Department of Health

Five Years On

Delivering the Diabetes National Service Framework

Department of Health

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Foreword

When the National Service Framework Delivery Strategy was published in 2003, it spelled a new era for the care of people with diabetes.

For the first time, the NHS had a set of standards around which it could organise its diabetes services. We were clear that prevention and identification of diabetes were key, and that people with the disease should have access to the best clinical care that empowered them to manage their own condition on a day-to-day basis.

These standards have never been so important. The number of people with diabetes is rising, not only because of increasing levels of obesity in the population but also because the NHS is becoming so successful at helping people live into old age. In 2003 the delivery strategy estimated the number of people with diagnosed diabetes to be 1.3 million. We now know that there are nearly two million people with diagnosed diabetes on practice registers.

It is great news that the NHS is becoming so good at identifying people with diabetes, but we know that there may still be up to half a million people with undiagnosed diabetes who need to access services so that they do not develop the complications of the disease. We also know that there are people out there at risk of diabetes – as well as other diseases that share the same risk factors – whom we need to find now in order to stop them developing the condition.

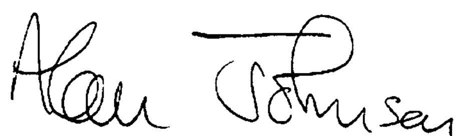
This is why I launched *Putting Prevention First* in April this year. It sets out our plans for a programme of vascular risk assessment and management to find those who are most at risk of diabetes, heart disease, kidney disease and stroke, and to support them to reduce that risk. Implementing this programme within the NHS will be a big step in tackling the dramatic impact that diabetes has on both our health service and the people who develop the condition.

This year's Diabetes National Service Framework progress report is a particularly important one as it marks the halfway stage of the strategy. Five years in, how are we performing?

There are clear improvements in diabetes care – the Quality and Outcomes Framework shows that more and more people are getting the tests and measurements that they need, and their outcomes are getting better too.

But we still have a long way to go to ensure that every person with diabetes is receiving the kind of care set out in the National Service Framework. This report makes clear that, despite the improvements we are seeing, there are still areas where further progress is needed. Outcomes for children with diabetes are still not good enough, for example. And we need to match advances in the delivery of care processes with improvements in the personalisation of services, as Lord Darzi set out in his report *High Quality Care for All*.

The signs for improvement are good. Diabetes, along with other long-term conditions, is a major feature in the local visions published by England's strategic health authorities as part of the NHS Next Stage Review. The importance of prevention is becoming more and more embedded within the NHS. And lastly, we have an enthusiastic and committed diabetes workforce who are experts in making these improvements happen. I am confident that they are able to rise to the challenge.



Alan Johnson
Secretary of State for Health

Introduction

Every person with diabetes deserves the best possible care, no matter where, when or by whom that care is delivered.

This has been the message I have been delivering to the diabetes community since I began my role as National Clinical Director for Diabetes in June this year.

It sounds simple but, as my colleagues in the NHS know, the challenge is to deliver it in practice. The rise in the number of people with diabetes adds to the pressure on those working to deliver their care, and makes it even more vital that the care they do receive is of the highest quality.

The way the NHS has responded in the first five years of the National Service Framework period has been impressive. I am constantly being told about excellent practice in diabetes care, and this report highlights a few examples.

But there is certainly no room for complacency. Some diabetes services have a very long way to go before they are meeting the standards that the National Service Framework set out. Our aim over the next five years must be to bring all services up to the standard of the very best. Anything less than that means that some people with diabetes will still not be getting the care they deserve.

We are in an excellent position to do this. The Government's emphasis on prevention means that we are tackling the root causes of diabetes. The way that primary care is organised – rewarding practices for delivering the right care – is helping us to improve routine care for people with diabetes. The UK Diabetes Research Network is recognising the importance of diabetes to the health of the nation and supporting clinical research into the condition. And the work of the National Diabetes Support Team and other key partners such as Diabetes UK means that we have a range of tools and guidance to support the NHS in making the changes that are needed. I'd like to take the opportunity to thank these organisations for their invaluable help in getting us this far.

So, looking forward to the second half of the National Service Framework period, what will our priorities be? My challenge will be to build on the work of the previous National Clinical Director, Dr Sue Roberts, who provided the diabetes community with such excellent leadership.

Part of my role will be to support the local NHS in delivering the changes set out in the regional visions for improving healthcare over the next 10 years, which were developed as part of the Next Stage Review. Over the last nine months, groups of clinicians have worked in each region to define what high-quality care looks like for people with long-term conditions such as diabetes, and to make recommendations for improvement. These recommendations have now been published by strategic health authorities in their vision documents. As primary care trusts begin to develop their operational plans, we look forward to seeing this work start to turn into real change for people with diabetes.

We also need to look at where specific action is needed, and to support the NHS in addressing this. We need to develop our diabetes specialists. Good specialist leadership should be at the core of any diabetes service but, although the number of hospitals with a single-handed diabetes consultant is falling, there are still too few specialists working in the field. The King's Fund diabetes leadership course is supporting this – the latest course for registrars is helping us to ensure we have the leadership capacity for the future.

The care of people with diabetes who are hospital inpatients is an area where good progress has been made but where there is still room for improvement. Poor-quality care for this group of people can have enormous consequences for them and is also very costly for the NHS.

We need to continue our push on screening for diabetic retinopathy. The number of people being offered screening is rising every quarter, but we cannot rest until we have reached every person with diabetes to save them from this devastating complication.

We need to support women with diabetes who are likely to become pregnant or who are pregnant – including those with gestational diabetes – to give them the best chance of giving birth to a healthy baby.

More generally, we need to tackle the inequalities that exist within diabetes care. This includes looking at the way that the disease affects different groups of people, such as those from different ethnic backgrounds and social classes, older people and young people, and also variations in the way that different groups are able to access services.

And throughout everything we do we must work with people who have diabetes to ensure that their care truly fits their needs.

As I begin my tenure as National Clinical Director I can already see how dedicated and passionate the diabetes community is about providing the best services they can to the people they serve. This is something I have experienced throughout my career in the NHS and I still see as a practising diabetologist in Hillingdon. I look forward to working in partnership with them to continue to deliver the standards set out in the National Service Framework and improve care for all people with diabetes.

Dr Rowan Hillson MBE
National Clinical Director for Diabetes

1 Preventing and identifying diabetes

Standard 1: The NHS will develop, implement and monitor strategies to reduce the risk of developing type 2 diabetes in the population as a whole and to reduce the inequalities in the risk of developing type 2 diabetes.

Standard 2: The NHS will develop, implement and monitor strategies to identify people who do not know they have diabetes.

Prevention

The number of people with diabetes in England is rising. We can't prevent all cases of diabetes, but we do now know that we can prevent some of this increase.

The first standard of the National Service Framework aims to prevent people getting diabetes in the first place. This is fundamentally important. Despite all the recent advances in diabetes care, and the continuous improvement in diabetes services, the burden of ill health and death associated with the condition is still great. Recent work estimates that over 12% of all deaths in the 20–79-year-old category are a result of diabetes.[1] This means that prevention is vital.

There are a range of factors contributing to the rise in the number of people with diabetes. Our risk of diabetes increases as we age, so the ageing population is partly responsible. However, it is thought that just over half of the forecast increase in diabetes cases between 2005 and 2010 will be attributable to the increase in overweight and obese people.

Tackling obesity therefore has to be a top priority, and the Government has responded to the challenge with its obesity strategy, published in early 2008.

Healthy Weight, Healthy Lives[2] sets the Government a challenging ambition – to be the first major country to reverse the tide of obesity by ensuring that

1 Yorkshire and Humber Public Health Observatory, 2008, *Diabetes Attributable Deaths.* www.yhpho.org.uk/Download/Public/1480/1/Attributable%20deaths%20_template2.pdf

2 HM Government, 2008, *Healthy Weight, Healthy Lives: A cross-government strategy for England.* www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_082378

everyone is able to achieve and maintain a healthy weight. Its main focus is on children but, in support of early-years and school-based programmes, the strategy also sets out population-wide plans to promote healthier food choices, make it easier to build physical activity into our lives, and create incentives for better health.

The link with diabetes is clear. The strategy recognises that the risk of developing diabetes is around 20 times greater in the very obese (those with a body mass index of over 35) than in people with a body mass index of between 18 and 25. As a result of this, it proposes to model obesity rates in the population using the number of new cases of type 2 diabetes in adults as an indicator. This is good news in that it will continue to highlight the link between reducing obesity and halting the increase in diabetes.

Preventing diabetes in Berkshire

East Berkshire Diabetes Network is helping to prevent the progression to diabetes thanks to guidelines it has developed on impaired glucose tolerance (IGT) and impaired fasting glycaemia (IFG).

The guidelines have fed into a *Living Well* information pack and group education sessions for people with IGT and IFG. The aim is to prevent progression to diabetes, or to facilitate earlier identification and treatment.

The *Living Well* information pack consists of four A5 booklets:

- *Impaired Glucose Tolerance and Impaired Fasting Glycaemia: Information for those with the condition*
- *Information on Stopping Smoking, Weight Management and Exercise Schemes*
- *Physical Activity: practical ways to keep active*
- *Healthy Eating: simple ways to eat healthily.*

The dedicated group education sessions are run by a dietitian and cover subjects such as:

- low-GI diet
- weight management
- lifestyle changes.

Feedback so far has been very positive. Dietitian Lorraine Knibbs says "Having an opportunity to meet other people rather than just reading leaflets was appreciated, although having literature to back up the session in a complete pack is very useful to reinforce the message on diet and lifestyle changes." An audit of outcomes for those involved in the sessions is in the planning stages.

For more information, email lorraine.knibbs@berkshire.nhs.uk

Although diabetes is a metabolic condition, it shares many risk factors with other conditions such as coronary heart disease, chronic kidney disease and stroke. There are also major complications associated with diabetes. In 2005 the Diabetes, Heart Disease and Stroke Prevention Project recommended that screening for type 2 diabetes should be looked at as part of an overall strategy to reduce people's cardiovascular risk.[3]

In April the Secretary of State for Health launched *Putting Prevention First*,[4] which set out plans for the NHS to deliver a national programme of vascular checks for everybody aged 40–74. This ambitious programme will, for the first time, carry out a systematic, integrated risk assessment of those members of the population who are most at risk and who, according to the evidence, have the biggest opportunity to benefit.

Putting Prevention First

The national programme of vascular checks will:

- be for everyone aged 40–74
- adopt a systematic call and recall approach
- ask simple questions about height, weight, family history and lifestyle
- include tests for cholesterol and, in some cases, glucose
- assess vascular risk and offer appropriate lifestyle and, if necessary, pharmaceutical interventions
- be accompanied by a 'Reduce your Risk' campaign to raise awareness.

It is anticipated that the programme will prevent approximately 4,000 cases of diabetes each year and identify around 25,000 people with diabetes or kidney disease.

Although the vascular checks programme is still in the early stages of development, economic modelling has shown that it is likely to be both clinically and cost effective.[5] The Department of Health is working with a wide range of stakeholders to develop a programme that can work in practice.

To support this, we will be learning from some of the many PCTs in England that have recognised the importance of prevention – of diabetes and other

3 www.screening.nhs.uk/diabetes/home.htm
4 Department of Health, 2008, *Putting Prevention First: Vascular checks – risk assessment and management*. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_083822
5 Department of Health, 2008, *Economic Modelling for Vascular Checks*. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085869

vascular conditions – and are already implementing their own programmes. Many of these PCTs are using a valuable resource recently published by the UK National Screening Committee and the University of Leicester. *The Handbook for Vascular Risk Assessment, Risk Reduction and Risk Management*[6] outlines the evidence in support of a co-ordinated vascular risk programme to identify and reduce the risk of cardiovascular disease in the population, and provides examples of tools and resources that can be used by health professionals undertaking vascular risk assessment.

It is well known that diabetes has a disproportionate impact on some ethnic communities in England, and this means that their different needs and cultural identities have to be taken into account when developing strategies to prevent diabetes. One initiative aiming for this is 'Apnee Sehat' in the West Midlands.

Apnee Sehat ('Our Health')

The Apnee Sehat project is a social enterprise pathfinder which is tailoring lifestyle programmes to meet the needs of Britain's South Asian communities.

The project currently works with communities in Leamington, Warwickshire and more recently Foleshill, Coventry to raise awareness of vascular disease and assess the risk of developing it. The aim is to reduce the risk of stroke, heart attack and diabetes by encouraging preventative lifestyle changes through the provision of education, supported self-care and screening programmes.

6 UK National Screening Committee, 2008, *The Handbook for Vascular Risk Assessment, Risk Reduction and Risk Management*. www.screening.nhs.uk/vascular/VascularRiskAssessment.pdf

Identification

Early identification of diabetes is vital so that people can receive the advice, support and treatment they need to manage their condition. If diabetes is diagnosed early, action can be taken to prevent or delay its complications.

When the National Service Framework standards were first published in 2001, only around 1.3 million people were diagnosed with diabetes, and it was thought that around a million had diabetes without knowing it. Since then, the Quality and Outcomes Framework (QOF) has been introduced as part of the GP contract, rewarding GP practices for the identification and treatment of people with diabetes in their area.

As a result of the QOF, there are now almost 2 million people over the age of 17 recorded on practice registers as having diabetes. This means that around 600,000 people have been diagnosed in the last five years – equivalent to 2,000 a week – and are now benefiting from the support they need to manage their diabetes.

The vascular checks programme will also support the earlier identification of diabetes. Although the main aim of the programme is to assess people's risk of developing vascular diseases, it will also help GP practices to pick up those people who already have as yet undiagnosed diseases including diabetes. The economic modelling work predicts that the programme will identify 25,000 cases of diabetes and kidney disease every year.

But we still have a long way to go in order to ensure that we are finding every person with diabetes as soon as we can, and that we are helping them to manage their condition. The Yorkshire and Humber Public Health Observatory estimates that there are around 2.44 million people with diabetes in England;[7] since the number recorded on practice registers is less than 2 million, there may still be over 400,000 people with undiagnosed diabetes in England.

Strategies like Diabetes UK's 'Measure Up' campaign are vital to raising awareness of the risk factors for diabetes, and are a welcome part of the drive to raise awareness, reduce risk and find unidentified diabetes.

7 Data extrapolated from Yorkshire and Humber Public Health Observatory, 2008, *PBS Diabetes Prevalence Model Phase 3*. www.yhpho.org.uk/Download/Public/1478/1/PBS%20Phase%203%20-%20%20Findings.pdf

2 Partnership in decision-making

Standard 3: All children, young people and adults with diabetes will receive a service which encourages partnership in decision-making, supports them in managing their diabetes and helps them to adopt and maintain a healthy lifestyle. This will be reflected in an agreed and shared care plan in an appropriate format and language. Where appropriate, parents and carers should be fully engaged in this process.

Good diabetes care doesn't just involve clinical and pharmaceutical interventions. People with diabetes spend every day of their lives taking care of themselves, and it is vital that they have the support they need to do this.

In May 2007 the then National Clinical Director, Dr Sue Roberts, published her report *Working Together for Better Diabetes Care*.[8] This set out the 'better outcomes equation', and proposed that NHS services reorganise themselves to achieve it.

Achieving this requires a rethink, making people with diabetes partners in their own care. Education and care planning approaches must be adopted so that patients are genuinely empowered.

8 Department of Health, 2007, *Working Together for Better Diabetes Care*. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_074702

Education

More and more diabetes healthcare professionals are recognising the importance of structured education in equipping people with diabetes to manage their condition. A number of programmes are available, along with a range of practical tools and guidance to help local services choose the best programme for them.

Structured patient education in diabetes – practical tools

- National Institute for Health and Clinical Excellence (NICE), *Guidance on the Use of Patient-Education Models for Diabetes*[9]
- Department of Health and Diabetes UK, *Structured Patient Education in Diabetes: Report from the Patient Education Working Group*[10]
- National Diabetes Support Team and Diabetes UK, *How to Assess Structured Diabetes Education: An improvement toolkit for commissioners and local diabetes communities*[11]

There are also other opportunities for support. The Diabetes Education Network (formerly known as the Type 1 Education Network) provides support and information to diabetes teams who deliver local education programmes, and runs workshops to help teams develop programmes to meet the criteria for patient education set out by the National Institute for Health and Clinical Excellence. For more details go to www.diabetes-education.net

9 NICE, 2003, *Guidance on the Use of Patient-Education Models for Diabetes* (TA60). www.nice.org.uk/nicemedia/pdf/60Patienteducationmodelsfullguidance.pdf

10 Department of Health and Diabetes UK, 2005, *Structured Patient Education in Diabetes: Report from the Patient Education Working Group*. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4113195

11 National Diabetes Support Team and Diabetes UK, 2006, *How to Assess Structured Diabetes Education: An improvement toolkit for commissioners and local diabetes communities*. www.diabetes.nhs.uk/downloads/Patient_Education_Tools_Project/Patient_Education_Tools_Project_2006.pdf

Structured education makes a difference for South Asian communities

A structured group education programme, X-PERT, has been adapted to cater for members of South Asian communities in West London, thanks to the Dietetic and Research and Development Department at Hounslow Primary Care Trust.

South Asian people with type 2 diabetes can now take part in a course called Aap Ki Sehat Aap Ke Haath ('Your Health in Your Hands') to improve the management of their condition, and results so far are encouraging.

The programme is split into five weekly sessions:

- Understanding diabetes
- Diet and weight management
- Carbohydrates/fat/healthy cooking tips
- Complications and foot care
- Medication/action planning and goal setting.

Venues for the sessions include day centres, temples, mosques and women's centres. The interactive sessions are delivered in Punjabi or Hindi by a trained dietetic assistant, with Asian recipes, cooking tips and DVDs.

Two months after the course is completed, outcomes including HbA1c, body mass index (BMI), waist circumference, cholesterol and blood pressure are measured.

Results from the first course showed that:

- HbA1c decreased by between 0.1% and 1.6% in 70% of those tested
- BMI decreased by between 0.1 and 1.4 in 46% of those measured
- waist measurement decreased by between 2cm and 7cm in 56% of those measured
- total cholesterol decreased in 33% of those tested.

The knowledge and empowerment questionnaires completed by participants have been translated to obtain more qualitative data:

- "I feel very happy about what I learnt and hope I can look after myself properly."
- "Very informative and continues to be an eye-opener, particularly calories and fats."

- "I learnt the benefits of doing exercise and tips for healthier Asian cooking."
- "I never exercised until I came to these sessions. Now I go for a walk daily."

One person who took part said afterwards: "I had read lots of literature before but could only understand it after attending these classes."

For more information, email Rupindar Sahota or Ripanjit Gill at rupindar.sahota@hounslowpct.nhs.uk or ripanjit.gill@hounslowpct.nhs.uk

For more information about the X-PERT structured education programme, go to www.xpert-diabetes.org.uk

Uptake of two of the main education programmes that meet the NICE criteria, DAFNE (Dose Adjustment for Normal Eating, for people with type 1 diabetes) and DESMOND (Diabetes Education and Self Management for Ongoing and Newly Diagnosed, for people with type 2 diabetes), is continuing to rise.

DAFNE

- 68 centres are up and running in the UK and Ireland (54 in England), with three more due to complete training during 2008/09
- 1460 DAFNE courses have now been delivered, with a total of almost 10,000 DAFNE graduates
- A five-year research programme funded by the National Institute of Health Research will inform the development of DAFNE, with results that will be transferable to other education programmes for long-term conditions.

DESMOND

- 75 health organisations from the UK and Ireland are currently providing DESMOND.
- A training team of 25 is working across the UK, with DESMOND being delivered to more than 20,000 people since 2005.
- Several active research studies are investigating the effectiveness of using lay educators to deliver the programme, developing a diabetes prevention education programme, and examining the transferability of DESMOND to other long-term conditions.

However, there is still a long way to go. In the Healthcare Commission's 2006 survey of people with diabetes,[12] only 11% of respondents said they had participated in an education course to help them manage their diabetes. There was also considerable variation between primary care trusts. It is vital that this figure increases and that commissioners of NHS services are able to see the benefits that structured education can bring. The National Diabetes Support Team is currently working with Diabetes UK and a range of other partners to explore how we can continue to support the spread of education programmes across the NHS.

Care planning

Care planning is a key part of managing long-term conditions, and its importance has been stated in a number of major policy documents. The final report of Lord Darzi's NHS Next Stage Review, *High Quality Care for All*,[13] emphasises the role of care planning in personalised care and states that, over the next two years, everyone with a long-term condition should be offered a personalised care plan. This ambition is reinforced in the vision documents produced by strategic health authorities in response to the Next Stage Review.

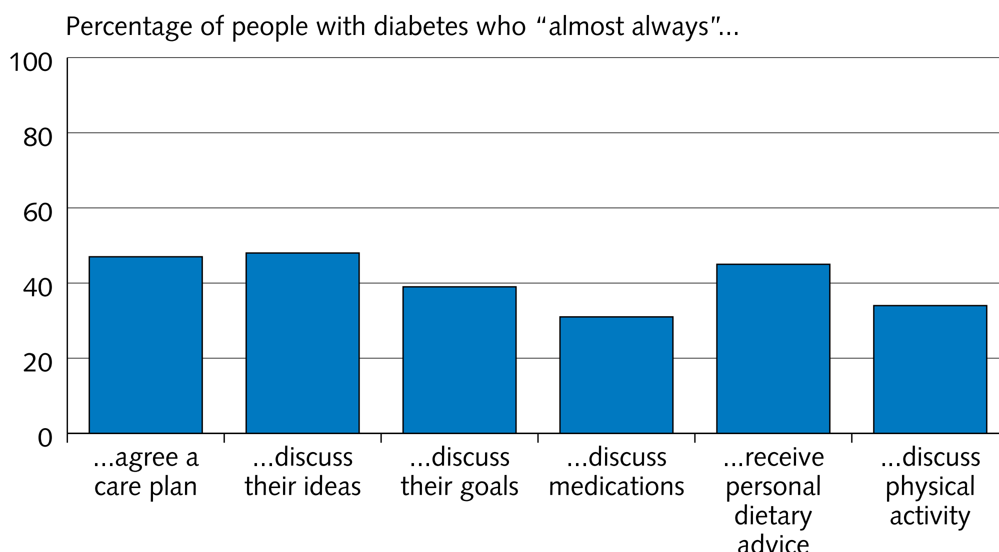
Self-care and care planning – practical tools

- Skills for Health/Skills for Care, *Common Core Principles to Support Self Care: A guide to support implementation*[14]
- Department of Health, *Raising the Profile of Long Term Conditions Care: A compendium of information*[15]
- Department of Health, *Care Planning in Diabetes*[16]
- Department of Health, *Supporting People with Long Term Conditions to Self Care: A guide to developing local strategies and good practice*[17]
- National Diabetes Support Team, *Partners in Care: A guide to implementing a care planning approach to diabetes care*[18]

12 Healthcare Commission, 2007, *The Views of People with Diabetes: Key findings from the 2006 survey.* www.healthcarecommission.org.uk/_db/_documents/Diabetes_survey_2006_summary.pdf
13 Professor the Lord Darzi of Denham KBE, 2008, *High Quality Care for All: NHS Next Stage Review final report*. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085825
14 Skills for Health/Skills for Care, 2008, *Common Core Principles to Support Self Care: A guide to support implementation*. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_084505
15 Department of Health, 2008, *Raising the Profile of Long Term Conditions Care: A compendium of information*. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_082069
16 Department of Health, 2006, *Care Planning in Diabetes: Report from the joint Department of Health and Diabetes UK Care Planning Working Group*. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_063081
17 Department of Health, 2006, *Supporting People with Long Term Conditions to Self Care: A guide to developing local strategies and good practice*. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4130725
18 National Diabetes Support Team, 2008, *Partners in Care: A guide to implementing a care planning approach to diabetes care*. www.diabetes.nhs.uk/news-1/Partners%20in%20Care.pdf

Nevertheless, standards are still variable across the country. In the 2006 Healthcare Commission survey of people with diabetes, 47% of respondents said that they "almost always" agreed a plan to manage their diabetes, and 48% reported that they "almost always" discussed their ideas about the best way to manage their diabetes. This means that half of people with diabetes are not being offered the opportunity to be partners in their own care.

Fig 1: Healthcare Commission survey results on care planning



Source: Healthcare Commission 2007

In February 2008 the National Diabetes Support Team produced *Partners in Care*, its guide to implementing care planning in diabetes. The National Diabetes Support Team is also working with Diabetes UK and other key partners through a working group; this group is looking at how it can support the NHS in embedding the principles of care planning into the delivery of diabetes services.

Year of Care

The Year of Care project is care planning in action. It aims to transform the annual review process – which can sometimes be little more than a 'tick-box' exercise – into a genuine discussion between the person with diabetes and the healthcare professional. A Year of Care describes the ongoing care that the person can expect to receive in a year, including support for self-management, which can be costed and commissioned.

The Year of Care approach uses care planning as a vehicle for engaging and empowering people with diabetes. It gives them more time to consider and discuss the information that is important to them, and more options for the kind of care and support for self-management that they need.

The Year of Care project is led by Diabetes UK and the National Diabetes Support Team, in partnership with the Health Foundation and the Department of Health. Three local NHS teams have been recruited as pilot sites to look at what needs to happen for Year of Care to become a reality across their populations. They will focus on developing the infrastructure to support care planning in routine practice, including the training of clinicians in consultation skills. They will also look at how to commission the right services for individuals. This will involve:

- working with people to understand what services they need, particularly support for self-care
- developing healthcare providers to provide that support
- linking individual people's preferences, expressed through the care planning process, into population-level commissioning
- understanding the cost of services and support.

The NHS is already beginning to see the benefits that a Year of Care approach can deliver. NHS Yorkshire and the Humber, in its local vision document *Healthy Ambitions*, proposes that the Year of Care approach should be seen as an exemplar for work in other long-term conditions.[19] For more information on Year of Care, go to www.diabetes.org.uk/en/Professionals/Year-of-Care/Year-of-Care-project

Emotional and psychological support

Diabetes is a progressive, lifelong condition. Many people with diabetes will need some form of emotional and psychological support to be able to tackle the challenges this presents and to care for themselves effectively from day to day.

Despite this, a Diabetes UK survey of primary care trusts in 2007[20] found that only 38% provided psychological support for adults with diabetes, rising to 51% for children and young people.

This situation needs to change, and the Department of Health has asked Diabetes UK to chair a group looking at how the NHS can improve the emotional and psychological support it provides to people with diabetes to enable them to self-care effectively. This will build, where appropriate, on the Improving Access to Psychological Therapies (IAPT) programme. You can find more information on IAPT at www.mhchoice.csip.org.uk/psychological-therapies

19 www.ournhs.nhs.uk/wp-content/uploads/2008/06/yh-vision-doc.pdf
20 Diabetes UK, 2007, *Primary Care Organisation Progress Survey 2007: Access to healthcare services at a glance*. www.diabetes.org.uk/Documents/Reports/PCTandLHB2007AtaGlanceReport.pdf

Yoga for emotional wellbeing in diabetes

People with diabetes are being offered yoga sessions at a GP practice in Bungay, Suffolk to help improve their emotional wellbeing.

Practice nurse Judy Bailey was awarded funding by the Queen's Nursing Institute to put her ideas for yoga sessions into action. People with heart disease and diabetes were invited to attend a series of six yoga sessions free of charge. Their anxiety and depression scores were taken, along with their weight and waist circumference measurement, at the beginning and end of the series.

Judy said: "We don't just want to give people anti-depressants. I wanted to be able to do something to help that was non-pharmaceutical."

The aims and objectives were to:

- offer a non-pharmaceutical option in response to depression case finding arising from the GMS contract
- promote exercise as a means of improving participants' mood
- offer a group exercise programme within the surgery
- provide exercise for non-mobile clients in a residential care setting.

Following the popularity of the first sessions, a new group was established for those who would benefit from chair-based exercise.

After the sessions, most participants had reduced anxiety and depression scores, and most lost weight.

One participant, a 71-year-old woman with type 2 diabetes and a weight of 130kg, took part in chair-based exercise in conjunction with joining a slimming club, which was partly paid for by vouchers from the surgery. Four months later she had lost 25% of her body weight. Her HbA1c and blood pressure were also reduced, as were her anxiety and depression scores.

Judy is hoping that the yoga sessions will continue into the future. "The participants have shared their stories and supported each other. Some have buddied up and started swimming together or going to the gym. It's been empowering," she said. "It seems to have been the right thing at the right time. There's been a transformation in some people. It's been really rewarding being an agent for change."

For more information, email Judith.bailey@gp-d83034.nhs.uk

Involving people with diabetes

A major theme of the National Service Framework is the importance of the relationship between healthcare professionals and people with diabetes, and Standard 3 sets out an expectation that people with diabetes will be encouraged to enter into partnerships in decision-making. This principle needs to extend back into the way that care is planned, as the involvement of service users in the design, development and review of services is equally important.

Involving people with diabetes – National Diabetes Support Team

A user involvement project commissioned by the National Diabetes Support Team in 2006 is being delivered by Diabetes UK and London Metropolitan University.

The National Diabetes Support Team wished to develop the input and influence of service users within its own organisational routines and decision-making processes, and therefore commissioned the formation of a service user reference group. Innovative recruitment techniques, including advertising in local newspapers, were used to ensure that as wide a representation as possible was obtained.

The group comprises 17 individuals and is representative of a range of people with diabetes in terms of diagnosis, age, gender and ethnic group. Its purpose is to advise and inform the Department of Health and the National Diabetes Support Team of the needs and views of people with diabetes, on a proactive as well as a reactive basis.

As part of the project the partners were commissioned to:

- design and deliver a training programme to diabetes networks so that they could successfully train service users within their own networks
- provide a training material toolkit to networks and other groups to enhance local engagement of service users.

Additionally, four documents were produced to support others in engaging people who use services:

- *Involving Service Users in Diabetes Services: Self-assessment tool for NHS services*
- *Involving People Whose Voices Are Not Normally Heard: Guidance for diabetes services*
- *Making a Difference: How you can help improve diabetes services*
- *Adults Don't Always Know Best: Involving children and young people in diabetes services.*

They are available at www.diabetes.nhs.uk/work-areas/user-involvement/strategic-development

User involvement for improvement in Gateshead

A service user reference group is making an impact on decision-making in Gateshead's diabetes services. Gateshead Diabetes Network set up the group, using National Diabetes Support Team pump-priming funding, in order to get people with diabetes more involved in shaping the way services are delivered. An event called 'Diabetes: Have your say', organised by the Gateshead Primary Care Trust (PCT) diabetes facilitator, was publicised with posters in public spaces and information in the local newspaper. Any member of the public could come along, and views from the meeting helped develop the terms of reference for a regular group.

The resulting service user reference group is a key part of diabetes service development in Gateshead. All minutes from operational and strategic meetings are shared with the group, and new ideas go to the group for its views. The PCT's lead officer for long-term conditions, Kim Mansfield, said: "The reference group members are very much involved with any plans. If we are developing protocols or guidelines, they go to the group in the development stage."

The meetings are held every two months, and usually between 10 and 20 people attend; the spectrum of attendees covers both type 1 and type 2 diabetes. Since the group was established in 2005, it has been involved in many important decisions and was central in the development of the network's policy on blood glucose monitoring.

Kim added: "It's had a very positive impact. It makes us think of things that as healthcare professionals we wouldn't normally do. Their input is invaluable."

For more information, email Kim Mansfield at kim.mansfield@ghpct.nhs.uk or Margaret Kerrison at Margaret.kerrison@ghpct.nhs.uk

3 Clinical care of adults with diabetes

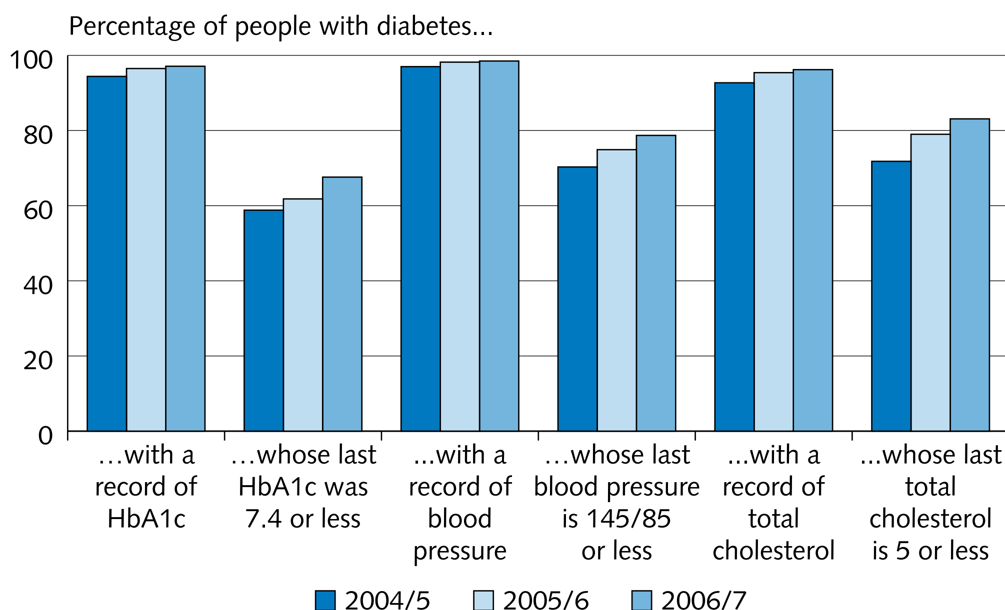
Standard 4: All adults with diabetes will receive high-quality care throughout their lifetime, including support to optimise the control of their blood glucose, blood pressure and other risk factors for developing the complications of diabetes.

We have seen that good outcomes for people with diabetes need patients that are engaged and empowered. But it's also important that the services provided to those patients are organised and proactive.

Management of diabetes in primary care

Primary care is getting better at managing diabetes. It is one of the outstanding achievements of the Quality and Outcomes Framework that the number of people with diabetes receiving the essential tests and measurements (for example, blood pressure and cholesterol) has been increasing year on year. Even more importantly, the results of those tests have also been improving.

Fig 2: Trends in delivering key tests and measurements



Source: Quality and Outcomes Framework 2004/5 to 2006/7

It is important to note, however, that the 2005/6 National Diabetes Audit[21] found that not everyone is receiving every care process that they need – indicating that we still have some way to go.

It's also vital that the person with diabetes is provided with as much information as possible prior to their appointment, to help them use their time with the healthcare professional as well as possible. This was a theme of the final report of the NHS Next Stage Review,[22] which acknowledged that too few people have access to information about their own care.

Making the most of appointments with the doctor

A GP practice in North Tyneside is encouraging patient-centred care with a series of leaflets helping people get the most from appointments.

GP Dave Tomson was keen that patients should make the most of the time they spend with doctors and nurses at the Collingwood Health Group. He put together a leaflet entitled *Ten Ways of Making the Most of Your Time with the Staff at Collingwood Surgery*, which contains information on:

- getting to the right person or piece of information
- managing time well
- making the most of a consultation with the nurse or doctor.

It also suggests making lists, writing down what the doctor says, taking someone to the appointment with you and asking for more information.

The leaflet is available in the waiting rooms for everyone to access. Dr Tomson said: "More people come with lists, people are asking for information. People are feeling comfortable about bringing others into the room. We think it's made a difference."

Following the success of the leaflet, the practice has developed another to support patients who are going to see a consultant. It gives similar tips, but also suggests questions to ask about tests and treatment. The leaflet is sent to patients with their referral letter.

For more information, email d.p.c.tomson@ncl.ac.uk

21 Information Centre for Health and Social Care, 2007, *National Diabetes Audit Abridged Report* for the audit period 2005–2006. www.ic.nhs.uk/webfiles/Services/NCASP/audits%20and%20reports/19040707%20IC%20Diabetes-%20AbridgedReport.FV.pdf

22 Professor the Lord Darzi of Denham KBE, 2008, *High Quality Care for All: NHS Next Stage Review final report*. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085825

Strategic health authorities' local visions, published this year as part of the NHS Next Stage Review, have highlighted the important role that primary care has to play in the management of long-term conditions such as diabetes. NHS North East's strategy, *Our Vision, Our Future*, pledges to offer support and training to GPs and other case managers to help them develop the way they offer holistic support to people with long-term conditions across health and social care.[23]

Insulin pump therapy

Although not suitable for everybody, continuous subcutaneous insulin infusion – or insulin pump therapy – is a good way for some people with type 1 diabetes to improve their control over their condition.

NICE published guidance on insulin pump therapy in 2003,[24] which was revised earlier this year,[25] recommending it as a treatment option in particular circumstances. Despite this, access to insulin pumps has been variable, and some people who would benefit cannot access them. To try to tackle this, the Department of Health has worked with Diabetes UK, frontline staff and people with diabetes to develop guidelines that will help improve access to insulin pump therapy.[26] The guidelines build on NICE's recommendations, and also set out a best-practice model to help local services develop a specification for insulin pump care.

Practical support is important too. NHS Supply Chain is in the process of developing a specification for a home delivery service for insulin pumps and the associated consumables, which it is hoped will be trialled in 2009. The service will make it easier for NHS trusts to procure these products, and will allow patients to manage their product requirements more effectively. The Department of Health will also be working with Diabetes UK and organisations representing insulin pump users to develop a national curriculum of education for insulin pump services and a set of national audit standards.

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23 www.ournhs.nhs.uk/wp-content/uploads/2008/05/north-east-vision-document.pdf
24 NICE, 2003, *Guidance on the Use of Continuous Subcutaneous Insulin Infusion for Diabetes* (TA57). www.nice.org.uk/nicemedia/pdf/57_Insulin_pumps_fullguidance.pdf
25 NICE, 2008, *Continuous Subcutaneous Insulin Infusion for the Treatment of Diabetes Mellitus: Review of TA57*. www.nice.org.uk/nicemedia/pdf/TA151Guidance.pdf
26 Department of Health, 2007, *Insulin Pump Services: Report of the Insulin Pumps Working Group*. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_072777

Other advances

For some people with type 1 diabetes, a specialised islet transplantation service will offer them the chance to live free from the fear of hypoglycaemia. Following research funded by Diabetes UK, the National Specialised Commissioning Group on behalf of the NHS is investing up to £2.34 million in islet transplant services across six centres around England in the first year, increasing to a maximum of £7.32 million to meet the predicted annual need in the longer term.

It is expected that a small number of transplants will take place in the first year, with the service then expanding to approximately 80 transplants in subsequent years. Each of the people receiving a transplant will have suffered from recurrent hypoglycaemia or have had a kidney transplant.

Although this service is in the very early stages and can be offered to only a small number of patients, this is a good example of the NHS being at the clinical forefront for people with diabetes.

4: Clinical care of children and young people with diabetes

Standard 5: All children and young people with diabetes will receive consistently high-quality care and they, with their families and others involved in their day-to-day care, will be supported to optimise the control of their blood glucose and their physical, psychological, intellectual, educational and social development.

Standard 6: All young people with diabetes will experience a smooth transition of care from paediatric diabetes services, whether hospital or community-based, either directly or via a young people's clinic. The transition will be organised in partnership with each individual and at an age appropriate to and agreed with them.

The number of children and young people diagnosed with diabetes continues to increase. There are thought to be around 20,000 children under 15 with type 1 diabetes in the UK, and an estimated 1,000 to 1,500 with type 2 diabetes.

The management of diabetes in children and young people is complex and significantly different from adult care. Although service provision for children and young people has improved significantly, current diabetes care can be variable and does not always meet the needs of this very special group. Data from the National Diabetes Audit (NDA) shows that, although children's diabetes control is improving year on year, the percentage of children achieving good glycaemic control is still too low.[27]

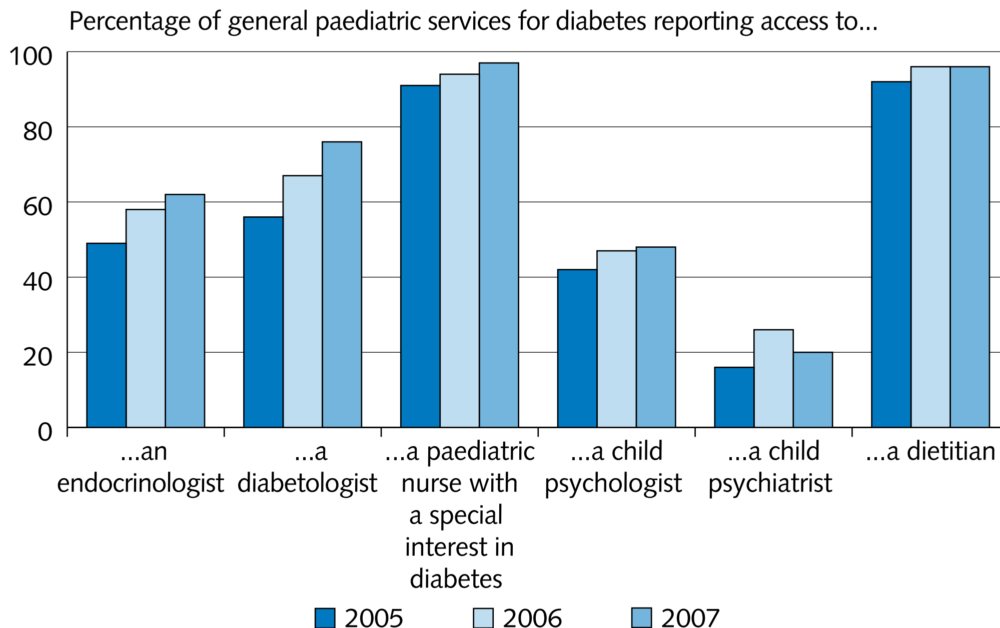
There are a number of challenges to be addressed. These include ensuring access to dedicated services with appropriate caseloads, providing good diabetes care when children are admitted to hospital for any reason, offering support during school time, and managing the transition from children's to adults' services.

27 National Diabetes Audit annual reports show that in 2003/4, 14.7% of children achieved an HbA1c of less than 7.5%, in 2004/5 15.5% achieved this, and in 2005/6 16.6% achieved it. www.ic.nhs.uk/our-services/improving-patient-care/national-clinical-audit-support-programme-ncasp/audit-reports/diabetes

Access to specialist services

Access to the right specialist support is vital for anyone with diabetes, and particularly for children and young people. The Diabetes UK progress report on the National Service Framework noted that "many parents and children report that they receive very supportive and high quality care from their local paediatric diabetes team"[28] although it drew attention to high caseloads in some areas. Data from the Child Health Mapping exercise undertaken by Durham University on behalf of the Department of Health suggests that access to specialist care is getting better. However, it also shows that children with diabetes need better access to emotional and psychological support. This is being considered through the work on supporting the development of emotional and psychological services described in Chapter 2.

Fig 3: Trends in access to expertise in diabetes



Source: Child Health, CAMHS and Maternity Service Mapping Exercise

28 Diabetes UK, 2008, *The National Service Framework for Diabetes: Five years on... are we half way there*? www.diabetes.org.uk/Documents/Reports/Five_years_on_-_are_we_half_way_there2008.pdf

Guidance

Extensive quality guidance is now available to support improved child- and young person-oriented services. The Royal College of Nursing's *Adolescent Transition Care: Guidance for nursing staff*[29] aims to help practitioners provide a seamless transfer for adolescents from paediatric to adult healthcare, and contains an overview of the issues to consider while planning transition services as well as a practical framework for working with young people at each stage of adolescence. The NICE Clinical Guideline on the management of type 1 diabetes in children, young people and adults[30] also stresses the importance of an integrated package of care from a multidisciplinary paediatric diabetes care team. Local guidance, booklets and patient information leaflets are also increasingly available.

Audit

Gathering and analysing data on children's diabetes is vital if we are to be able to look at services and outcomes at a local and a national level. The NDA includes a separate paediatric audit which collects data on children and young people with diabetes from participating paediatric units.

The 2005/06 NDA report[31] shows a year-on-year increase in the number of children and young people with a recorded HbA1c, but – as this report has already mentioned – the percentage of children achieving good glucose control still needs to improve.

There has also been a 65% increase in participation, so the paediatric audit now has information on nearly 13,000 children and young people with diabetes. This is good news, but only when all units are participating will we be able to get a real picture of paediatric diabetes services across the country. As the NDA continues to develop, it will be looking closely at increasing participation from paediatric diabetes units.

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29 Royal College of Nursing, 2004, *Adolescent Transition Care: Guidance for nursing staff*. www.rcn.org.uk/__data/assets/pdf_file/0011/78617/002313.pdf

30 NICE, 2004, *Type 1 Diabetes: Diagnosis and management of type 1 diabetes in children, young people and adults* (CG15). www.nice.org.uk/nicemedia/pdf/CG015NICEguideline.pdf

31 Information Centre for Health and Social Care, 2007, *National Diabetes Audit: Key findings about the quality of care for children and young people with diabetes in England and Wales – Report for the audit period 2005–2006*. www.ic.nhs.uk/webfiles/Services/NCASP/audits%20and%20reports/19040607%20IC%20Diabetes-PaediatricReport.FV.pdf

Booklets for children with diabetes

Children with diabetes and their families in Waltham Forest, North East London are getting improved support and information from a series of booklets:

- *Type 2 Diabetes in Children and Young People*
- *Childhood Diabetes – Management in School*
- *From Hospital to Home: A guide for families of children with newly diagnosed insulin dependent diabetes.*

The development of the booklets was funded by the Single Regeneration Fund and followed concerns that the information available was not child-friendly. There was also a lack of information about type 2 diabetes in children and diabetes management in schools.

Diabetes specialist nurse Lynne Ellis said: "Young people and their parents have found the booklets very useful. They are bright and well-suited for the children."

The booklet aimed at schools has been particularly well received. Education sessions run alongside the booklets have also proved popular with children and parents, particularly for peer support. Staff at Waltham Forest Primary Care Trust report that HbA1c results have improved among the children who took part in the project.

The booklets can be downloaded at www.walthamforest-pct.nhs.uk/services/diabeteschildrens.htm

For more information, email lynne.ellis@whippsx.nhs.uk

Maturity-Onset Diabetes of the Young (monogenic diabetes)

Diabetes care for children and young people can also be complicated by the different possible types of diagnosis. One rarer form of diabetes is Maturity-Onset Diabetes of the Young (MODY, also called monogenic diabetes), which is not always recognised straight away and requires different types of treatment. The National Diabetes Support Team has worked with clinicians to produce a bulletin on monogenic diabetes which describes the different variants and how to diagnose and treat them.[32]

32 National Diabetes Support Team, 2008, *Diabetes Bulletin – Monogenic Diabetes*. www.diabetes.nhs.uk/reading-room/bulletins/bulletins

Children and Young People with Diabetes Working Group

To begin to tackle the variations that exist in diabetes care for children and young people, the Department of Health set up a working group in October 2005 in partnership with a wide range of stakeholders including Diabetes UK, healthcare professionals and service users. This group published its report *Making Every Young Person With Diabetes Matter*[33] in April 2007. The report provides NHS organisations with suggestions on the commissioning, organisation and provision of services and workforce. It also offers practical tools including a generic best practice specification for a children and young people's diabetes service.

However, providing these tools is not an end in itself, and a Children and Young People Implementation Support Group is now taking forward the report's recommendations. The group is chaired by the National Clinical Director for Children, Dr Sheila Shribman, and includes representation from Diabetes UK, the Royal Colleges, young people with diabetes, parents of children with diabetes, and representatives from other organisations with an interest in this area, including the Healthcare Commission. The implementation support group has identified its major priorities and is taking forward specific work on these areas.

Support in schools

A subgroup of the implementation support group on the management of diabetes in schools is focusing on what is needed to promote better care for children with diabetes in the school environment. A failure to support children in managing their diabetes can adversely affect their time at school – for example, they may miss out on physical activities and school trips. Guidance on ways to support children with medical needs at school is readily available to schools on the dedicated online resource Teachernet, at:

www.teachernet.gov.uk/wholeschool/healthandsafety/medical

Diabetes UK has contributed to new resources to help schools and school healthcare professionals support all pupils with diabetes and other long-term conditions. *Medical Conditions at School: A policy resource pack* is available at:

www.medicalconditionsatschool.org.uk

33 Department of Health, 2007, *Making Every Young Person with Diabetes Matter*. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_073674

Supporting children with diabetes in Nottingham

Schools in Nottinghamshire have recognised the importance of supporting children with diabetes to take their insulin when it is best for them to do so. A dedicated guide, *Supporting the Administration of Insulin in Schools*, has been produced in Nottinghamshire in a collaboration between city and county local authorities and primary care trusts. Schools have been sent a copy of this guidance and have been asked to display a poster summarising the necessary support measures for children and young people with diabetes attending school.

For more information, email Alison Weaver at alison.weaver@lea.nottinghamcity.gov.uk

Inpatient care

The National Diabetes Support Team report *Improving Emergency and Inpatient Care for People with Diabetes*[34] notes that children share many of the difficulties faced by adult hospital inpatients with diabetes. Additional issues include their age and development, their access to paediatric diabetic specialist services, the potential for mis-communication, and the exclusion of them and their parents or carers from decisions about their diabetes care.

A subgroup of the implementation support group on inpatient care for children and young people with diabetes is tackling the issues encountered by children and their parents and carers when admitted to hospital, including the support they receive prior to admission, their treatment in the accident and emergency department and during their time as an inpatient, right through to their discharge home. The output of the group will be to identify the levers available to improve inpatient care for children and young people with diabetes, and to support the NHS in using them effectively.

These groups will review progress in early 2009.

34 National Diabetes Support Team, 2008, *Improving Emergency and Inpatient Care for People with Diabetes*. www.diabetes.nhs.uk/news-1/Inpatient%20care.pdf

5 Diabetic emergencies and inpatient care

Standard 7: The NHS will develop, implement and monitor agreed protocols for rapid and effective treatment of diabetic emergencies by appropriately trained healthcare professionals. Protocols will include the management of acute complications and procedures to minimise the risk of recurrence.

Standard 8: All children, young people and adults with diabetes admitted to hospital, for whatever reason, will receive effective care of their diabetes. Wherever possible, they will continue to be involved in decisions concerning the management of their diabetes.

No matter how well people manage their diabetes most of the time, diabetic emergencies can still occur. It is important that people have access to the right support and treatment to minimise the chance of these emergencies happening. When they do happen – and severe acute hypoglycaemia and diabetic ketoacidosis (DKA) are the most common – it is vital that people receive the best and most timely treatment possible.

The 2008 report *Improving Emergency and Inpatient Care for People with Diabetes*, and a companion report, also published in 2008 by the NIII,[35] looked at ways to address these challenges. The NDST report was authored by a working group of clinicians, representatives of the voluntary sector and people with diabetes, and considered in detail what could be done to improve care in three related areas:

- preventing diabetes emergencies out of hospital, and emergency admissions, with a emphasis on ambulance services
- improving quality and value for money for people in hospital with diabetes
- preventing and treating acute foot problems in hospital: strategies for improvement.

35 National Diabetes Support Team, 2008, *Improving Emergency and Inpatient Care for People with Diabetes*. www.diabetes.nhs.uk/news-1/Inpatient care.pdf and NIII, 2008 *Delivering Quality and Value and Focus on: Inpatient care for people with diabetes* http://www.diabetes.nhs.uk/news-1/focus-on-inpatient-care-for-people-with-diabetes-published-by-the-nhs-institute-for-innovation-and-improvement/?searchterm=inpatient

The report concludes that preventing emergency diabetic admissions requires an integrated package of services commissioned across a whole community. The key components of this are:

- basic structured education in 'sick day rules' (how to manage your condition when you are ill) for everyone with diabetes
- proactive intervention in high-risk groups
- access to emergency support for unexpected events
- prompt and appropriate intervention by emergency services
- close links to routine services to prevent recurrences.

Patient call-back system

The East of England Ambulance Service NHS Trust has set up a new 24-hour patient call-back system run by specially trained paramedics and nurses in response to a review of diabetes care in the trust.

In appropriate cases, ambulance staff will leave a person with diabetes who has experienced a hypoglycaemic episode at home with a responsible adult after treating them. A trained nurse or paramedic in Ambulance Control will telephone the patient two to four hours after the ambulance crew leave the scene to check on the patient's condition. The telephone contact gives staff extra time to speak with the patient, so they can offer advice and ensure that the patient's diabetes team is informed by either the patient or by the ambulance service (with the patient's permission).

As well as assisting in risk management for the 'left at home' patient, the system may help prevent the recurrence of acute emergencies by reinforcing or facilitating engagement with routine diabetes care.

For more information, email Steve Mortley at steve.mortley@eastamb.nhs.uk

When people with diabetes do go to hospital, either because of their diabetes or for another reason, their experience can be variable. For example, they may:

- receive care that is not personalised, so they do not feel that their individual needs are being listened to
- encounter insufficient knowledge or training about diabetes in general ward staff, leading to a lack of confidence and sometimes inappropriate care.

As well as leading to a poor patient experience, this can result in an increased length of stay – costing more money – and poorer clinical outcomes.

The report looks at ways of improving standards of inpatient care. Some trusts have found that employing diabetes inpatient specialist nurses (DISNs), diabetes specialist nurses (DSNs) or diabetes nurse educators (DNEs) has significantly reduced inpatients' length of stay. The report helps NHS organisations to understand the benefits – both financial and related to patient experience – that investment in these posts can bring.

Auditing inpatient care for people with diabetes

An audit of the service that people with diabetes receive in hospital has been undertaken in Brighton and Sussex University Hospitals Trust.

Working alongside the patient safety team, the diabetes team outlined the five most important basic care needs of an inpatient with diabetes:

1. Must have insulin or oral hypoglycaemic agents if needed.
2. Must have adequate carbohydrate intake.
3. Must have appropriate management of diabetes prior/during/post procedure and during times of fasting.
4. Must have appropriate treatment for any episodes of hypoglycaemia.
5. Must have persistent hyperglycaemia reviewed.

The criteria were put into a spreadsheet and used in the audit, carried out in spring 2007, to measure reliability. The work showed that, in some areas of the trust, more than 50% of inpatients did not receive adequate care for all five areas.

During the audit period it was found that 15.9% of all beds were occupied by people with diabetes.

The trust is now looking into ways of improving services for people with diabetes in hospital. It plans to increase the number of DSNs available to provide support for people with diabetes and the healthcare professionals who look after them. The aim is to reduce hospital admissions, reduce length of stay and improve the standard of care received in hospital.

A PDSA (plan, do, study, act) is going to be carried out to test the hypothesis that a seven-day-per-week DSN service has the potential to save bed days as well as improving the quality of patient care.

For more information, email Kate Morel at kate.morel@bsuh.nhs.uk

6 Diabetes and pregnancy

Standard 9: The NHS will develop, implement and monitor policies that seek to empower and support women with pre-existing diabetes and those who develop diabetes during pregnancy to optimise the outcomes of their pregnancy.

It is estimated that between 2% and 5% of pregnancies in England and Wales are complicated by diabetes. Around 87.5% of these are due to gestational diabetes, with the remainder due to pre-existing type 1 or type 2 diabetes.

It is well known that pregnancy outcomes for women with diabetes and their babies are poor compared to those for women who do not have diabetes. Diabetes in pregnancy is associated with risks to the mother and the developing fetus, including miscarriage, pre-eclampsia and pre-term labour. Stillbirth and congenital malformations are more common in babies born to women with pre-existing diabetes, and pregnancy can also worsen complications of diabetes such as diabetic retinopathy.

In February 2007 the Confidential Enquiry into Maternal and Child Health (CEMACH) found that, while progress had been made in improving services for women with diabetes and their babies, there was still much to be done to meet the standards recommended by the National Service Framework.[36]

The CEMACH report, together with the new guidelines on the management of diabetes in pregnancy issued by NICE in March 2008,[37] provides a wealth of advice and recommendations for teams looking after women with diabetes who may become pregnant or who are at risk of gestational diabetes. The Department of Health, working with the National Diabetes Support Team and other partner organisations, will be using these resources to support improvements in the quality of care for women with diabetes in pregnancy throughout 2008 and 2009. Further details of this work will be made available later in the year.

36 CEMACH, 2007, *Diabetes in Pregnancy: Are we providing the best care?* www.cemach.org.uk/getattachment/ce7b601d-9a14-443e-982c-bcda4fd92ca3/Diabetes-in-Pregnancy.aspx

37 NICE, 2008, *Diabetes in Pregnancy: Management of diabetes and its complications from pre-conception to the postnatal period* (CG63, reissued). www.nice.org.uk/nicemedia/pdf/CG063NICEGuideline.pdf

7 Detection and management of long-term complications

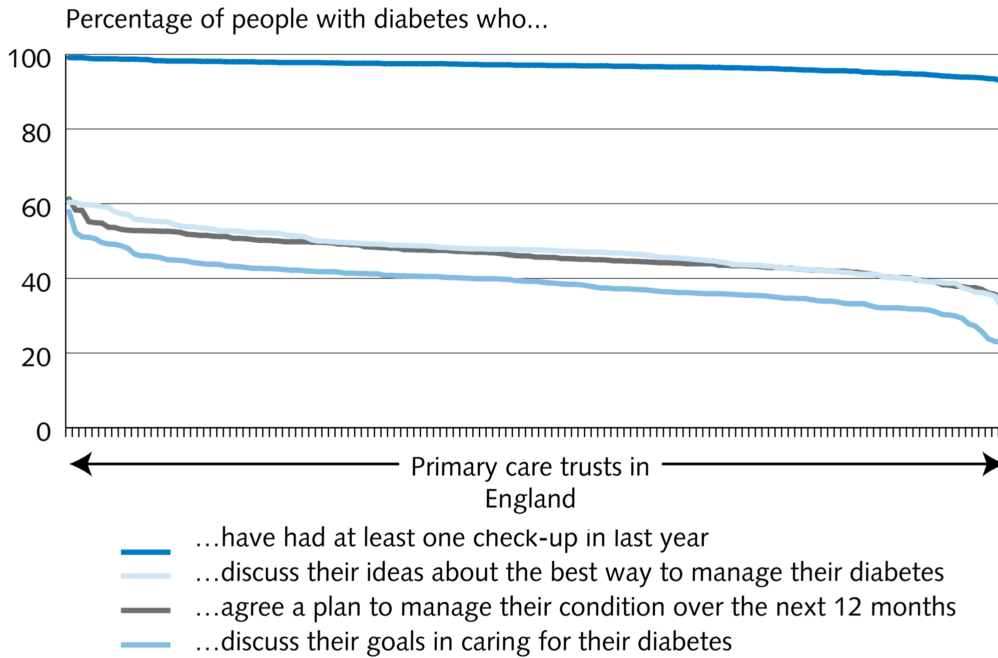
Standard 10:	All young people and adults with diabetes will receive regular surveillance for the long-term complications of diabetes.
Standard 11:	The NHS will develop, implement and monitor agreed protocols and systems of care to ensure that all people who develop long-term complications of diabetes receive timely, appropriate and effective investigation and treatment to reduce their risk of disability and premature death.
Standard 12:	All people with diabetes requiring multi-agency support will receive integrated health and social care.

As we saw in Chapter 3, data from the Quality and Outcomes Framework (QOF) demonstrates a great improvement in screening for the complications of diabetes. We still have a long way to go – as Chapter 3 also sets out, the National Diabetes Audit reports that not everyone is receiving every process of care. But the year-on-year improvements in QOF data on both the numbers being checked and the outcomes of those checks are very encouraging. The NHS is also continuing to make this a priority: NHS South West's *Draft Strategic Framework for Improving Health in the South West*, published earlier this year as part of the NHS Next Stage Review, proposes a number of ambitions to improve the care of people with long-term conditions, including exceeding QOF targets for blood glucose control and blood pressure in people with diabetes.[38]

The 2006 Healthcare Commission survey of people with diabetes confirmed that the overwhelming majority receive regular check-ups for their condition.[39] What the graph across England also shows, however, is that these regular check-ups do not always include proper dialogue between the person with diabetes and their healthcare professional.

38 www.ournhs.nhs.uk/wp-content/uploads/2008/06/sw-vision-doc.pdf
39 Healthcare Commission, 2007, *The Views of People with Diabetes: Key findings from the 2006 survey.* www.healthcarecommission.org.uk/_db/_documents/Diabetes_survey_2006_summary.pdf

Fig 4: Number of people with diabetes receiving check-ups, compared to those who can regularly discuss their care, in different primary care trusts across England



Source: Healthcare Commission, Managing Diabetes: Improving services for people with diabetes, 2007

Local services need to adopt different strategies to ensure that the annual check-ups received by people with diabetes reflect their personal needs and circumstances. There are many innovative examples demonstrating that local services can be adapted to meet the needs of different sections of the community, ensuring equality in services for those who are disproportionally affected by diabetes or have specific service needs.

Delivering an at-home annual review

Older people with diabetes are receiving a better annual review in Sefton Primary Care Trust, Liverpool.

The diabetes community team developed a structured care process for those who are housebound or living in care homes, making better use of the specialist diabetes team, district nurses and senior care home staff. This replaced the existing service provision, which was more reactive and did not include routine visits to care homes.

To start with, a pilot study was undertaken to assess feasibility and effectiveness. An action plan was devised to:

- formulate a procedure for an at-home annual review
- design an assessment
- design a database, record of assessment, referrals and audit tool.

Subsequently, two diabetes nurse practitioners (DNPs) were employed. Their objectives were to:

- identify all those diagnosed with diabetes who were housebound or in care homes
- manage an annual review for those identified
- manage diabetes control and medication reviews to optimise treatment
- manage early interventions in the newly diagnosed
- manage referral to, and liaison with, the wider diabetes management team and other social support and health professionals
- educate and support patients and their carers, including care home staff, to increase empowerment, satisfaction and quality of life
- create awareness and understanding of the new DNP service.

There has been an increase in direct referrals to the DNP service, as well as increased diabetes skills and knowledge among care home staff. In the first year of the service, HbA1c rates have improved, with 68% of the target population having a level of 7.4% or below. All of them received an annual review, as opposed to just 58% before the service was set up.

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Preventing or delaying the long-term complications of diabetes has great health and quality-of-life benefits for people living with the condition. The onset of complications, particularly the threat of blindness or amputation, can be a major concern for people with diabetes.

Foot problems are costly, not just to people with diabetes but also to the NHS. A large proportion of people with diabetes develop a foot ulcer – there is some evidence to suggest that the lifetime risk is as high as 25%.[40] Amputations, among the most feared complications of diabetes, are preceded by foot ulcers in more than 80% of cases,[41] and length of stay in hospital is particularly long in people with diabetes who have foot problems. The evidence shows, however, that amputations can be prevented with the right teamwork in place.[42] This is emphasised in NICE guidance[43] which recommends, alongside a regular review of patients' feet, care from a multi-disciplinary foot care team.

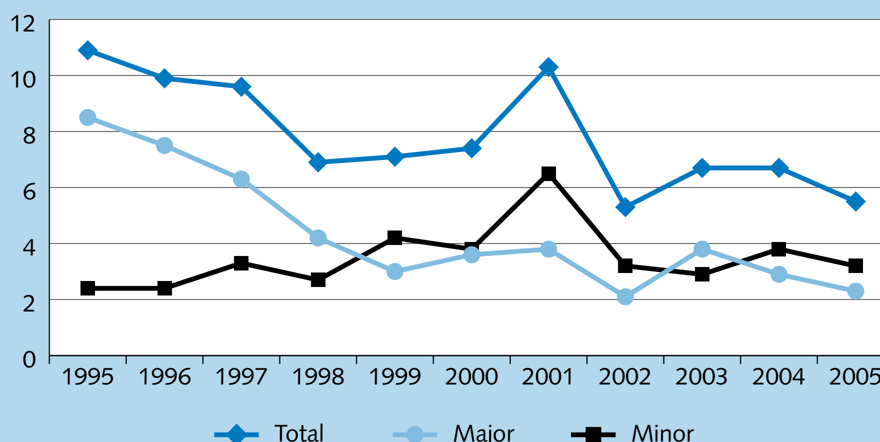
Inpatient foot care in Ipswich

In Ipswich, a specialist diabetes podiatrist and diabetes specialist nurse (DSN) with an interest in foot care started twice-weekly ward visits to all wards in order to:

- identify and co-ordinate the management of all inpatients with diabetes and foot problems
- educate medical and nursing staff.

Major and total amputation rates fell over the following years. When the team was withdrawn in 2000, total amputation rates started to increase again. Using the data they had collected, the team were able to show that savings on bed days alone were four to five times greater than staff costs. The DSN post was reinstated and amputation rates fell again.

Amputation rates per 100,000 of general population in Ipswich



40 Singh N, Armstrong DG, Lipsky BA, Preventing foot ulcers in patients with diabetes, *JAMA* 2005, 293, 217–228. http://jama.ama-assn.org/cgi/content/abstract/293/2/217

41 Pecoraro RE, Reiber GE, Burgess EM, Pathways to diabetic limb amputation: basis for prevention, *Diabetes Care* 1990,13, 513–521. http://care.diabetesjournals.org/cgi/content/abstract/13/5/513

42 Krishnan S, Nash F, Baker N, Fowler D, Rayman G, Reduction in diabetic amputations over 11 years in a defined UK population: benefits of multidisciplinary team work and continuous prospective audit, *Diabetes Care* 2008, 31, 99–101. http://care.diabetesjournals.org/cgi/content/abstract/31/1/99

43 NICE, 2004, *Type 2 Diabetes: Prevention and management of foot problems* (CG10). www.nice.org.uk/nicemedia/pdf/CG010NICEguideline.pdf

Diabetic retinopathy screening

The Diabetes National Service Framework Delivery Strategy set an extremely challenging target: that by the end of 2007, 100% of people with diabetes would be offered screening for diabetic retinopathy.

This target is challenging for a number of reasons, but the increasing numbers of people being identified as having diabetes makes it particularly difficult to meet. Data from April 2008 shows that 89.4% of people with diabetes were offered screening for retinopathy in the previous 12 months. Although there is still a way to go to meet the target, this is a huge achievement for the NHS. The number of people being offered screening for retinopathy is now much greater than the number of people who were identified as having diabetes when the target was first set.

The Department of Health is continuing its emphasis on retinopathy screening, reflected in its inclusion in the Operating Framework for 2008/9.[44] However, the NHS needs not only to continue working towards the 100% target, but also needs to focus on increasing the number of people who are actually being screened rather than simply offering screening. The Department of Health and the National Screening Committee will continue to work with primary care trusts to make sure that retinopathy screening remains a priority.

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44 Department of Health, 2007, *The NHS in England: The Operating Framework for 2008/09*. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081094

8 Further resources

This report gives an overview of the progress that has been made since the Diabetes National Service Framework Delivery Strategy was published in 2003.

It makes reference to tools and guidance that are available to support the NHS in delivering specific areas of the National Service Framework. Other, more generic tools such as the Diabetes Commissioning Toolkit are also available. These can be found on the websites of the National Diabetes Support Team:

www.diabetes.nhs.uk

or the Department of Health:

www.dh.gov.uk/en/Healthcare/NationalServiceFrameworks/Diabetes

Following a review by the Office of the Strategic Health Authorities (OSHA), the National Diabetes Support Team will continue to provide support to diabetes services in implementing the National Service Framework. It will also expand to offer support to kidney services, forming part of a larger organisation called NHS Diabetes and Kidney Care.

The Department of Health and the National Diabetes Support Team are working in partnership with the Information Centre for Health and Social Care to develop a National Diabetes Information Service (NDIS). Access to data on diabetes is vital in enabling NHS organisations to plan and deliver services that are right for their communities, and NDIS will help to ensure that this information is easily accessible and understandable for those delivering diabetes services.

In the meantime, the National Diabetes Support Team and the Yorkshire and Humber Public Health Observatory (YHPHO) have been working together to develop a Diabetes Data Directory to improve access to and understanding of the range of tools and datasets available:

www.yhpho.org.uk/diabetesdatadirectory/introddd.asp

Participation in the National Diabetes Audit (NDA) is crucial in giving NHS organisations information about their diabetes services and outcomes. NDA annual reports are available at:

www.ic.nhs.uk/our-services/improving-patient-care/national-clinical-audit-support-programme-ncasp/audit-reports/diabetes

Skills for Health, the Sector Skills Council for the UK health sector, has worked with key partners to develop competencies for the diabetes workforce, including care for children, young people and adults with diabetes. These competencies are available at:

www.skillsforhealth.org.uk/page/competences/completed-competences-projects/list/diabetes?id=40

The National Diabetes Support Team and Skills for Health have also published the National Diabetes Workforce Strategy to support the NHS in planning and designing the diabetes workforce. This is available at:

www.diabetes.nhs.uk/downloads/workforcestrategy.pdf

For people with diabetes, Diabetes UK's website is a comprehensive source of information. It can be accessed at:

www.diabetes.org.uk

The NHS Choices website has been developed to support the public in accessing information about health-related matters, including healthy living and specific conditions and diseases. The interactive NHS guide on diabetes can be found at:

www.nhs.uk/Pathways/diabetes