

# STATE OF THE NATION

Challenges for 2015  
and beyond



Wales

**DiABETES UK**  
CARE. CONNECT. CAMPAIGN.  
GOFALU. CYSYLLTU. YMGYRCHU.  
CYMRU

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## About Diabetes UK

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

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

# Foreword



If it was announced that a new condition had emerged that was doubling in prevalence every 17 years, and around 750,000 people in Wales were already directly affected or at serious risk, this would be seen as an epidemic and a national crisis. Over the last twelve months, the number of newly diagnosed continues to rise and the rate of increase is now starting to accelerate.

With over 500,000 people in Wales at high risk of developing Type 2 diabetes, the need for a high profile, sustained programme of risk identification and prevention is needed now more than ever. While NHS England prepares to launch its pioneering National Diabetes

Prevention Programme, commitments made by NHS Wales to deliver a range of diabetes prevention initiatives over a year ago have simply not materialised. With research showing that effective interventions can reduce the numbers developing the condition by between 30-60%, a lack of action feels short-sighted and extremely disappointing.

Last year's State of the Nation report welcomed the Welsh Government's national diabetes strategy, Together for Health: A Diabetes Delivery Plan and the clear recommendations for diabetes services' improvement contained in the Welsh Assembly's Health & Social Care Committee Inquiry into Diabetes Services. Over the last twelve months, the appointment of a Diabetes Clinical Lead, the establishment of the All Wales Diabetes Implementation Group, the creation of a Paediatric Clinical Network and the hard work that has been conducted to articulate a more effective approach to better provision of Structured Diabetes Education are to be applauded.

While these appointments and initiatives are overwhelmingly constructive, over the last twelve months it has become evident that the seemingly perennial issue of poor translation of national commitments into changes in local diabetes services continues to be a serious problem for NHS Wales. Through the report, we look in detail at the key priorities in Together for Health and the Welsh Assembly's Inquiry into Diabetes Services and find that many areas identified as requiring attention have made little or no progress and we note with some concern the difficulties that are being experienced when trying to create better co-ordination and synergy between national and local work commitments.

During 2014, we welcomed four national diabetes audit reports, covering care processes and treatment targets, inpatients, children and young people, and pregnancy in women with diabetes. This means we now have a comprehensive national and health board picture of the healthcare received by people with diabetes. Unfortunately, while the audit reports indicate some signs of progress, there is clearly a long way to go before everyone with diabetes receives high quality care.

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

Many people with diabetes are also failing to receive the support they need to self-manage their condition effectively – again, elevating the risk of long-term complications. Few people are currently offered or attend diabetes education, have personalised care plans, or have access to emotional support and specialist psychological care. In some respects, the Welsh Government's increasing emphasis on prudent healthcare will be hampered if these areas are not addressed.

As well as highlighting this situation, our State of the Nation report sets out a range of actions to address the challenges Wales faces. The overarching messages from this State of the Nation report are that good care now for everyone with diabetes, and a greater focus on prevention, can save money in the longer term – money that would otherwise be spent on treating avoidable complications, and on caring for people with avoidable cases of Type 2 diabetes. We all have to act before the number of people with diabetes overwhelms our health and social care systems and consumes an even greater proportion of NHS Wales' budget.

**Dai Williams**  
**Director, Diabetes UK Cymru**

# The state of the nation: diabetes in 2014

## Diabetes is an increasingly urgent health issue

Diabetes is the fastest growing health threat of our times and an urgent public health issue<sup>1</sup>. Since 1996, the number of people living with diabetes in Wales has more than doubled.

**182,600 people in Wales<sup>2</sup> now have diabetes.**

A further 70,000 people are estimated to have Type 2 diabetes, but do not know it<sup>3</sup>.

**Another 540,000 people in Wales are at high risk of getting Type 2 diabetes, and that number is rising dramatically every year<sup>4</sup>.**

**If diabetes identification and diagnosis improves, the figure will exceed 300,000<sup>5</sup> by 2025.**

## Diabetes is expensive to treat and manage

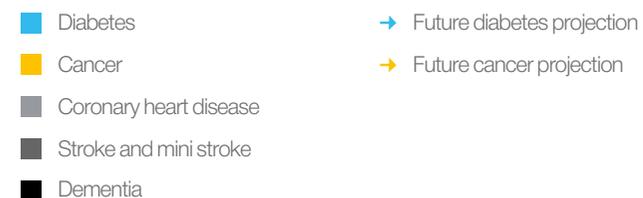
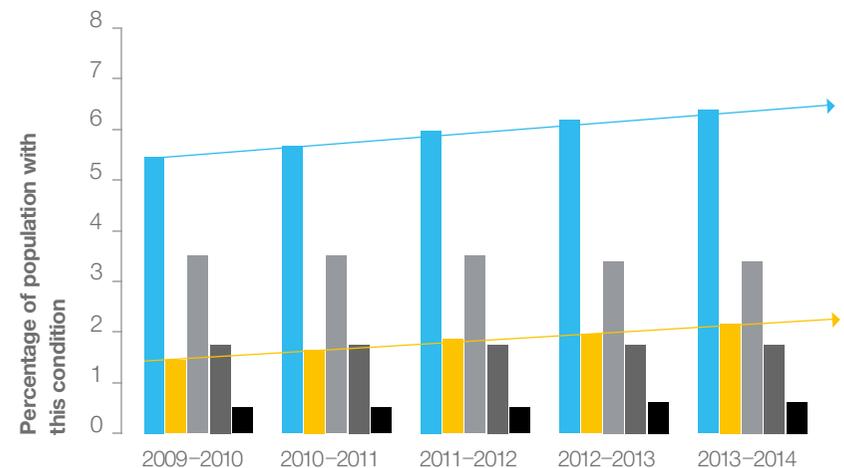
**Diabetes accounts for around 10 per cent of the annual NHS Wales budget. This is approximately £500m a year<sup>6</sup>.**

Eighty per cent of NHS spending on diabetes goes on managing complications, most of which could be prevented<sup>7</sup>.

One in 20 people with diabetes incurs social services costs. More than three-quarters of these costs are associated with residential and nursing care<sup>8</sup>.

The total cost (including direct care and indirect costs) associated with diabetes in the UK is currently estimated at £23.7 billion. These costs are predicted to rise to £39.8 billion by 2035–36<sup>6</sup>.

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



Source: Quality and Outcomes Framework prevalence data, 2009–2014

## Diabetes can cause serious complications and early death

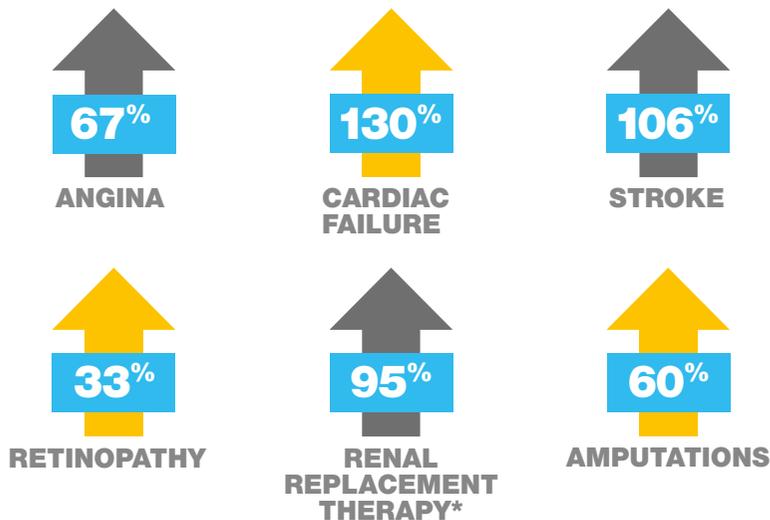
Every year, around 20,000 people with diabetes in the UK die early<sup>9</sup>.

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

Diabetes is:

- responsible for more than 300 amputations each year in Wales<sup>10</sup>
- the leading cause of preventable sight loss in people of working age<sup>11</sup>
- a major contributor to kidney failure, heart attack, and stroke<sup>12</sup>.

**Between 2007 and 2012, avoidable complications increased significantly<sup>13</sup>**



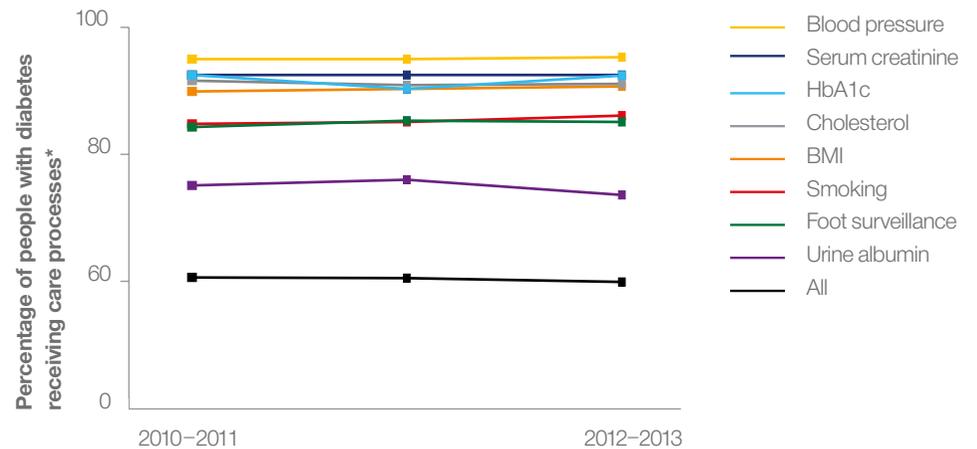
\*Term used for life-supporting treatments required to treat end stage kidney disease

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

**Too many people with diabetes are still not receiving all of the vital annual checks for the effectiveness of diabetes treatment, cardiovascular risk factors, and the emergence of early complications<sup>14</sup>.**

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

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

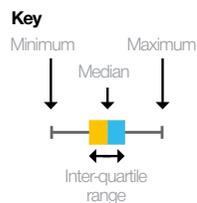
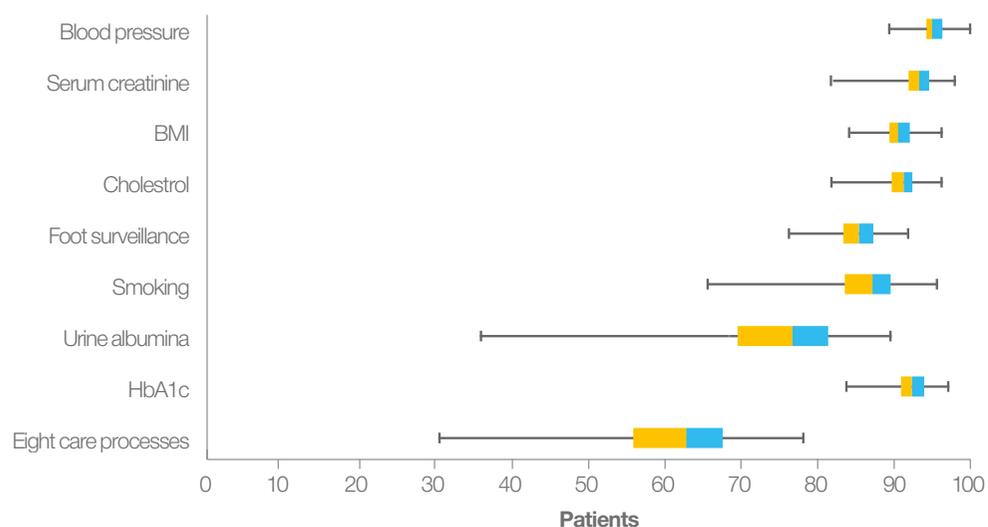


\* Excluding eye screening

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

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

**The range of CCG/LHB care process completion in England and Wales, 2012–2013**



### It is not too late to reverse these trends

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

To halt the rise in Type 2 diabetes, NHS Wales should:

- deliver its commitment to a sustained diabetes risk assessment campaign in all pharmacies in Wales to identify people at risk of Type 2 diabetes
- collaborate with NHS England on its pioneering Type 2 diabetes prevention programme to support those identified as being at high risk
- adopt measures that help everyone to maintain a healthy weight.

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

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

We need action now to:

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

# Health & Social Care Committee: Diabetes Inquiry – Progress report

**After two days of evidence from clinicians, Welsh Government representatives, professional bodies such as the BMA, RCN and patient representatives, the Health and Social Care Committee of the Welsh Assembly produced a report and thirteen recommendations to improve diabetes services in Wales. The report<sup>15</sup> was released in June 2013. After eighteen months, Diabetes UK has assessed what progress has been made utilising a RAG scoring system.**

**Recommendation 1:** The Welsh Government should ensure implementation of the National Service Framework (NSF) through strengthened oversight and monitoring arrangements, as a priority in the forthcoming delivery plan. We believe this should include a national leadership post to coordinate health board progress in delivering the NSF, and to facilitate the sharing of experiences and good practice between health boards.

- **Current position:** A mixed picture. A national Diabetes Clinical Lead has been appointed and this is excellent news. Nevertheless, there still remains a lack of oversight and monitoring of performance. A commitment that each health board produces a Diabetes Annual Report has only been partially achieved.

**Recommendation 2:** The Welsh Government commits to taking appropriate action should health boards fail to deliver the services outlined in the plan.

- **Current position:** No assessment is being made of health board plans based on Together for Health directives for local health board actions. It is not possible to take action if assessment is not currently being made.

**Recommendation 3:** The forthcoming delivery plan should include a requirement for all GP practices to participate in the National Diabetes Audit.

- **Current position:** NDA participation has decreased across England and Wales (87.9 per cent in 2011–2012 to 70.5 per cent in 2012–2013) but no specific figures exist for Wales.

**Recommendation 4:** The Welsh Government's delivery plan should require that all diabetes patients are offered all nine key annual health checks, and that health boards' performance in meeting this requirement should be monitored through full participation in the National Diabetes Audit.

- **Current position:** There has been modest improvement but people with Type 1 diabetes and those of working age record much lower levels of annual check realisation suggesting that targeted work needs to be considered to improve support for these groups.

**Recommendation 5:** The forthcoming diabetes delivery plan should ensure that local Diabetes Planning and Delivery Groups' (DPDG) relationships with health boards are formalised. Health Boards should demonstrate how they take account of DPDG recommendations and fully engage with their work. Arrangements should be put in place to adopt a national approach for DPDGs, to include national terms of reference for their operation and a requirement to meet with each other to share best practice.

- **Current position:** DPDGs exist in all health boards and some have management board representation. No national terms of reference have been produced and no meetings to share best practice occur. It is unclear if key priority areas identified for 2015 have been included in health board local diabetes delivery plans.

**Recommendation 6:** The introduction of an integrated diabetes patient management system should be a priority for the Welsh Government. We note the commitment already made to introduce such a system, and recommend that a clear timetable for its introduction is included in the forthcoming diabetes delivery plan.

- **Current position:** No agreement has been reached.

**Recommendation 7:** Future public health campaigns on diabetes should reflect the need to raise awareness of the risk factors associated with – and the early symptoms of – diabetes.

- **Current position:** No public campaigns have been agreed or delivered even though it is a priority area of the AWDIG.

**Recommendation 8:** The Welsh Government and health boards should work together to expand the role of pharmacies in conducting risk assessments, to help improve early identification of people with diabetes. Pharmacies should also play a direct role in future public health campaigns. We believe the Welsh Government should specifically consider the value of including the HbA1c test for existing patients as an enhanced service as part of the Community Pharmacy Contractual Framework.

- **Current position:** No pharmacy campaigns have been agreed or delivered even though it is a priority area of the AWDIG.

**Recommendation 9:** Welsh Government should urgently address the variances in the provision of structured education for people with diabetes. The forthcoming delivery plan should require all health boards to provide NICE-compliant structured education programmes and ensure equality of access to appropriate, timely education for all patients across Wales.

- **Current position:** The AWDIG has produced an All Wales approach to improving education provision but health board provision remains much lower than other nations in the UK and some areas deliver no education for people with either Type 1 or Type 2 diabetes.

**Recommendation 10:** Insulin pump therapy and the necessary accompanying education should be available to all suitable candidates to improve their quality of life. We recommend that the Welsh Government's forthcoming delivery plan include a requirement to improve the availability of education and training on the use of insulin pumps.

- **Current position:** No national approach has been adopted. There remains high variability across many health boards.

**Recommendation 11:** The Think Glucose programme should be introduced in all health boards across Wales.

- **Current position:** Two health boards have Think Glucose and a third intends to introduce the initiative in 2015/2016. A pan Wales approach is being worked on but it requires buy in from all health boards. Hospitals with Think Glucose have some of the lowest medication and insulin errors for diabetes inpatients'. In Wales' worst performing hospital for medication errors, over half of diabetes inpatients experienced an error while in hospital.

**Recommendation 12:** The Welsh Government undertake an audit of the number of diabetes specialist nurses in post across Wales, and the proportion of their time spent on general duties. The Welsh Government should consider the merits of issuing guidance to health boards on recommended numbers of diabetes nurses per head of population.

- **Current position:** The audit was initiated over fifteen months ago but the report has not been released.

**Recommendation 13:** The Welsh Government monitors the capacity of the Diabetic Retinopathy Screening Service to provide annual checks for diabetic patients as the growing prevalence of diabetes increases demand for the service.

- **Current position:** The DRSSW achieves some of the best outcomes of retinopathy services across the UK but it has a static budget and increasing demand.

# The All Wales Diabetes Implementation Group

## Progress report

**The AWDIG has agreed four priority areas in its first year; diabetes services for children and young people, education and self management, preventing diabetes, and improvement in foot care services. We have again assessed progress with a RAG scoring system.**

### Children and Young People

The AWDIG agreed three specific work commitments; the establishment of a new paediatric clinical network; the recruitment of a Paediatric Clinical Lead and Network Co-ordinator; and the delivery of a peer review audit across all children's diabetes units across Wales. Good progress has been made. Peer review of thirteen of the fourteen children units has occurred and a Paediatric Clinical Network has been established. The recruitment of a Paediatric Clinical Lead and Network Co-ordinator has been agreed but has yet to occur. It is not clear why there has been a delay.

- **Next steps:** The peer review process will identify areas of good practice and areas that require improvement. Paediatric diabetes services that require attention may require service redesign and workforce augmentation. The Welsh Government has undertaken a workforce audit that has assessed Diabetes Specialist Nurse and Paediatric Diabetes Specialist Nurse numbers and duties in health boards. The report is long overdue and needs to be released.

### Structured diabetes education

The AWIG has produced an All Wales strategy for improving the provision of Structured Diabetes Education (SDE) and it has set annual performance targets for each health board. The latest data on provision of SDE in Wales shows significantly poorer performance than England and high variability in provision between different health boards in Wales. Some health boards deliver no SDE for people with either Type 1 or Type 2 diabetes.

- **Next steps:** The AWDIG has constructed a roadmap to improve SDE across Wales. For too long health boards have not viewed SDE provision as a priority issue. The success of an All Wales approach to improving SDE resides with health

board buy-in. Health boards need to include augmentation of their SDE provision in their Integrated Medium Term Planning or work will not progress.

### Prevention of diabetes in Wales

The AWDIG agreed three specific work commitments in this area; an All Wales communications campaign to raise awareness of the risks of developing diabetes, piloting information prescriptions to better enable people at high risk of diabetes to minimise their risk; and a pharmacy campaign to identify the estimated 70,000 people in Wales with undiagnosed diabetes. While some initial work with NWIS is exploring the use of Audit Plus IT to flag patients at high risk, no piloting work has been conducted. No progress has been made for the other commitments.

- **Next steps:** Lack of progress has been very disappointing. NHS England/ Public Health England have recently committed to the development of a National Diabetes Prevention Programme. NHS Wales/Public Health Wales could kick start work in this area by seeking opportunities to collaborate.

### Foot Care

The Wales Foot Audit data will be received in spring 2015 and will enable NHS Wales to identify where diabetes foot care services are working efficiently and where additional work needs to be conducted. Together for Health provides clear performance indicators relating to the Putting Feet First pathway and little progress has been made over the last twelve months.

- **Next steps:** Improvements in foot care services can be best achieved if the AWDIG provides a thorough assessment of the Wales Foot Audit and articulates a pan Wales approach for improvement.

# Together for health<sup>16</sup>

## – improving delivery of the plan

### Health Board Reporting

NHS Wales' first Diabetes Annual Report contains information on a range of population level diabetes health outcomes but it does not provide an assessment of the progress made by health boards in the commitments they have made in their local diabetes delivery plans. Health boards have been tasked with this responsibility in their own annual diabetes reports. A number of health boards have failed to produce reports and where they have been produced, it is not clear how these reports are being assessed. Lack of reporting and oversight was a key concern acknowledged in the Health & Social Care Committee Inquiry into Diabetes Services. It remains an unresolved issue.

- Diabetes UK is exploring work with the Welsh Government's Performance Unit and the Diabetes Clinical Lead to gather this information and regularly report to CEOs and chairs of health boards, the Minister and Welsh Government civil servants to rectify this shortfall.

### The All Wales Diabetes Implementation Group (AWDIG)

The AWDIG was established to provide a pan-Wales approach to diabetes service improvement. It has been a positive and constructive addition and has enabled NHS Wales to identify priority areas for diabetes services improvement. Nevertheless, membership is dwindling and not all health boards are represented on the group meaning that it has been difficult to ensure that the AWDIG's priority areas are being effectively translated to health board local delivery plans.

- Diabetes UK would like to see the Welsh Government and NHS Wales require all health boards to provide representation to the group and explicitly clarify how the AWDIG works with health boards to ensure more effective national and local work collaboration.

### Improved Collaboration between Health Boards

The Health & Social Care Committee recommended that arrangements be put in place to enable health boards to meet with each other to share best practice. The AWDIG meets for two hours once every three months. It has focussed its efforts on national priority areas and is not configured to facilitate sharing of best practice and opportunities for collaboration between health boards.

- Diabetes UK is in discussion with the Diabetes Clinical Lead to establish the most effective way to rectify this situation. The charity seeks a commitment from NHS Wales to support this work and provide an extremely modest sum to make this happen.

### A funded pan-Wales model of service improvement

Devolution of the entire diabetes budget to health boards means that the AWDIG and the Diabetes Clinical Lead have no means to financially drive work that has been agreed at an All Wales level. Separate negotiations need to occur with each of the seven health boards leading to long delays. In Scotland, while NHS Boards receive the vast majority of funding for diabetes services, the Scottish Government retains a small portion of the budget to drive national initiatives.

- Diabetes UK would like to see the AWDIG and NHS Wales' Diabetes Clinical Lead receive a modest budget allocation to support the work it has been tasked to articulate and deliver at a national level.

# Preventing Type 2 diabetes

**Type 2 diabetes accounts for 90 per cent of all cases of diabetes<sup>14</sup>. The number of people with Type 2 diabetes is increasing – from 117,000 in 2006 to more than 182,000 in 2014<sup>17</sup>.**

**Moreover, over 500,000 people in Wales are at high risk of getting Type 2 diabetes, and that number is rising every year<sup>4</sup>.**

Unlike Type 1 diabetes, which is not preventable, up to 80 per cent of cases of Type 2 diabetes can be delayed or prevented<sup>18</sup>. This can be done by:

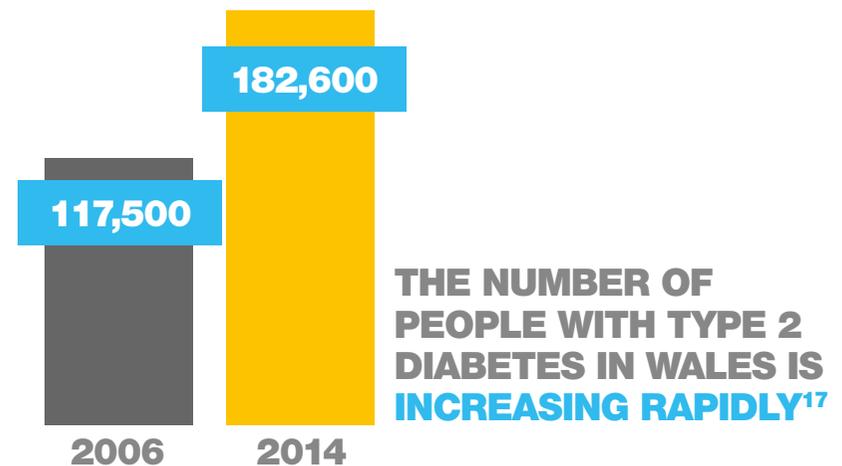
- widespread implementation of a Type 2 diabetes prevention pathway
- helping people to maintain a healthy weight, through whole population -level interventions.

## Early identification

The Welsh Assembly's Health & Social Care Committee has recommended risk assessment initiatives through pharmacies to identify those with high risk and it has also recommended that the consideration of HbA1c testing through pharmacies should be explored.

**Together for Health: A Diabetes Delivery Plan** has directed health boards to collaborate on a pharmacy based campaign and the All Wales Diabetes Implementation Group has agreed prevention of diabetes as a priority. It confirmed the requirement for a pharmacy campaign and a co-ordinated NHS Wales awareness-raising campaign. While diabetes risk assessment has been integrated into the Welsh Government's Add to your Life initiative no further risk assessment or preventative work has been conducted at a pan Wales level.

Despite the Health & Social Care Committee Inquiry, Together for Health: A Diabetes Delivery Plan, and the All Wales Diabetes Implementation Group commitment to risk assessment campaigns for diabetes, nothing has happened.



## Helping everyone to maintain a healthy weight

**Being overweight or obese is the most significant risk factor for Type 2 diabetes, and accounts for 80 to 85 per cent of the risk of developing this condition<sup>19</sup>.**

Maintaining a healthy weight, eating a balanced diet, and being active, are therefore the most effective ways of preventing Type 2 diabetes. However, there has been a marked increase in obesity over the past 20 years. In Wales, 59 per cent of adults and 30 per cent of children are now overweight or obese<sup>20,21</sup>. Almost nine out of every 10 people diagnosed with Type 2 diabetes are overweight<sup>22</sup>.

## What needs to happen now?

- ✓ Public Health Wales needs to adopt a stronger leadership role to translate Welsh Government and NHS Wales commitments for a sustainable pharmacy campaign into reality.
- ✓ Through the Five Year Forward View, NHS England and Public Health England are developing a national, evidence based diabetes prevention programme. This is the right time to collaborate. Public Health Wales and NHS Wales should explore the benefits that could accrue from partnership to enjoy a more methodical and cost effective response for Wales in the future.

# 15 Healthcare Essentials for everyone with diabetes

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

The Diabetes UK 15 Healthcare Essentials set out the care that all people with diabetes should expect to receive from their healthcare team every year. They include the nine care process checks recommended by NICE<sup>23</sup>, and provide a starting point for ensuring everyone gets high quality and effective care.

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

- 1 Get your blood glucose levels (HbA1c) measured** at least once every year. This will measure your overall blood glucose control and help you and your healthcare team set a target.
- 2 Have your blood pressure measured** and recorded at least once a year, and set a personal target that is right for you.
- 3 Have your blood fats, such as cholesterol, measured** every year. You should have a target that is realistic and achievable.
- 4 Have your eyes screened** for signs of retinopathy every year.
- 5 Have your feet checked.** The skin, circulation and nerve supply of your feet should be examined annually. You should then be told if you have any risk of foot problems and how serious they are.
- 6 Have your kidney function monitored** annually. This should involve two tests: a urine test for protein and a blood test to measure kidney function.
- 7 Have your weight checked and your waist measured** to see if you need to lose weight.
- 8 Get support if you are a smoker,** including advice and support on how to quit.
- 9 Engage in care planning discussions** with your healthcare team to talk about your individual needs and set targets.
- 10 Attend an education course** in your local area to help you understand and manage your diabetes.
- 11 Receive care from a specialist paediatric team** if you are a child or young person.
- 12 Receive high-quality care if admitted to hospital from specialist diabetes healthcare professionals,** regardless of whether or not you have been admitted due to your diabetes.
- 13 Get information and specialist care if you are planning to have a baby** as your diabetes control has to be a lot tighter and monitored very closely. You should expect care and support from specialists at every stage, from preconception to postnatal care.
- 14 See specialist diabetes healthcare professionals** to help you manage your diabetes, such as podiatrists, ophthalmologists, and dietitians.
- 15 Get emotional and psychological support.** Being diagnosed with diabetes and living with a long-term condition can be difficult, and you should be able to talk about issues and concerns with specialist healthcare professionals.

# Variations in diabetes care and outcomes

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

An integral part of this is the receipt of NICE-recommended care processes. These are the annual checks for the effectiveness of diabetes treatment (HbA1c), cardiovascular risk factors (blood pressure, serum cholesterol, BMI, smoking), and emergence of early complications (foot checks, eye screening, and two tests for kidney function). Unfortunately, the 2012–2013 National Diabetes Audit showed that annual completion rates for eight of these care processes continue to plateau – at 60 per cent<sup>24</sup>.

Moreover, there are worrying variations in the care and treatment received by some population groups, and in different parts of Wales.

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

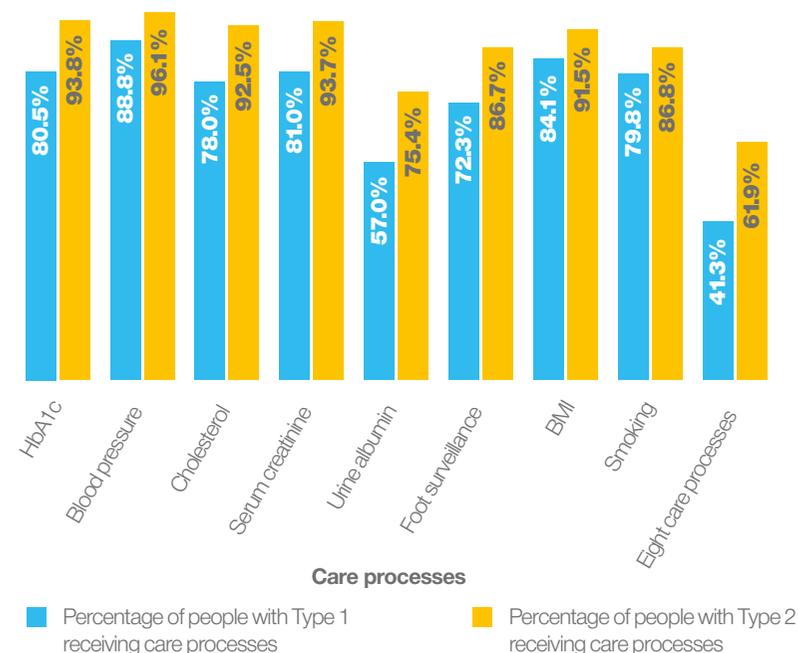
People with Type 1 diabetes – of all ages and ethnic groups – routinely receive worse care and treatment than people with Type 2 diabetes.

In 2012–2013, fewer people with Type 1 diabetes received each of the eight recommended care processes. Overall, only 41 per cent of people with Type 1 diabetes received all eight care processes, compared with 62 per cent of people with Type 2. People with Type 1 were also less likely to meet the recommended treatment targets for blood glucose (HbA1c) and cholesterol<sup>14</sup>.

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

Foreword, National Diabetes Audit 2012–13

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



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

## Working age people receive poorer care

People of working age with Type 1 or Type 2 diabetes are less likely than older people to receive the recommended care processes and meet treatment targets. In the under 40s, only 29 per cent of people with Type 1 diabetes and 46 per cent with Type 2 diabetes received eight care processes. In comparison, more than 60 per cent of people in the 65 to 79 age group received all these processes<sup>14</sup>.

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

Only 15 per cent of people with Type 1 diabetes under 65 age met all three treatment targets, compared with more than 20 per cent in the older age groups. Similarly, the targets were met by less than one-third of people with Type 2 diabetes in the younger age groups, but more than 40 per cent of those aged 65 and above<sup>14</sup>.

## Too many children and young people also receive poor care

Children and young people are even less likely to receive the recommended care processes. In 2012–2013, only 12 per cent of young people aged between 12 and 19 had all their care processes recorded<sup>25</sup>. Although this figure had almost doubled – from 6.7 per cent in 2011–2012 – it continues to be well below results for adults with Type 1 diabetes<sup>26</sup>.

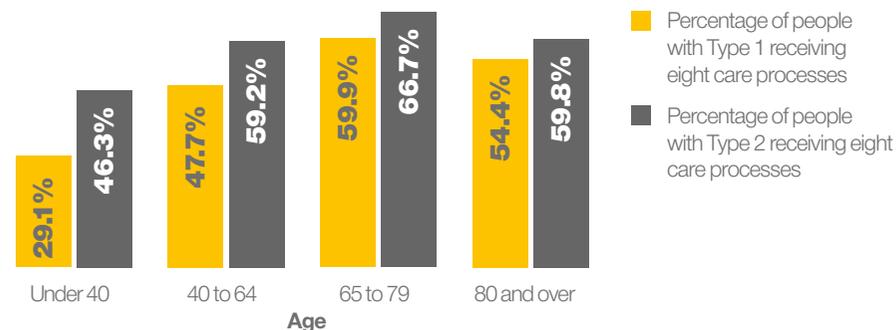
Children and young people also have problems controlling their diabetes. One in four had worryingly high HbA1c levels (over 80mmol/mol). This proportion was even higher among children from ethnic minorities<sup>25</sup>.

## There are geographical variations in care and outcomes

As highlighted throughout this report, there are considerable variations between GP clinics in all health boards in terms of care process completion rates and the achievement of treatment targets in all people with diabetes.

Where a person lives has a significant impact on their ability to receive the care they need and achieve good outcomes.

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



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



For Health Board level data, see the Diabetes Watch online tool: [diabeteswatch.diabetes.org.uk](http://diabeteswatch.diabetes.org.uk)

# 1 HbA1c

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

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

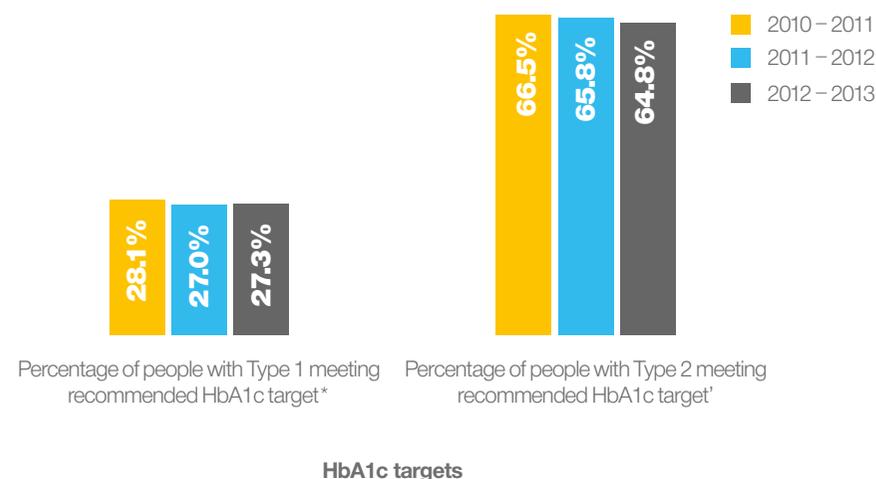
This check is carried out frequently. In 2012–2013, more than 90 per cent of all people with diabetes were recorded as having an annual HbA1c check<sup>14</sup>.

People with Type 1 diabetes were much less likely to receive this check, though – only 80 per cent, compared with 94 per cent of people with Type 2 diabetes. This situation is getting worse – in 2010–2011, the figure for people with Type 1 diabetes was 86 per cent<sup>14</sup>.

**There has been a worrying lack of progress with achieving the NICE recommended treatment targets for HbA1c.**

Of particular concern is that:

- substantial numbers of people have exceptionally high-risk glucose levels – 17 per cent of Type 1 and 7 per cent of Type 2 patients had HbA1c equal to or above 86mmol/mol.
- people with Type 1 diabetes were much less likely to reach recommended targets than people with Type 2 diabetes.



\*HbA1c  $\leq$ 58mmol/mol (7.5%)

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



For Health Board level data, see the Diabetes Watch online tool:  
[diabeteswatch.diabetes.org.uk](http://diabeteswatch.diabetes.org.uk)

# 2 Blood pressure

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

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

Cardiovascular disease (CVD) is a major cause of death and disability in people with diabetes, accounting for 44 per cent of fatalities in people with Type 1 diabetes and 52 per cent in people with Type 2<sup>12</sup>.

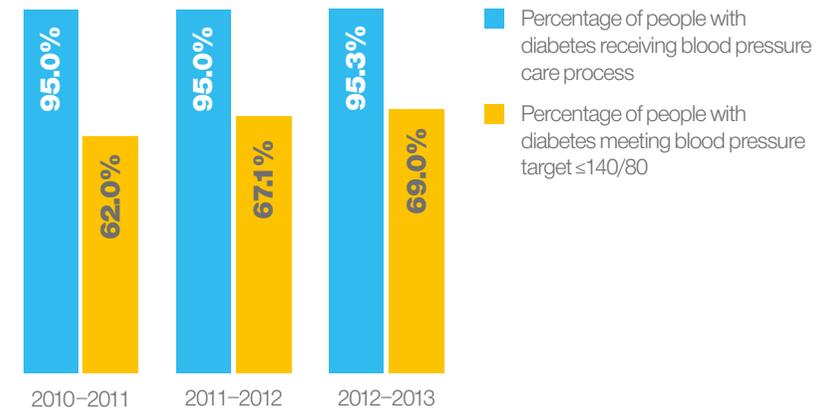
Poor blood pressure control further increases the risk of developing this complication, and of suffering a stroke in particular. It also increases the risk of kidney disease. NICE recommends people with diabetes have their blood pressure measured at least once a year, and provides recommendations for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

In 2012–2013, 95 per cent of people with diabetes in Wales had their blood pressure checked – a similar figure to previous years. However, only 69 per cent of those people met the recommended treatment target – a small improvement from 2011–2012<sup>14</sup>.

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

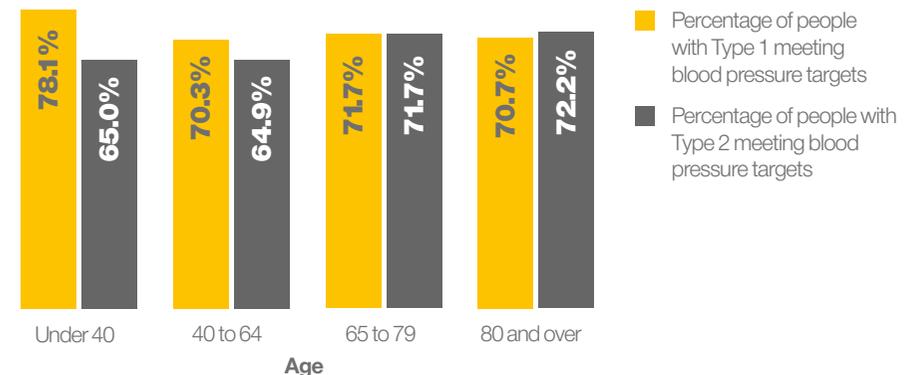
There was a considerable variation in blood pressure target achievement rates by GP clinics in health boards, for patients with both types of diabetes<sup>14</sup>.

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



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

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



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



For Health Board level data, see the Diabetes Watch online tool: [diabeteswatch.diabetes.org.uk](http://diabeteswatch.diabetes.org.uk)

# 3 Cholesterol

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

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

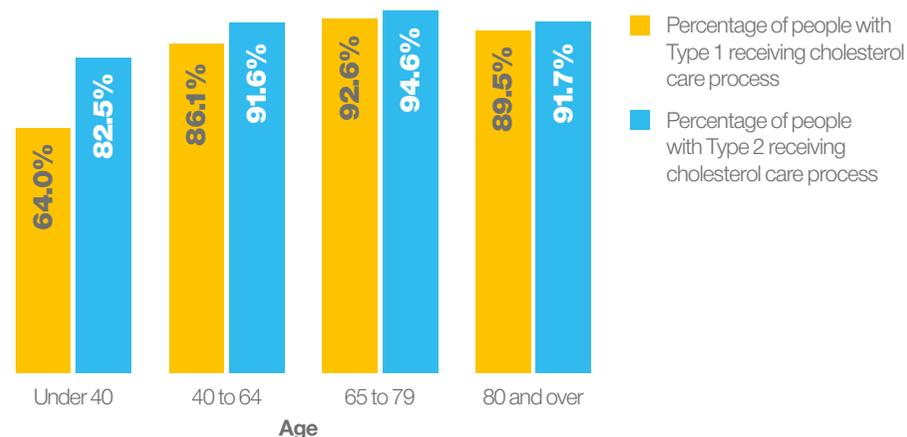
In 2012–2013, while 92 per cent of people with Type 2 diabetes received a cholesterol check, only 78 per cent of people with Type 1 had this essential check<sup>14</sup>.

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

As with treatment targets for HbA1c and blood pressure, there were large variations in achievement rates across GP clinics in all health boards in Wales. This indicates there is considerable scope for improvement in many areas.

A quarter of all people with diabetes did not meet the cholesterol treatment target increasing their risk of complications.

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



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



For Health Board level data, see the Diabetes Watch online tool:  
[diabeteswatch.diabetes.org.uk](http://diabeteswatch.diabetes.org.uk)

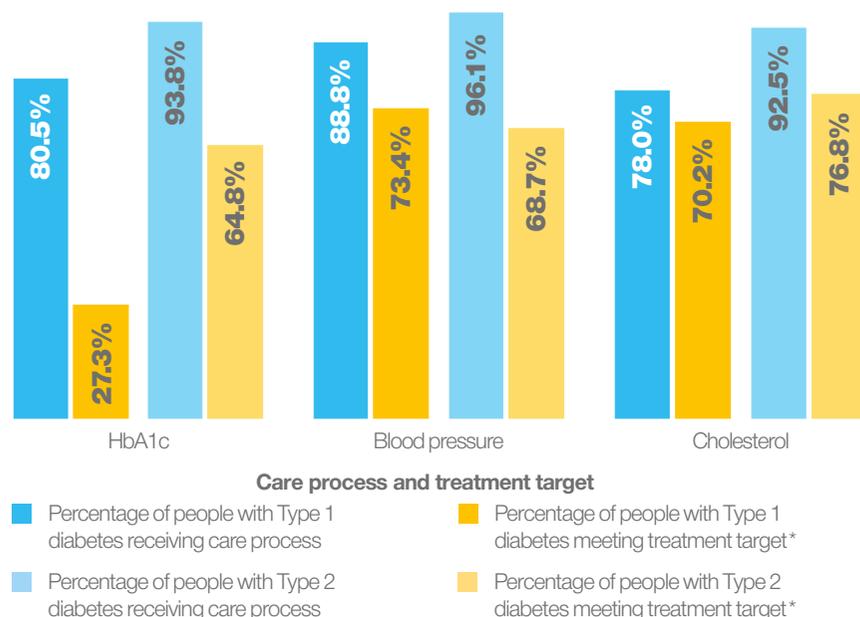
# Actions to improve care processes and outcomes

**Only 16 per cent of people with Type 1 diabetes and 37 per cent of people with Type 2 meet their key clinical treatment targets**

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

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

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



\* HbA1c ≤58mmol/mol (7.5%), BP ≤140/80, Cholesterol <5mmol/L  
Source: National Diabetes Audit 2012–13 (figures for England and Wales)

**There continues to be high variability between different GP practices in Wales and considerable progress is required in relation to better achievement of treatment targets.** The best performing GP practices achieve double the number of patients achieving key treatment targets than the worst performing GP practices in the same area. In 2012–2013:

- 36 per cent of people with diabetes met all three targets – the same as in 2011–2012
- working age people were less likely to achieve treatment targets than those aged 65 and over.

## What needs to happen now?

- ✓ **All health boards** need to set themselves performance improvement targets and implement plans of action to reduce the high variability in checks and treatment target realisation that people with diabetes receive.
- ✓ **The bottom 25 per cent of GP practices** need to take steps to achieve levels of performance similar to the middle 50 per cent in their health board as a matter of urgency.
- ✓ **Primary healthcare professionals** need to make use of information prescriptions to help people with high blood pressure, HbA1c, or cholesterol. Information prescriptions provide people with diabetes with information and support that enables them to live well with their condition. They have recently been embedded in primary care IT systems in Wales. It is up to healthcare professionals to use these new tools to support care planning and behavioural change in their patients.

# 4 Eye screening

Many people with diabetes are not having their eyes checked regularly

**Retinopathy is a serious complication that can affect anyone with diabetes. Diabetic retinopathy accounts for around 7 per cent of people who are registered blind<sup>27</sup>. People with diabetes also have an increased risk of developing glaucoma and cataracts.**

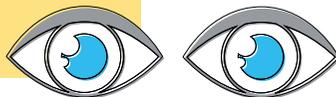
Keeping blood glucose, blood pressure and cholesterol levels under control can help to reduce the risk of developing retinopathy. People with diabetes should also have their eyes screened for retinopathy every 15 months to ensure problems are identified and treated as early as possible.

- Number eligible, active patients for screening 156,342.<sup>28</sup>
- 115,528 patients attended an appointment.<sup>28</sup>
- There was a 20.48 per cent DNA rate.<sup>28</sup>
- The incidence of retinopathy in the total population screened was 29.22 per cent.<sup>28</sup>
- Referable rate to hospital eyes services was (3.3 – 1.98 per cent) for DR and (1.32 per cent) for non DR.<sup>28</sup>
- Scheduled appointments offered 145,278<sup>28</sup>

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

**Less than half of people realise diabetes can cause blindness.**

Ipsos MORI survey for Diabetes UK, 2014



The charity welcomes efforts by the Diabetic Retinopathy Screening Service for Wales to provide increased self-management and prevention of complications information to people with diabetes who attend retinopathy appointments.

## What needs to happen now?

- ✓ **Everyone with diabetes** needs to be informed about the risks to their sight and preventative measures, as part of care planning with their healthcare professionals, and through participation in learning opportunities.
- ✓ **Welsh Government** and NHS Wales should collaborate with the DRSSW to ensure that appropriate resource is applied to enable the service to increase its information and prevention work.

# 5 Foot checks

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

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

Over 300 people with diabetes have a leg, foot or toe amputation each year in Wales<sup>9</sup>. It is estimated that approximately 2,000 people with diabetes in Wales have foot ulcers at any given time. Amputations and foot ulcers have a huge impact on quality of life and they also cost lives. Up to 80 per cent of people die within five years of having an amputation<sup>29</sup>.

People with diabetes are more likely to be admitted to hospital with a foot ulcer than with any other complication of diabetes. Foot ulcers and amputations are very costly to the NHS.

Foot ulcers and amputations are estimated to cost between £30–35m each year. 80 per cent of amputations are potentially preventable through improved awareness among people with diabetes about their risk status, and improved access to good-quality structured care<sup>30</sup>.

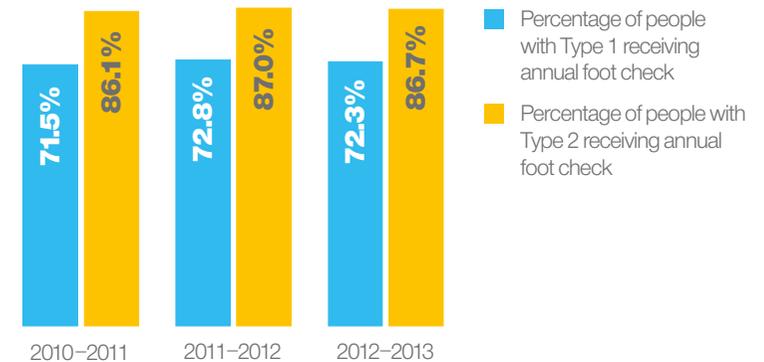
## Annual foot checks

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

Despite this, 28 per cent of people with Type 1 diabetes and 13 per cent of people with Type 2 diabetes are still not receiving an annual foot check<sup>14</sup>. These figures have hardly changed over recent years.

We are also continuing to see significant variations between health board areas. In the best-performing areas, more than 90 per cent of people with diabetes had their feet checked in 2012–2013; in the worst, only 75 per cent did. The gap is even greater in people with Type 1 diabetes<sup>14</sup>.

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



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



For Health Board level data, see the Diabetes Watch online tool: [diabeteswatch.diabetes.org.uk](http://diabeteswatch.diabetes.org.uk)



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

Ipsos MORI survey for Diabetes UK, 2014

## Integrated foot care services

**The risk of amputation can be reduced through provision of an integrated foot care pathway**, with trained staff in community foot protection services and quick access to multidisciplinary specialist teams<sup>31</sup>. These teams can save more than four times their cost<sup>30</sup>.

**Together for Health: A Diabetes Delivery Plan** directs health boards that 'all patients with a diabetes related foot problem, or found to have one following initial assessment, should be referred to a multidisciplinary foot-care team within 24 hours of admission'.

The percentage of hospitals with multidisciplinary foot care teams has been increasing from 61 per cent in 2010 to 72 per cent in 2013. However, this still means more than a quarter of hospitals are without such a team<sup>32</sup>.

It is vital that people with foot infections or ulcers are seen by a member of a multidisciplinary team within 24 hours of referral. While improvements have been made, in 2013 more than 40% of patients did not receive input from this team in this timeframe<sup>32</sup>.

## Foot protection in hospital

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

The percentage of in-patients with diabetes who developed a foot ulcer fell significantly between 2010 and 2013 – from 2.2 per cent to 1.4 per cent. However, in 2013, only 42 per cent of people had their feet examined at any point during their hospital stay. This suggests there is still considerable room for improvement<sup>32</sup>.

**Together for Health: A Diabetes Delivery Plan** fully supports the Putting Feet First Pathway. It directs health boards to 'Implement the Putting Feet First Pathway and quality standards set for prevention and management of diabetic foot disease'.

The All Wales Diabetes Implementation Group has identified foot-care as a priority work-stream and is undertaking an audit of foot-care services across all health boards in Wales.

## What needs to happen now?

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

# 6 Kidney function

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

**Kidney disease is more common in people with diabetes than the general population. It is an expensive complication to treat. It accounts for 21 per cent of deaths in people with Type 1 diabetes and 11 per cent in people with Type 2 diabetes<sup>12</sup>.**

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

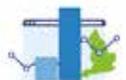
NICE recommends two tests: a urine test for protein – which is a sign of possible kidney problems – and a blood test to measure kidney function.

While the blood test was measured in a high percentage of patients with diabetes in 2012–2013 (92.5 per cent overall), measurement of the urine test was the lowest of all of the NICE-recommended care processes<sup>14</sup>. It has consistently been below target and provision of checks is becoming worse.

**In 2012–2013, only 74 per cent of all patients received the urine albumin screening test.** Recorded rates for completion of this test were particularly low in people with Type 1 diabetes (57 per cent) and in people aged under 40 (44 per cent in people with Type 1 diabetes and 59 per cent in people with Type 2)<sup>14</sup>. In some GP clinics, as few as 35% of people with diabetes received the check.

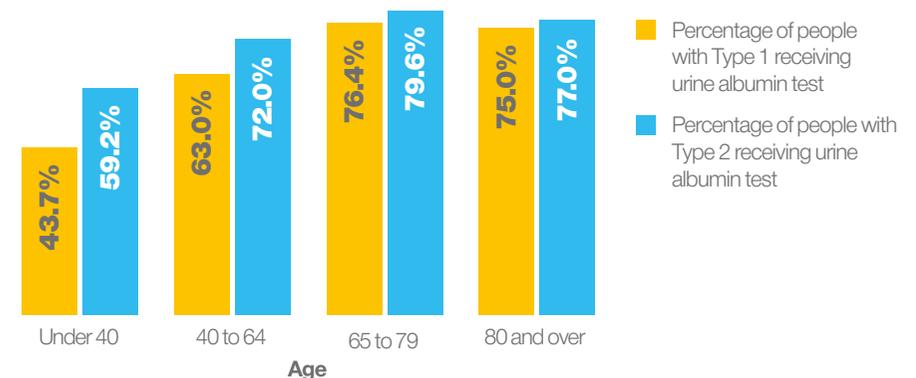
**Only 10 per cent of people realise diabetes can lead to kidney failure.**

Ipsos MORI survey for Diabetes UK, 2014



For Health Board level data, see the Diabetes Watch online tool: [diabeteswatch.diabetes.org.uk](http://diabeteswatch.diabetes.org.uk)

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



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

## What needs to happen now?

- ✓ **People with diabetes and their healthcare teams** need to understand why urine albumin tests are important, and ensure they happen.
- ✓ **Health boards** need to review National Diabetes Audit data on urine albumin screening for their GP clinics, set targets for improvement for the poorest performing areas, and implement action plans to achieve these targets.

# 7 Weight

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

**People with diabetes have a higher chance of developing cardiovascular disease (CVD) than the general population<sup>33</sup>, and being overweight or obese increases that risk. Weight loss can improve blood pressure, cholesterol and blood glucose levels, which are CVD risk factors.**

In 2012–2013, 91 per cent of people with Type 2 diabetes had their body mass index (BMI) recorded and of these people, 86 per cent were classed as overweight or obese. In comparison, 62 per cent of people with Type 1 diabetes whose BMI was recorded were overweight or obese<sup>34</sup>.

People with either type of diabetes who were obese were least likely to meet all the treatment targets for blood glucose (HbA1c), blood pressure and cholesterol. This puts them at an increased risk of developing complications like CVD<sup>14</sup>.

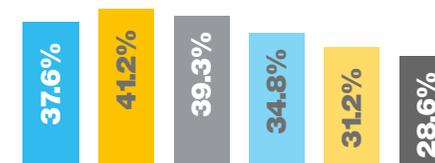
While the majority of people with diabetes had their weight monitored and BMI calculated, it is unclear what – if any – support was provided to those people who would benefit from losing weight, and need help to do this. There is a lack of information about referrals to weight management programmes or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

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



For Health Board level data, see the Diabetes Watch online tool:  
[diabeteswatch.diabetes.org.uk](http://diabeteswatch.diabetes.org.uk)

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



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



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

### What needs to happen now?

- ✓ **GPs and other healthcare professionals** should identify people with diabetes who need support to lose weight and refer them to appropriate services.
- ✓ **Increased use of personal care plans** would enable more effective goals setting and consistent monitoring of progress.

# 8 Smoking

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

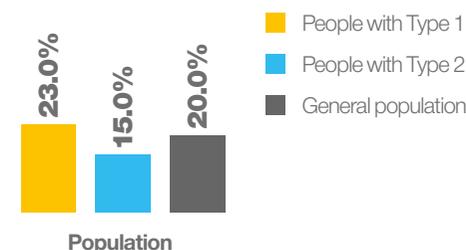
**Smoking increases the risks of suffering serious complications – like heart attack, stroke, and amputation – that are associated with diabetes. People with diabetes should have their smoking status checked and, if they smoke, be given help to stop.**

In 2012–13, 86 per cent of people with diabetes in Wales had their smoking status recorded. Only 80 per cent of people with Type 1 diabetes received this check, though, compared with 87 per cent of people with Type 2<sup>14</sup>.

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

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

*Smoking prevalence in people with recorded smoking status*



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

### What needs to happen now?

- ✓ **Health boards** should make sure smokers with diabetes, particularly people at risk of foot problems, neuropathy, or other complications, are being identified and referred to smoking cessation services.
- ✓ **GPs and other healthcare professionals** should use personal care plans and care planning sessions to support people with diabetes who need to stop smoking, refer them to appropriate sources of advice, and check their progress.



For Health Board level data, see the Diabetes Watch online tool:  
[diabeteswatch.diabetes.org.uk](http://diabeteswatch.diabetes.org.uk)

# 9 Personalised care planning

Collaborative care planning is still not widely used

**Care planning is a continuous process, in which patients and clinicians work together to agree goals, identify support needs, develop and implement action plans, and monitor progress. It has been shown to improve the skills, knowledge and experiences of patients and healthcare professionals, and can enable people with diabetes to make positive changes to their behaviour<sup>35</sup>.**

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

The Welsh Government's National Service Framework on Diabetes (2003–2013) and Together for Health: A Diabetes Delivery Plan (2014–2017) explicitly states that all people with diabetes should have a personalised care plan in place. The directive has never been uniformly implemented. Some GP surgeries use them while others do not, creating confusion for many people with diabetes who contact the charity.

**Only 40 per cent of respondents said they had developed a care plan with their healthcare professional,** and decided this by discussing their individual needs and setting targets<sup>36</sup>.

## What needs to happen now?

- ✓ **Poorly managed diabetes leads to serious complications.** Only 16 per cent of people with Type 1 diabetes and 37 per cent of people with Type 2 diabetes met all the treatment targets. If a commitment to personal health care planning is serious, NHS Wales needs to reconsider and articulate a different approach. Many people with diabetes are not receiving what they are told they should receive to better enable them to manage their diabetes.

# 10 Education and support for self-management

**Supported self-management is integral to the successful daily management of diabetes. Personalised care planning, psychological and emotional support, and access to information and learning can all contribute to effective self-management<sup>37</sup>.**

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

3.4 per cent of people with Type 1 diabetes, and 1.2 per cent with Type 2, were recorded as attending structured education.

The Health & Social Care Committee Inquiry into the implementation of the National Service Framework for diabetes in Wales and its future direction states:

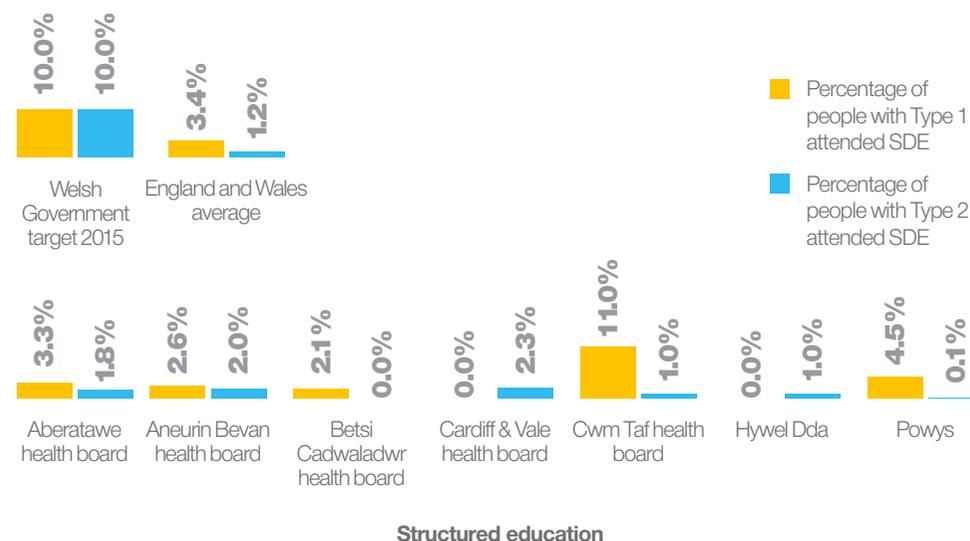
- **Recommendation 9:** the Welsh Government should urgently address the variances in the provision of structured education for people with diabetes.
- **Together for Health: A Diabetes Delivery Plan** should require all health boards to provide NICE-compliant structured education programmes and ensure equality of access to appropriate, timely education for all patients across Wales.
- **Together for Health: A Diabetes Delivery Plan** directs health boards to deliver a 'significant improvement in delivery of structured education'. The All Wales Diabetes Implementation Group has agreed that all health boards achieve:
  - 2015 – 10 per cent of newly diagnosed attend SDE, 2016 – 30 per cent of newly diagnosed attend SDE, 2017 – 50 per cent of newly diagnosed attend SDE.



For Health Board level data, see the Diabetes Watch online tool: [diabeteswatch.diabetes.org.uk](http://diabeteswatch.diabetes.org.uk)

## Structured Diabetes Education

The All Wales Diabetes Implementation Group<sup>38</sup> recently conducted an audit of structured diabetes education across health boards in Wales:



## What needs to happen now?

- ✓ **Health boards** need to urgently reconfigure their services and workforce to enable them to deliver the DAFNE structured diabetes education programme for people with Type 1 diabetes and the XPERT programme for people with Type 2 diabetes.

# 11 Care for children and young people

Around 96 per cent of the 1,400 children and young people in Wales with diabetes have Type 1<sup>25</sup>. Unlike Type 2 diabetes, Type 1 diabetes cannot be prevented, and tends to develop earlier in life.

## Early identification of Type 1 diabetes is vital

Around 15 per cent of cases of Type 1 diabetes are diagnosed after children develop Diabetic Ketoacidosis (DKA) – where abnormally high blood glucose levels can lead to organ damage, coma or death<sup>39</sup>. It is crucial therefore that Type 1 diabetes is identified early.

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

## Quality healthcare for children and young people

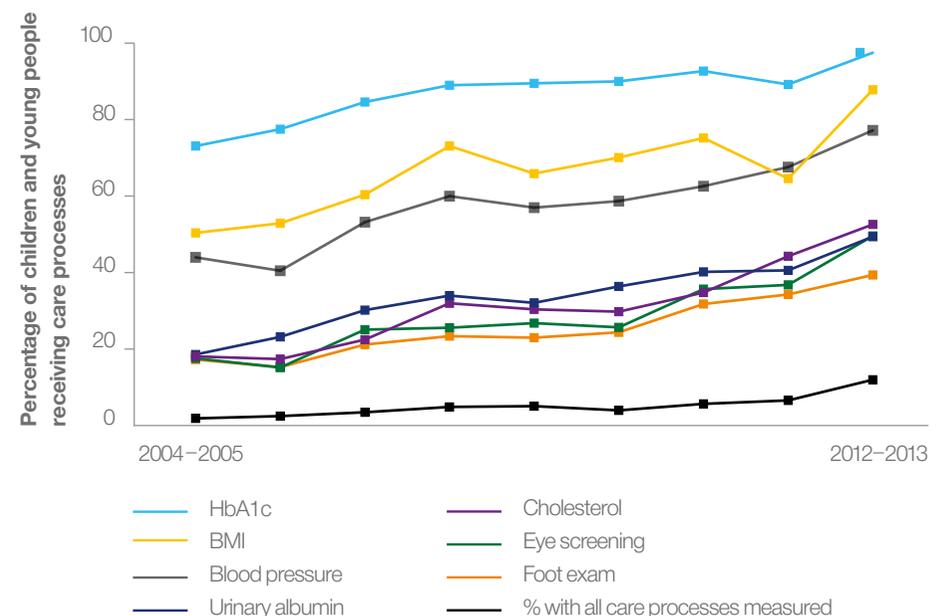
Children and young people with diabetes should have access to high-quality care from specialist paediatric healthcare professionals, and receive seven key processes of care every year<sup>40</sup>.

Increasing numbers of young people (aged between 12 and 24) are getting each of the seven care processes. The percentage of young people having all of these important checks has almost doubled – from 6.7 per cent in 2011–2012 to 12.1 per cent in 2012–2013<sup>25</sup>.

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

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

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



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

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

## More than a quarter of children and young people with diabetes have unacceptable blood glucose levels, and only 12 per cent receive all of the recommended health checks – these poor standards of care cannot continue<sup>25</sup>

### Supporting children with diabetes at school

In England, schools now have a legal responsibility to look after children with diabetes to improve the support they provide to children with diabetes<sup>41</sup>. Guidance for Welsh schools through 'Access to Education and Support for Children and Young People with Medical Needs'<sup>142</sup> is less comprehensive, less directive and is nearly five years old.

Failure to review and update Welsh school guidance informed by the more comprehensive approach adopted in England will increasingly lead to a poorer and less systematic framework of support experienced by children with Type 1 diabetes in Wales.

### Effective transition to adult services

Around a quarter of admissions for DKA are in the 16 to 25 age group<sup>39</sup>.

Diabetes control often deteriorates during adolescence, and young people are particularly vulnerable when their care is transferred from child to adult diabetes services. This is also a time when life-long health behaviours are developed.

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

**Together for Health: A Diabetes Delivery Plan** has demonstrated positive Welsh Government commitments to improvements in diabetes services for children and young people. The charity welcomes:

- The establishment of a Paediatric Diabetes Clinical Network to facilitate better collaboration between the 14 paediatric diabetes units in Wales
- The recruitment of a Paediatric Clinical Lead and Network Co-ordinator to drive work through the Paediatric Diabetes Clinical Network
- The delivery of Peer Review of the 14 paediatric diabetes units in Wales

### What needs to happen now?

- ✓ **The Welsh Government** commits to a review and update of Access to Education and Support for Children and Young People with Medical Needs to avoid falling behind in the support it provides to children with diabetes in Welsh schools.
- ✓ **Peer Review will identify both strengths and weakness in Welsh paediatric care.** The Welsh Government and NHS Wales needs to ensure that health boards demonstrate a robust and constructive response to recommendations that emerge following peer review of their paediatric diabetes services.

# 12 Inpatient care

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

**People with diabetes need to receive specialist care and support when they are in hospital, regardless of the reason for their admission. This is essential to ensure their diabetes is well managed, to minimise the risk of complications arising, and to prevent patient harm. While 6 per cent of the population of Wales has diabetes, over 15 per cent of hospital in-patients have the condition.**

Evidence suggests specialist diabetes in-patient teams save three times their cost. They reduce prescribing errors and improve patient outcomes, leading to fewer expensive complications in hospital and a shorter stay<sup>43</sup>.

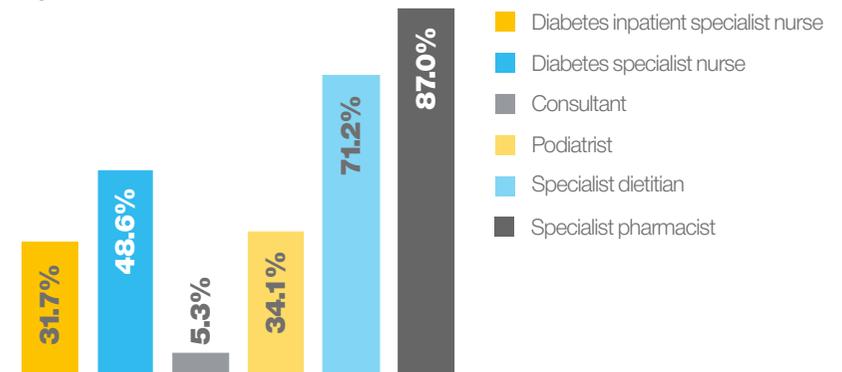
The 2013 National Diabetes Inpatient Audit (NDiA) showed that:

- only around a third of in-patients with diabetes were seen by a member of the diabetes team
- almost one-third of sites did not have a diabetes in-patient specialist nurse, and a similar proportion did not have a multidisciplinary foot care team.

Nearly a quarter of in-patients who responded to the patient experience questionnaire in the National Diabetes Inpatient Audit (NDiA) said they would have liked more involvement in the planning of their diabetes treatment. Some respondents found it difficult to self-manage their condition during their stay because they were unable to test their blood glucose levels, or were not provided with the right type of food.

In one hospital in Wales, more than half of in-patients with diabetes experienced a medication error.

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



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

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

**Think Glucose<sup>44</sup> is a diabetes initiative developed by the NHS Institute for Innovation and Improvement to improve the care of people with diabetes when they are admitted to hospital. It provides a comprehensive package of service improvement, leading to a clinical pathway that ensures that all staff are better equipped to care for patients with diabetes. It has been shown to reduce errors, reduce duration of inpatient stay and save money.**

The National Institute for Health and Care Excellence conducted a Quality, Innovation, Productivity and Prevention Assessment of Think Glucose and examined in detail outcomes achieved by Dudley Clinical Commissioning Group. It found:

- Average length of stay reduced by 0.61 days generating savings of £422,000 in the first 8 months.
- HbA1c reduced by 1.71% for new-onset diabetes patients.
- Insulin prescription errors reduced from 24.6 per cent to 6.4 per cent.

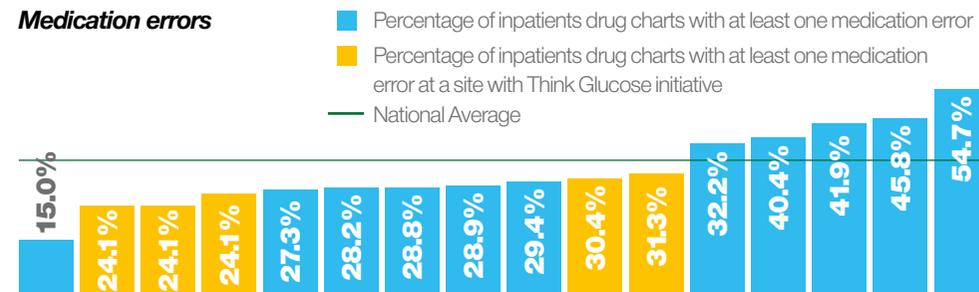
In June 2013, the Welsh Government’s Health & Social Care Committee conducted the ‘Inquiry into the Implementation of the National Service Framework for Diabetes in Wales and its future direction’. It assessed ThinkGlucose and noted support from the Royal College of Nursing and all clinicians who gave evidence.

The Committee concluded that ‘rolling out the programme to other health boards would improve patient care’. It went further and provided a specific recommendation.

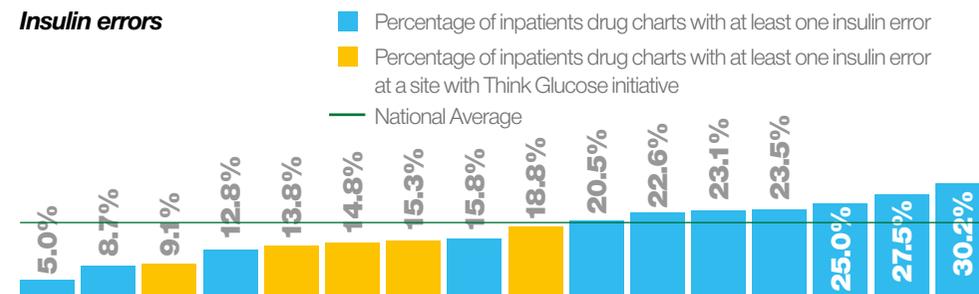
**Recommendation 11:** We recommend that the Think Glucose programme should be introduced in all health boards in Wales.

In June 2013, two health boards in Wales were delivering Think Glucose. In 2015, no progress has been made. The situation remains unchanged.

#### Medication errors



#### Insulin errors



### What needs to happen now?

- ✓ **The Welsh Government,** NHS Wales and health boards need to reflect on why advice on inpatient care has been ignored and change the nature of their reporting, oversight and managerial relationship.
- ✓ **To reduce medical errors,** patient harm and future litigation, all health boards in Wales should implement Think Glucose across their hospital wards.

# 13 Pregnancy care

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

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

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

In 2014, the first national pregnancy in diabetes audit reported on data collected from 1,700 pregnancies and 128 participating organisations. Nearly half of the women included had Type 2 diabetes. The audit provided a wealth of useful information, but raised concerns about the care given to women with diabetes<sup>45</sup>.

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

- Only 5 per cent of women with Type 1 diabetes, and 18.5 per cent of women with Type 2 diabetes, achieved the target blood glucose levels. 11 per cent of women with Type 1 diabetes, and 9 per cent with Type 2, had blood glucose measurements at the level at which NICE guidelines recommend pregnancy is avoided.
- Some of the medicines used to treat diabetes must not be taken during pregnancy. Despite this, one in 10 women with Type 2 diabetes became pregnant while taking a potentially hazardous glucose-lowering medication.
- First contact with a specialist antenatal diabetes team should happen as early as possible. While more than half (51.2 per cent) of women with Type 1 diabetes had their first contact with this team prior to eight weeks gestation, only just over one third (36.6 per cent) of women with Type 2 had their first contact with the team in this timeframe.

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

**Rates of stillbirths and neonatal deaths remain high. 30 per cent of babies required intensive or specialist neonatal care.**

## What needs to happen now?

- ✓ **Diabetes and maternity services need to better collaborate to:**
  - address the high number of pregnant women who would benefit from improved glucose control during pregnancy
  - incorporate information about pregnancy into patient education programmes and other learning opportunities
  - screen for complications (which can get worse during pregnancy)

# 14 Specialist care

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

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

Integrated pathways of care across primary, community and specialist care are the ideal way of ensuring people with diabetes get the support and treatment they need in the right place, and at the right time, in a coordinated manner.

In an integrated model of care, local diabetes services are configured in a way that focuses on the patient's perspective, needs and circumstances. This can deliver value for both the individual and the health system.

Diabetes specialist nurses (DSNs) are integral to achieving good patient care and outcomes. They play an important role in preventing expensive and debilitating complications, supporting people with complex needs, and helping people to self-manage their diabetes. In primary care, their specialist expertise can reduce hospital admissions; in hospitals, their skills can help to reduce prescribing errors and length of stay<sup>43</sup>.

**Evidence suggests diabetes specialist nurses are a key part of high quality, cost-effective care. Despite this, and the fact that the incidence of diabetes is increasing, DSN numbers are stagnating, posts are being frozen, and skill levels are still under threat<sup>46</sup>.**

In June 2013, the Welsh Government's Health & Social Care Committee conducted an 'Inquiry into the implementation of the National Service Framework for diabetes in Wales and its future direction' and expressed concerns relating to workforce resources for diabetes specialists. It provided the following recommendation.

**Recommendation 12:** the Welsh Government undertake an audit of the number of diabetes specialist nurses in post across Wales, and the proportion of their time spent on general duties. The Welsh Government should consider the merits of issuing guidance to health boards on recommended numbers of diabetes nurses per head of population.

A workforce audit of DSN and Paediatric Diabetes Specialist Nurses (PDSNs) undertaken by Welsh Government has failed to report its findings. Without the report, NHS Wales is unable to direct health boards to rectify areas where under-resourced staffing is damaging diabetes care.

In the 2013 National Diabetes Inpatient Audit, 31 per cent of sites said they had no diabetes inpatient specialist nurses, 71 per cent of sites had no specialist dietetic time for inpatient care for people with diabetes, and 34 per cent had no podiatrists<sup>32</sup>.

## What needs to happen now?

**Failure to report the findings of the Diabetes Workforce Audit undertaken by Welsh Government is a disappointment.**

- ✓ It needs to be completed and urgently released. Without a stipulation of minimum staffing levels and concerted effort to address identified shortfalls, health board remedial action is unlikely.

# 15 Emotional and psychological support

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

People with diabetes have a significantly higher risk of depression, anxiety, and eating disorders than the general population<sup>47</sup>. This can limit their ability to self-manage their condition and reduce medication adherence – leading to poorer diabetes control and a greater likelihood of complications.

Access to emotional support and specialist treatment can reduce psychological distress and improve outcomes for people with diabetes<sup>48</sup>. Information and education programmes can also help to reduce anxiety related to managing diabetes, and equip people with tools to cope with their condition.

Despite this, there continues to be significant gaps in the provision of psychological support and care for people with diabetes. **Around three quarters of adults and children do not have access to psychological services, and have not received emotional support when needed<sup>49</sup>.** As noted earlier, attendance at diabetes education programmes is relatively rare, even among people with recent diagnoses.

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

## What needs to happen now?

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

- ✓ **Health boards** should work together to design and implement integrated diabetes services in their area, which cover the full spectrum of mental and physical healthcare.
- ✓ **Collaboration between health boards** to share specialised psychological resource should be considered where no specialised psychological resource currently exists.

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