE POOREST PERFORMANCE IN EUROPE FOR BOTH DIAGNOSIS AND ONGOING MANAGEMENT

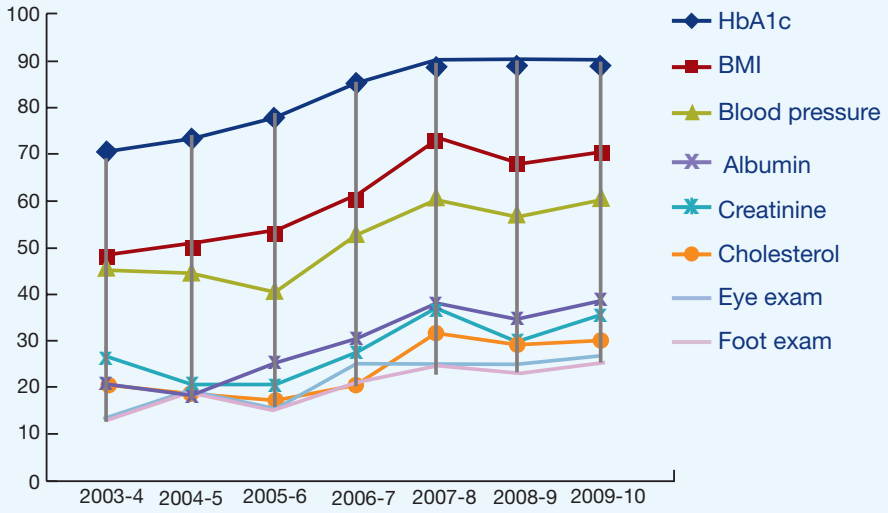
Children and young people with diabetes should receive high quality paediatric care, from specialist diabetes paediatric healthcare professionals. When the time comes to leave paediatric care, they should know exactly what to expect so they have a smooth transition over to adult health services.

The specialist care they require is not routinely in place, 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[51].

In 2009/10 only 4 per cent of children and young people with diabetes received all their annual checks.

More than 85 per cent of children and young people over the age of 12 have blood glucose levels higher than recommended targets. The percentage of children and young people achieving the HbA1c target of <7.5 per cent varies from 1.6 per cent to 37.2 per cent[52].

% of children with diabetes having key care processes carried out (England and Wales)



Source: National Paediatric Diabetes Audit 2009-10

"After having Type 1 diabetes for 12 years and now being 16 years of age, it is time for my son to take more responsibility for his own condition. However, we still cannot access any structured education for him. This is an absolute disgrace"

Parent

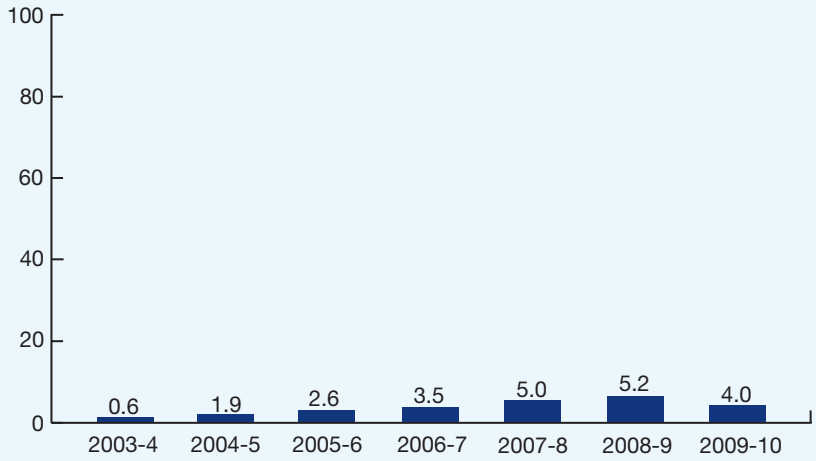
11. CONTINUED →

11 PAEDIATRIC DIABETES CARE

CONTINUED...

15.5 per cent of children and young people have had one episode of Diabetic Ketoacidosis (DKA)* in the last five years, and 10.4 per cent of children and young people have had two or more episodes of DKA in the last five years[53].

*** DKA is a critical, life-threatening condition caused by prolonged raised blood glucose levels (hyperglycaemia) that requires immediate medical attention.**



Source: National Paediatric Diabetes Audit 2009-10

WHAT NEEDS TO BE DONE

- **there needs to be better awareness of the signs and symptoms of diabetes, in order to reduce the 25 per cent rate of DKA at diagnosis**
- **more must be done to improve the levels of key process attainment in children and young people**
- **self-management activities and education need to be available and uptake encouraged so that action can be taken to improve and manage the diabetes of children and young people**
- **the commissioning of local paediatric diabetes services should be carried out by specialist commissioning teams which include clinical expertise and experience in diabetes, in accordance with the requirements of the Paediatric Diabetes tariff**
- **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**
- **children and young people should have access to treatments such as pumps.**

12 INPATIENT CARE

PEOPLE WITH DIABETES REQUIRE SPECIALIST INPUT WHEN THEY GO INTO HOSPITAL, BUT PROVISION OF INPATIENT SPECIALIST SUPPORT IS LOW

At any one time, people with diabetes account for around 19 per cent of all inpatients being cared for in hospitals in England. They may be in 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.

The National Diabetes Inpatient Audit (NaDIA) data for 2011 showed that inpatient support (in the form of inpatient DSN, inpatient dietetic support and inpatient podiatry) was not available to people in 26–69 per cent of eligible sites[54].

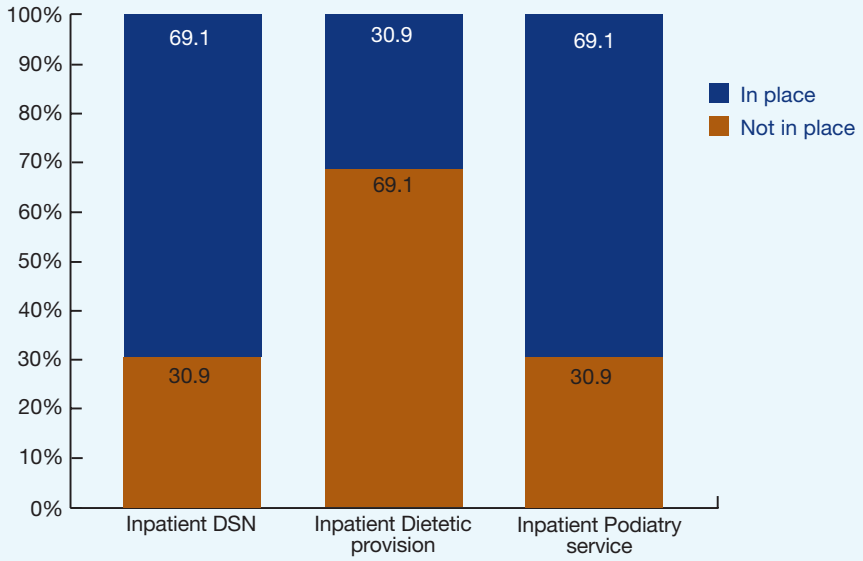
30.5 per cent of people had been seen by a member of their diabetes team.

32.4 per cent of inpatients with diabetes experienced at least one medication error.

Only 22.4 per cent of patients with diabetes had their feet examined at any time during admission.

People with diabetes tend to stay longer in hospital compared to people without diabetes (on average three days longer (NHSD).

Provision of Inpatient Diabetes Support



Source: National Diabetes Inpatient Audit 2011

WHAT NEEDS TO BE DONE

- **there should be diabetes inpatient specialist teams in every hospital, to deliver high-quality support and expertise to reduce length of stay and ensure delivery of safe, person-centred care**
- **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, and protocols should be in place that 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 21 PER CENT AND 13 PER CENT RESPECTIVELY OF SPECIALIST TEAMS DON'T HAVE THE SYSTEMS AND POLICIES IN PLACE

Having children is big decision for anyone. Many women who have diabetes (Type 1, Type 2, or gestational*) have healthy pregnancies and healthy babies but it requires a lot of work and dedication on their part. They should see a specialist healthcare professional at every stage.

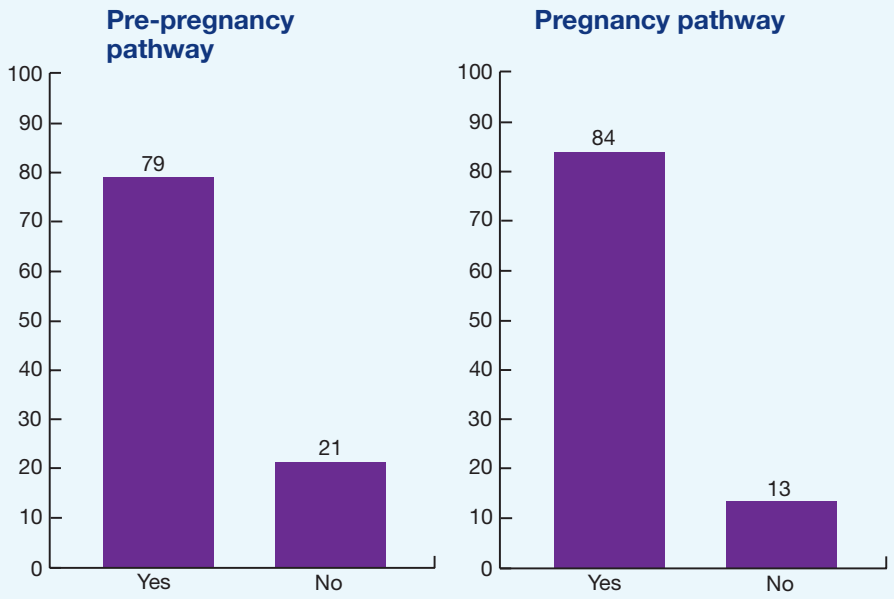
Diabetes UK has published specific guidance and care recommendations around the management of pre-pregnancy care and pregnancy in women with diabetes, to ensure that they receive high quality management and support from a multi-disciplinary team with expertise in diabetes and obstetric care[55].

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.

Data from Diabetes E shows that 79 per cent of specialist provider units that took part have a pre-pregnancy pathway in place, and 84 per cent have a pregnancy pathway in place[56].

* Gestational diabetes is a type of diabetes that arises during pregnancy.

% of specialist provider units with published pregnancy pathway in place for the management of women with diabetes



Source: DiabetesE

WHAT NEEDS TO BE DONE

- **all women with diabetes who are planning a pregnancy 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.**

14 SPECIALIST CARE

ACCESS TO SPECIALIST CARE IS VITAL, HOWEVER NUMBERS OF SPECIALIST STAFF ARE NOT REACHING RECOMMENDED GUIDELINES[57] 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.

Key findings of 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.

Diabetes UK has received reports of staff and posts being cut which directly impact on the provision of specialist patient care, and reduce access in to specialist services.

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

Diabetes Specialist Nurse Workforce Audits[58] show that DSN posts are being frozen or not replaced as vacancies arise.

The Dietetic Workforce Audit[59] has shown that the provision of specialist diabetic dietitians is below Diabetes UK's recommended minimum staffing levels.

The annual Consultant Workforce Audit shows an overall downward trend in the appointment of Consultant Diabetologists over the last four years[60].

The 15 Healthcare Essentials online survey showed that 40 per cent of people who took part said that they had not been referred to specialist care when needed[61].

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

85 PER CENT OF PEOPLE WITH DIABETES DO NOT HAVE ACCESS TO PSYCHOLOGICAL SERVICES. WHERE THEY DO, THERE ARE UNACCEPTABLE WAITING TIMES

Being diagnosed with diabetes and living with a long-term condition can be difficult. People with diabetes should be able to talk about their issues and concerns with specialist healthcare professionals, trained in psychological care and in diabetes.

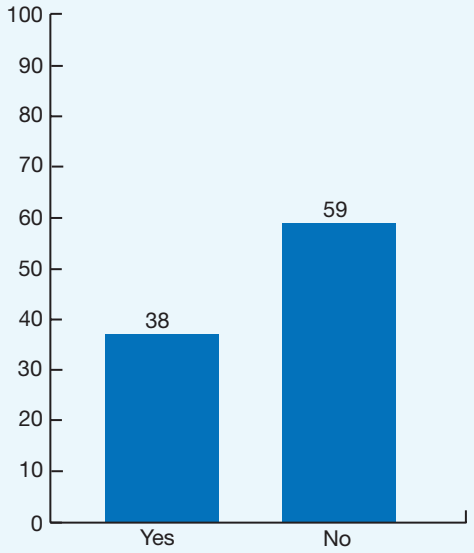
The Diabetes UK report ***Minding the Gap*** (2008)[62] demonstrated that 85 per cent of people with diabetes do not have access to specialist psychological services, and even where a service is available the waiting time to be seen frequently exceeds three months.

No national data is routinely collected in relation to the provision of emotional and psychological support for people with diabetes.

The report estimated that around 41 per cent of people with diabetes suffer with poor psychological well-being. The rate of depression is doubled in people with diabetes.

The 'costs' of untreated depression in diabetes are high, due to its negative impact on diabetes self-care and medication adherence, leading to hyperglycaemia and increased complications and healthcare costs.

% of Specialist Provider Units with Emotional and Psychologial support available to adults



Source: DiabetesE

WHAT NEEDS TO BE DONE

- **services should be needs-led, to meet local levels of need, avoiding delay in referral to services**
- **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**
- **above all, emotional and psychological care needs to become accepted as a routine part of diabetes management.**

RECOMMENDATIONS

Diabetes needs tackling *now*. We must stem the rise in cases, help people live more easily with their condition, and overhaul our approach to treatment and care to halt the rise in costly and serious complications.

Government and the NHS must lead the way, by making diabetes a top health priority. The NHS must improve how it manages screening, risk assessment and care, and create better links between services.

We are calling for an end to delayed diagnosis, an end to the variation in care across the country, and an end to the cutting of specialist posts and services that are vital to the effective management of this rapidly growing condition.

We want to see:

- A National Implementation Plan for Diabetes, to deliver in practice the outcomes of the National Service Framework and the NICE Quality Standards
- the full implementation of NHS Health Checks and increased levels of risk assessment and identification of diabetes before people develop life-threatening complications
- Increased awareness of the signs and symptoms of Type 1 diabetes to reduce cases of DKA at diagnosis
- greater clarity around how the NICE standards and guidelines can be delivered in the new phase of the NHS
- delivery of nationally agreed standards of care, including the 9 Key Care Processes and other services as outlined in the Diabetes UK's 15 Healthcare Essentials, to reduce variability and to improve outcomes resulting from those checks
- monitoring of diabetes care and outcomes within the NHS Outcomes Framework and the Commissioning Outcomes Framework.
- diabetes commissioning guidance produced by the NHS Commissioning Board
- better commissioning to implement the outcomes of the National Service Framework and the NICE Quality Standards and support team working and integrated care through:
  - effective local delivery networks with a responsible officer/ coordinator
  - self-management, education and support for people with diabetes
  - diabetes specialist nurses and paediatric diabetes specialist nurses
  - structured footcare and retinopathy screening services
  - education and training of primary care staff about diabetes
  - specialist diabetes services working with primary care.

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