Turning the Corner: Improving Diabetes Care

Report from Dr Sue Roberts
National Clinical Director for Diabetes
to the Secretary of State for Health
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**Description**
The Diabetes National Service Framework set out the first ever set of national standards for the treatment of diabetes to raise the quality of NHS services and reduce unacceptable variations between them. This report highlights progress over the first three years following the publication of the NSF Delivery Strategy.

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**For recipient’s use**
Turning the Corner: Improving Diabetes Care

Report from Dr Sue Roberts, National Clinical Director for Diabetes, to the Secretary of State for Health
## Diabetes NSF Standards to be reached by 2013

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<th>Prevention of Type 2 diabetes</th>
<th><strong>Standard 1</strong></th>
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<td></td>
<td>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.</td>
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<th><strong>Standard 2</strong></th>
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<td>The NHS will develop, implement and monitor strategies to identify people who do not know they have diabetes.</td>
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<td>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.</td>
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<th>Clinical care of adults with diabetes</th>
<th><strong>Standard 4</strong></th>
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<td></td>
<td>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.</td>
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<th>Clinical care of children and young people with diabetes</th>
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<td>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.</td>
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<td></td>
<td>All young people with diabetes will experience a smooth transition of care from paediatric diabetes services to adult 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.</td>
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**Management of diabetic emergencies**

*Standard 7*

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

**Care of people with diabetes during admission to hospital**

*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.

**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.

**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.

The report also takes into account the standards covered in section two of the National Service Framework for Children, Young People and Maternity Services: Children and young people who are ill.
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This third annual report on the progress of implementing the Diabetes NSF standards presents an encouraging picture. It outlines in graphic detail the growing challenge of diabetes and the real cost it imposes on people, their families and the NHS. It confirms the excellent work being done to provide a proper understanding of the challenges faced through establishing baseline information on prevalence and diagnosis. This enables real measurement of improvement to be made. Encouragingly it provides examples of what is working well but pulls no punches in saying that there are still areas where progress needs to be made. It also outlines the opportunities that the current focus on self care, integrated working and prevention provides for those working in diabetes.

This focus on diabetes care needs to be seen in the context of the emergence of the condition as one of the great health threats of the 21st century. The figures for this country and the world as a whole make sobering reading. There are an estimated 2.35m people with diabetes in England and this is predicted to grow to more than 2.5m by 2010. The impact of childhood obesity is seeing an alarming explosion in numbers of young people diagnosed with Type 2 diabetes, which was previously thought to be a condition of later life. The cost to the people affected and their families is considerable with life expectancy reduced by more than fifteen years for someone with Type 1 diabetes and up to ten years for Type 2. Diabetes also significantly increases the risks of heart attacks, strokes, blindness, kidney failure and amputation.

The costs of all of this to the NHS are considerable. When the Diabetes Delivery Strategy was published 5% of all NHS expenditure and 9% of hospital expenditure were accounted for by the disease. In addition to direct health costs the impact on social services expenditure, where diabetes complications increase costs four-fold, is significant. It is likely that with a population that is growing older, taking less exercise and more ethnically diverse, costs are going to increase even more.

It is not surprising therefore that the Government has taken significant steps to improve both the care of people with diabetes and address the substantial challenge of improving people's lifestyles so that the risks of Type 2 are considerably reduced. The standards of
care set out in the National Service Framework of 2002 are still valid and are the consistent driver for improving standards of care. It is significant that many of the initiatives outlined in the NSF and its delivery strategy have become embedded in two White Papers that looked at improving public health and people’s influence over the services they receive.

Both “Choosing Health” and “Our Health, Our Care, Our Say” emphasise the need to develop integrated services between health care professionals and the wider social care community to improve health. The role of multi-disciplinary teams delivering services at a time and in a place that is most convenient for service users chimes with much of the NSF. The focus on partnership between people and healthcare professionals in designing the services they receive so that there is real commitment to the improvements required is central to the way of working proposed by the NSF.

It is heartening that this report demonstrates that in many ways the diabetes community is already working in ways encouraged by the White Papers and this is a tribute to its innovation, commitment and energy. There is real evidence of integrated working across the health and social services spectrum as witnessed by the collaborative efforts at the Laurie Pike Health Centre in Birmingham.

Community based multi-disciplinary teams are already in place and the need to effectively engage with service users to promote and maintain health improvement is widely recognised. However it would be wrong to ignore the inequality of provision that still hampers people receiving the world class services they deserve. I am confident that with the support and commitment of the people at the frontline of delivering diabetes services the progress identified herein will widen and deepen. The aim is to ensure services that both healthcare professionals and people with diabetes can be justly proud of delivering and delighted to use.

The Rt Hon Patricia Hewitt MP
The Secretary of State for Health
This third report on the implementation of the Diabetes National Service Framework (NSF) standards shows some real progress in a number of areas. Apart from the examples of what is working well, I am particularly pleased by the developments that enable us to properly understand the nature of the challenge we face on a national scale. A more accurate prevalence model combined with the National Diabetes Audit, DiabetesE and the Quality and Outcomes Framework (QOF) outcomes are providing baseline data that will support effective measurement of improvement in diagnosis and care. We now know what the challenges are and it is up to us all to respond to them.

I welcome the continuing development of diabetes networks as essential components of a system of integrated diabetes care. This is accompanied by the increasing realisation by frontline staff that networks can drive through real improvements in care.

This has all taken place against a background of significant change for both how health services are organised and how care is commissioned and delivered. The impact of Delivering a Patient Led NHS, Payment by Results (PbR) and Practice Based Commissioning (PBC), all elements of what is collectively known as System Reform, on diabetes services still require full clarification. As an example PbR was originally calculated on the basis of elective surgery in the acute sector and we have worked to ensure that specialist diabetes services understand the challenge of PbR whilst at the same time that PbR reflects the needs of long term conditions. The recent White paper acknowledges that there is more thinking to be done on how long term conditions are properly catered for within system reform and our aim is to ensure diabetes is directly involved in that debate.

However events will not stand still and the year ahead sees further developments that will impact on diabetes services. Criteria for identifying what constitutes a quality service will be developed. Work on how effective models of integrated care can be commissioned, especially the concept of commissioning for health rather than illness will have great relevance for diabetes services. Putting quality at the centre of commissioning services rather than a singular emphasis on quantity will also support much of what diabetes teams are already doing.

Introduction
Taken together all of these elements of system reform provide extra challenges for people delivering services and it is to their credit that they have kept their eye on the ball so accurately.

These new challenges are also new opportunities and services should be using them to support working towards all the NSF standards. Commissioning high quality services that are properly patient focused, are integrated, multi-disciplinary and delivering care at the time and place people want is essential. These need to be supported by commissioning high quality services aimed at preventing diabetes rather than treating it. This will entail links with local authorities and independent sector providers in terms of healthy eating and fitness programmes.

In many ways this is a very exciting time to be working in diabetes. Many of the ways of working promoted by the NSF and its delivery strategy are central to recent policy initiatives. Recent White Papers with a focus on prevention, self care and patient centred services have enormous relevance to diabetes. The growing challenge of diabetes provides a stimulus to service providers to tackle the existing prevalence and examine how to stop people getting it. Prevention programmes will get a further boost from the decision of the Austrian president of the EU to have reducing the growth of Type 2 diabetes as one of the central themes of his presidency.

There are still a considerable number of challenges though. The need to deliver patient education that meets the National Institute for Health and Clinical Excellence (NICE) guidelines, the diabetic retinopathy screening target, effective care planning and the maintenance of diabetes networks through the restructuring of PCTs and introduction of an increasing number of Foundation Trusts will all require careful planning.

I am confident that many of the building blocks of moving diabetes services towards the NSF standards are in place. It is now up to the diabetes community to seize the opportunities currently provided and run with them to deliver the world class services users demand. I will conclude with one very sobering fact; the current generation is predicted to be the first to have a shorter life expectancy than its parents, with diabetes and its complications being a major contributor to that. It is up to us to avoid that dismal forecast and from my knowledge of the skills, energy and commitment of the diabetes community I know we will give it our very best.

Sue Roberts
National Clinical Director for Diabetes
1 Diabetes – the growing challenge

The fact of the global pandemic of diabetes is becoming ever more widely recognised. An increasing number of reports from the World Health Organization¹, the International Diabetes Federation² and others outline the truly massive and growing challenge of diabetes internationally. In this country recent reports on obesity in the young by the Royal College of Paediatrics and Child Health³ drive home the risks that an inactive and unhealthy eating lifestyle pose. Statistics on lack of exercise and obesity in the adult population reinforce the challenge that diabetes will present to the NHS and social care in the years ahead. This challenge to organisations will be matched by the reduced life expectancy and quality of life for people who get diabetes. There is an abundance of information indicating that tackling diabetes is one of the key issues facing health organisations in this country and elsewhere. What we cannot afford to do for either humanitarian or financial reasons is ignore or downplay this wealth of information; we cannot simply hope that the challenge will go away.

The real costs

The World Health Organization estimates that the number of people with diabetes worldwide in 2000 was 177 million. It predicts that this will increase to at least 300 million by 2025, ten times the number just 40 years previously. There are likely to be around 4 million deaths per year related to diabetes and its complications. This is about 9% of the global total and most of them are premature deaths where the people concerned are contributing economically to society.

How many people in England have diabetes?

- 2.35 million (4.7% of the population) are estimated to have diabetes in 2005. The latest Quality and Outcomes Framework (QOF) results show that 72% of this estimated total (1.8 million people) have their diabetes diagnosed.
- It is predicted that 5.05% of the population will have diabetes by 2010, this equates to more than 2.5 million people.
- The numbers of people registered with diabetes doubled between 1994 and 2003.
- It is predicted that the diabetes prevalence rate will increase by 15% between 2001 and 2010.

¹ http://www.who.int/diabetes/en/
² http://www.idf.org/home/
³ Storing up problems: the medical case for a slimmer nation, Report of a working party of the Royal College of Physicians, Royal College of Paediatrics and Child Health and the Faculty of Public Health Medicine, February 2004
The human cost of diabetes

The greatest cost of diabetes is to the people who have it, their families, carers and friends. The impact on them of reduced life expectancy and quality of life is considerable.

- Life expectancy is reduced, on average, by:
  - More than 15 years in people with Type 1 diabetes
  - Between 5 and 7 years in people with Type 2 diabetes (at age 55 years)
- Adults with diabetes have heart disease death rates about 2 to 4 times higher than adults without diabetes
- The risk of stroke is 2 to 4 times higher among people with diabetes
- Diabetes is the most common cause of non-traumatic lower limb amputation
- Diabetes has become the single most common cause of end stage renal disease
- Impotence may affect up to 50% of men with longstanding diabetes
- About 30% of patients with Type 2 diabetes develop overt kidney disease.

Babies of women with diabetes are:

- 5 times as likely to be stillborn;
• 3 times as likely to die in their first months of life;
• Twice as likely to have a major congenital anomaly.

A woman with diabetes is much more likely to:
• Have her baby delivered early;
• Require an induction of labour;
• Have her baby delivered by caesarean section.

Who gets diabetes?

Scenario of doctor-diagnosed diabetes within minority ethnic group

Some sectors of the population are more prone to diabetes than others, with black and minority ethnic communities being particularly adversely affected.

Source: Health Survey for England 2004

The risk of developing diabetes increases as body weight increases. The risk of Type 2 diabetes is almost 13 times greater in obese women than in women of normal weight. For men the risk is 5 times greater.

About 44% of men in England and 34% of women are overweight (a body mass index of 25-30 kg/m²), and an additional 23% of men and women are obese (a body mass index of more than 30 kg/m²).
Overweight and obesity increase with age. About 31% of men and 36% of women aged 16-24 are overweight or obese but 78% of men and 69% of women aged 55-64 are overweight or obese. Overweight and obesity are increasing. The percentage of adults who are obese has roughly doubled since the mid-1980s.

The National Audit Office suggest that 47% of Type 2 diabetes in England can be attributed to obesity.

The risk of developing Type 2 diabetes is increased by 30-40% in people who lead a sedentary lifestyle, compared with people who are regularly physically active. The reduction in risk associated with increased activity levels is independent of body mass index.

Both mortality and morbidity caused by diabetes are increased by socio-economic deprivation. Both incidence and prevalence of diabetes are greater in areas of higher deprivation. Trend analysis suggests that between 1994 and 2003 the prevalence of diabetes increased in all bands of deprivation but the greatest increase was found in the most deprived areas.

**Financial cost of diabetes**

This increase in the number of people with diabetes obviously means increased costs for the NHS. In England:

- Diabetes accounted for 5% of all NHS expenditure in 2002
- Recent estimates say it could now be as high as 10%
- The first Wanless report (2002) estimated the total annual cost of diabetes to the NHS to be £1.3 billion
- The presence of diabetic complications increases NHS costs for a patient more than five-fold
- In 1997 diabetes accounted for 9% of hospital costs
- Diabetes increases by five times the chance of a person needing hospital admission
- 1 in 20 people with diabetes incur social services costs
- More than three-quarters of these costs were associated with residential and nursing care, while home help services accounted for a further one-fifth
- The presence of complications increased social services costs four-fold.

The majority of the statistics quoted here can be found in the Key Diabetes Facts report produced by the Diabetes Public Health Intelligence Group supported by the Yorkshire and Humber Public Health Observatory. This report can be found at www.yhpho.org.uk.

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4 Securing Our Future Health: Taking a Long-Term View, Final Report, Derek Wanless, April 2002
Prevention

One of the tragedies about the growing challenge of diabetes is that the Type 2 form of the condition is preventable. In most cases, Type 2 diabetes is a lifestyle disease caused by a combination of unhealthy diet and relative inactivity. Total calorific consumption has stayed broadly stable over the last twenty years, but diets have generally become less healthy. Educating people about the risks of being overweight and unfit, combined with programmes to tackle obesity and lack of exercise are essential. Even for those who have a higher risk, who cannot do anything about increasing physical activity, keeping weight down will help.

Measuring improvement

Over the last year there have been a number of initiatives that have provided some much needed hard data to support improvements in diabetes care. This describes where people with diabetes live, how many there are, who they are in terms of gender, age, ethnicity and deprivation, how many have been diagnosed and the level of care provided by services. These have enabled a baseline of activity to be developed against which improvement can now be measured which will provide firm evidence that the NSF Standards are being worked towards.

The role of the Healthcare Commission in evaluating service delivery and performance around diabetes as part of its annual assessment will be crucially informed by engagement with such initiatives. It has made it clear that when conducting service improvement reviews, whether organisations contribute to the National Diabetes Audit and use data for service improvement will be taken into consideration.

Diabetes Prevalence

A vital element in measuring the effectiveness of diabetes care in any area is being able to estimate the percentage of people with diabetes who are diagnosed and receiving treatment. The Yorkshire and Humber Public Health Observatory (YHPHO) was involved in developing an evidence based diabetes prevalence model for England, called the PBS Diabetes Prevalence Model. It estimates diabetes prevalence rate and number by area, gender, age and ethnicity.

The PBS model is a key component of audit tools. It can be used by diabetes teams to assess performance and compare their work with others.

5 http://www.healthcarecommission.org.uk
The model can be used to compare expected prevalence between populations and over time. Potential uses include:

- Assessing the static completeness of diabetes registers in primary care by validating the completeness of case finding;
- Comparing complication rates or admission rates after adjustment for variation in expected prevalence;

The Slough Project

Certain ethnic minority communities have long been labelled ‘hard to reach’. But when Slough Primary Care Trust wanted to raise awareness about diabetes among black and minority ethnic communities, it was simply a question of changing tactics. Rather than rely on the traditional health service methods of getting health messages across, the Trust decided to turn to the marketing techniques of the private sector.

A computer programme developed by Dr Foster combines information about hospital admissions and medical treatment for particular conditions with data on the socio-economic background of a particular area’s population. “This is a tool that can identify where Asian businesses are, what television programmes people watch, what newspapers they read – even what cars they drive,” says Grace Vanterpool, Diabetes Specialist Nurse, who led the initiative. “It is fantastic because we can use it to map where we have increased incidence of diabetes in the community and how that relates to ethnicity, age and a range of other factors.”

“Our work with Dr Foster allows us to combine what we know about health statistics with what they know about broader social demographics,” said Grace. “If we know that people from the Pakistani community listen to a particular local radio programme or hire videos from a certain shop, we know those are good places to put health information.”

The pioneering work with Dr Foster played a key role in choosing locations around the city, which included a bingo hall, supermarkets, community centres, hospitals, leisure centres, mosques and shopping centres. “We are being able to target our health promotion work at places where people naturally congregate,” said Grace. “These are places where people are relaxed and more likely to take in information.”

More information can be found at http://www.raceforhealth.org/people.php?id=9&pid=92
• Comparing service provision with population need.

The PBS model is integrated into the National Diabetes Audit so that service providers can easily see their predicted as compared to registered number of people with diabetes and more easily compare their improvement with others. The PBS model estimates that there were 2.3m people with diabetes in England in 2005, of which an estimated one-quarter remain undiagnosed.

More information is available at http://www.yhpho.org.uk

**Quality and Outcomes Framework**

One of the significant drivers in both delivering and measuring improvement has been the Quality and Outcomes Framework\(^8\) (QOF). This system of paying primary care practitioners for both identifying people with diabetes and measuring their outcomes against a range of indicators has produced considerable improvement.

Because practices have been allowed to omit results from some patients the QOF figures themselves should be seen as a guide. Diabetes plays a substantial role within the QOF programme with nearly 10% of the total points and the largest single number for any medical area being awarded for diabetes care. The outcome has been that by 2005 the number of people diagnosed with diabetes reached 1.8m in England; 72% of the expected total. The figure below illustrates that this implied diagnosis rate ranges between 51% and 92% at PCT level.

\[\text{Implied rate of diagnosis} \quad \text{Primary Care Trusts in England}\]

\[\text{Source: QPID database (HSCIC) June 2005 / PBS Phase 2 model adjusted to 2005 levels}\]

\(^8\) [http://www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/PrimaryCare/PrimaryCareContracting/QOF/fs/en](http://www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/PrimaryCare/PrimaryCareContracting/QOF/fs/en)
QOF data gives a good indication of the proportion of patients who have had their health status checked for blood pressure, HbA1c (marker of long-term control of diabetes) and cholesterol. It also tells us the proportion of these patients meeting the target levels for each test and the improvement that still needs to be achieved.

1. HbA1c

Nationally, 94.4% of people on a diabetes register had a record of HbA1c (or equivalent) in their notes in the previous 15 months ranging between 90.7% in London and 96.7% in the South West region. Of these patients, 58.8% had a HbA1c that was 7.4 or less (the target level) ranging between 53.8% in London and 62.7% in the North West.

2. Blood Pressure

Nationally, 97.0% of people on a diabetes register had a record of blood pressure in their notes in the previous 15 months ranging between 95.7% in London and 97.9% in the North East. Of these patients, 70.3% had a blood pressure measurement that was 145/85 or less (the target level) ranging between 67.7% in the West Midlands and 71.6% in the North West.

3. Cholesterol

Nationally, 92.7% of people on a diabetes register had a record of cholesterol in their notes in the previous 15 months ranging between 89.5% in London and 95.6% in the North East. Of these patients, 71.8% had cholesterol levels of 5mmol or less (the target level) ranging between 66% in London and 74.8% in the North East.

Further information about QOF and the impact it is making on diabetes diagnosis and care can be seen at http://www.diabetes.nhs.uk/Reading_room/Factsheet.asp

**National Diabetes Audit**

The National Diabetes Audit (NDA) is sponsored by the Healthcare Commission. It enables routine data collection, analysis and feedback of diabetes related data for all people in England, including adults and children with diabetes. It forms a vital part of measuring how services have improved their diagnosis of diabetes against predicted prevalence. It is the only tool that looks at the final outcomes of diabetes such as amputation, heart attacks, blindness, renal failure and relates them back to the quality of care in the patients’ locality.

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* A measurement of blood glucose control
A number of important findings including significant variations in services have been identified from the 2003/04 data:

• As expected from QOF returns, the NDA reports that nearly three-quarters of the number of persons estimated to have diabetes have been identified, although there is considerable regional variation in this proportion. People who have diabetes but do not have their diagnosis recorded on practice registers will be unlikely to receive the routine care and monitoring required to optimise wellbeing and minimise long-term complications;

• There are wide regional variations in the rates of myocardial infarction, cardiac failure and stroke amongst people with diabetes. Effective preventative care could significantly reduce the increased risk of vascular disease in people with diabetes;

• Less than 50% of patients in 2003/04 are recorded as receiving eye checks compared to the 2006 NSF target of 80%. Diabetes is a leading cause of blindness. Early detection and treatment can prevent blindness in those at risk;

• In 2003/04 only 56% of people with diabetes achieved an HbA1c of less than 7.5%, the primary target level of glucose control recommended in NICE clinical guidelines. Only 23% achieved the secondary target of less than 6.5%. Maintaining controlled blood glucose levels reduces the risk of long-term complications such as blindness, renal failure and nerve damage;

• In the audit of specialist paediatric units 15% of children with diabetes achieved the primary target HbA1c (less than 7.5%); 65% of children with diabetes achieved less than or equal to 9.5%. Not achieving the NICE recommendations increases the risk of long term complications such as blindness, renal failure and nerve damage.

It is right to report that these finding predate the QOF and it is likely that significant improvements will be seen year-on-year.

The NDA supports the implementation of the Diabetes NSF and aims to improve the quality of patient care for all people with diabetes in England by enabling organisations to:

• Ensure that clinical standards are met;

• Compare the processes and outcomes of diabetes care with similar NHS organisations;

• Identify and share good practice of the care for people with diabetes.

10 Management of type 2 diabetes – Managing blood glucose levels (Guideline G) – http://www.nice.org.uk/page.aspx?o=36737
Participation in the NDA continues to grow with registration numbers rising. As at the end of May 2006, 182 PCTs, 3833 GP Practices, 75 hospital trusts and 100 paediatric units have registered for the audit. This growth will be further driven, as in 2006/07 participation in National Clinical Audit will be measured as part of the Healthcare Commission’s Health Check. They are also undertaking a diabetes improvement review in 2006 and one of the possible data sources is participation in the NDA.

More information about the NDA can be found at http://www.icservices.nhs.uk/ncasp/pages/audit_topics/diabetes/default-new.asp

**Better Metrics**

Metrics are measures of performance and ‘better metrics’ are aimed to relate to the day to day work of healthcare professionals. They measure what is important in clinical care that can then be used to set local targets and compared with other localities looking at the same area of care such as foot care, emergency care or education.

The Better Metrics Report, available at www.osha.nhs.uk, outlines the aims and objectives of the project and features all the metrics for each health area – 13 of which are specifically for diabetes care.

Also, the Healthcare Commission will consider developing criteria to assess clinical effectiveness in the areas covered by metrics. However, metrics are not an exhaustive test of performance, but a starting point for further information, reflecting both the priorities of patients as well as clinicians. The Better Metrics applicable to diabetes can be found at http://www.diabetes.nhs.uk/downloads/Diabetes_Better_Metrics.pdf

**DiabetesE**

DiabetesE is a standardised web-based, self-assessment quality improvement tool that measures and benchmarks the performance of all aspects of a system of diabetes care and actively encourages continuous improvement.

There are two assessments: one for the PCT and the specialist services it commissions, and one for each of its general practices. As of May 2006, 292 PCTs in England (96%) had registered to use DiabetesE and 186 PCTs have undertaken assessments. The remainder plan to undertake their assessment during 2006. A large number of PCTs have also begun a staged roll out of DiabetesE to their practices.

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11  www.diabetesE.net/demo and http://www.innove.co.uk/diabetesE.htm
2 Tackling the root cause

This report has already highlighted both the growing numbers of people with diabetes and the risk factors associated with getting it. There is no reason why the numbers of people with Type 2 Diabetes, should continue to grow because the knowledge and methods exist for this explosion in numbers to be successfully defused.

As a first step people need to become aware of the risks that their lifestyle has on their health and general well being and that there are measures to help them improve. Much of Type 2 diabetes can be prevented through healthy eating and exercise programmes. These need to be developed and integrated across all elements of health and social care, including independent sector providers, to enable the widest possible access for all communities. Social care needs to be interpreted as widely as possible to include education providers and those engaged in promoting healthy communities and environments. This can include transport, schools, sports clubs and dieting programmes. Care needs to taken to ensure that different cultural requirements are acknowledged and programmes are sufficiently flexible to meet all needs.

Lifestyle intervention can significantly reduce the likelihood that people at a high risk of diabetes actually get it. Progression rates to diabetes in people without diabetes was reduced by:

- 58% in the Diabetes Prevention Program (USA)
- 58% in the Finnish Diabetes Prevention Study (Finland)
- 40% in the Da Qing study (China)

Evidence indicates that 50% of people already have one or more of the complications associated with diabetes when they are diagnosed which might have been prevented with early diagnosis and treatment. Screening high risk people for diabetes is recommended by the NSF delivery strategy and can significantly improve detection rates. As stated later in this report The UK National Screening Committee (NSC) has advised that screening certain subgroups of the population for Type 2 diabetes is feasible and should be taken forward.

13 http://www.nsc.nhs.uk/
To intensify the exchange of expertise and to discuss potential steps at community level the Austrian Presidency 2006\(^{14}\) highlighted prevention of Type 2 diabetes.

After people are diagnosed with Type 2 diabetes lifestyle adjustments can still have a vital part to play in controlling the impact of diabetes on individuals. The importance of promoting self care in true partnership with service users through effective education programmes combined with an active multi-disciplinary team providing all the care resources needed cannot be overstated. Ensuring effective integration between primary, secondary and social care providers is also a key part of ensuring people with diabetes receive the care they need.

South Tyneside

The Choosing Health programme has been created to address health inequalities in South Tyneside, to assist at risk groups and individuals to choose a healthier lifestyle, through individually tailored advice and support. The Choosing Health team consists of six health and lifestyle advisors and six community health officers, the lifestyle advisors will design lifestyle programmes, which will include nutrition advice, smoking cessation advice, weight management, exercise options, health MOTs and maintains contact and offer support.

The community health officers will establish community activities, help create and maintain community groups and identify the health needs of their particular CAF (Common Assessment Framework) area, through the completion of an area health profile.

The team is giving practical support to people who want to improve their health. An example of this is in the Horsley Hill area of South Tyneside where the Choosing Health team has worked closely with local residents covering a range of health initiatives, including weight management and physical activity.

These interventions have proved so successful, that residents now provide healthy buffets during organised events, and have indicated they would like more in depth knowledge on nutrition. Due to this request the team are organising further courses, which will enable the residents to deliver health and weight management advice in their local area.

Through the physical intervention programme, the level of fitness of the residents increased, and the growth of their confidence was such that they now feel empowered to utilise their local gym facilities. A number of residents have become walk leaders, and are successfully leading health walks around South Tyneside for local members of the community. From the success of these walks, the groups are now gaining confidence to become more ambitious with their planning, and have progressed to expanding the walking programme all over the North East.

\(^{14}\) http://www.epha.org/a/1956
Prevention

The number of people with Type 2 diabetes is rising, with an increasing number of young people being diagnosed. Some risk factors for developing diabetes such as family history, increasing age and ethnic origin are unavoidable. However, other risk factors such as being overweight or obese, having an adverse distribution of body fat and being physically inactive are avoidable and need to be the focus of prevention strategies.

The new White Paper “Our Health, Our Care, Our Say”\textsuperscript{15} set out proposals for introducing social prescriptions for those with long-term conditions, to enable them to access a wider provision of services. A range of different ‘prescription’ schemes, such as exercise-on-prescription projects, have been established or piloted in a number of areas and have been very successful.

The Department of Health would like to see increasing uptake of well-being prescriptions by PCTs and their local partners, aimed at promoting good health and independence and ensuring people have easy access to a wide range of services, facilities and activities.

Bolsover Wellness Project

A physical activity project targeted at those at risk of stroke, coronary heart disease (CHD) and diabetes has made a promising start in North Eastern Derbyshire. The Bolsover Wellness Project is an enhanced physical activity scheme targeting the most at risk groups, aiming to improve life expectancy across the area.

People are referred to the Neighbourhood Renewal funded Bolsover Wellness Project by GPs and can take part for free for the first three months. Since its creation 18 months ago more than 800 clients have taken part – and 70% of those stayed on the course after the initial 12 week trial.

Formal evaluations are currently being undertaken into the project, but there is strong anecdotal evidence that patient experience is being improved, along with health.

One service user, Ann Bradley from Shirebrook, said “through attending the scheme I now have increased mobility which has meant that I can now look after my daughter’s children and have been able to cancel my request to move from a house to a council bungalow.”

\textsuperscript{15} http://www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/Modernisation/OurHealthOurCareOurSay/fs/en
In line with the Our Health, Our Care, Our Say White Paper multi-agency action is required to reduce the numbers of people who are physically inactive, overweight and obese, by promoting a balanced diet and physical activity across the population. In order to have the greatest impact, action must start in childhood. These interventions will also contribute to a reduction in the number of people who develop coronary heart disease (CHD).

**The Do Activity Stay Healthy Scheme (DASH)**

The award-winning scheme, DASH, run by Somerset Coast Primary Care Trust is taking steps to tackle the growing obesity crisis among children. Recent figures suggest that 13.7% of the United Kingdom’s children are obese, leading to an increased prevalence of Type 2 diabetes in young people.

The programme is run as an early morning school-based club where five-to-nine-year-olds are encouraged to do exercise and eat well in a fun environment. Children who are overweight, obese or otherwise at risk of diabetes and coronary heart disease (CHD) are targeted. Parents are involved in the project, often resulting in a whole family change. The programme consists of three exercise sessions and a health education session each week. The focus is on activity and fun, with anxieties talked through with the whole family.

Initially four schools were involved, with around 71 pupils taking part. Physical benefits were monitored through a progressive ‘bleep test’. After six weeks all participants had progressed up one level.

School Nurse Tracy Milton said: “The results are looking good and self esteem is improving too – a few of the children have lost quite significant amounts of weight.”

The PCT worked with the Somerset Activity and Sports Partnership to create DASH, which won a Public Health Award from the Dorset and Somerset SHA and the programme is now being rolled out to other schools in the area. Currently there are 10 schools involved across three PCTs.

Both Type 2 diabetes and CHD are more common in people of South Asian, African and African-Caribbean descent, and initiatives must include elements developed with, and appropriate for, these communities.
Type 2 diabetes can be prevented in two thirds of people by improved physical activity and diet. The White Paper Our Heath, Our Care, Our Say announced the implementation of a self-assessment ‘Life Check’ for everyone at key points in life. This will support individuals and communities at high risk of developing diabetes to get involved in more healthy lifestyles and environments.

The new NHS ‘Life Check’, will help people take charge of their own health and well-being. ‘Life Check’ will be an assessment people complete themselves. If the results show that they are at risk of poor health, they should be able to talk to a Health Trainer about

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**Apnee Sehat (Our Health)**

This is a project led by South Warwickshire Primary Care Trust in partnership with South Warwickshire General Hospitals Trust and the local community. It has been developed in response to the high rates of diabetes and heart disease in the Asian population, partly due to diet and lifestyle choices.

Activities so far undertaken include:

A DVD, billed as a healthy cooking and dining tool kit for the Asian family, aimed at encouraging Asian communities to make healthier choices for a better life. Copies of the DVD are available free to health professionals by calling 01737 815237.

Development of low fat low sugar Asian sweets which will allow people to enjoy Diwali and Eid without worrying too much about calories and sugar.

*Our Health DVD launch*
the help available from local services, specialist services, referral for further medical advice and to develop a Personal Health Plan.

PCTs should also be commissioning for well being, commissioning local projects that encourage people to exercise, eat healthily and combat mental and physical health problems. Healthy living services will be available from many different places. These will include local surgeries, pharmacies, voluntary organisations, leisure and community centres, sheltered housing, children’s centres and schools.

**Screening**

The UK National Screening Committee (NSC) was asked by Ministers to provide advice on targeted screening for diabetes in 2005. The NSC has advised that screening certain subgroups of the population for Type 2 diabetes is feasible and should be taken forward, but recommended that it should be part of a programme to detect and manage cardio-vascular risk of individuals with the aim of minimising the risk of an individual developing cardiovascular disease.

Further work is needed on the costs and benefits of different screening strategies on who to test as a priority. This “modelling” would include the impact of starting at different ages, how often CVD risk factors should be assessed, the interventions expected and detailed costings. The Department of Health is working closely with the NSC on the next steps.

**Vascular Programme**

Heart disease, stroke, and kidney disease often have a good deal in common with diabetes – and people with diabetes are more at risk of developing these conditions. Together, they are the biggest causes of ill-health, death and disability in England. They share common clinical and behavioural risk factors – smoking, poor diet, lack of exercise and obesity. Patients suffering from one disease are at higher risk of experiencing another, but public understanding of vascular risk is low and services tend to be fragmented.

In terms of treatment and management in primary care, there is also a significant shared agenda in managing high blood pressure, high cholesterol and lifestyle factors. As a result, the Department of Health policy teams have recently reorganised to seek to ensure more integrated policy development. The aim is to secure more joined up delivery of care to patients in the NHS and to minimise irritating duplication of messages to the field.
The Department has set up a Vascular Programme, covering the three constituent policy teams of diabetes, coronary heart disease and stroke, and to ensure close coordination with the public health and renal teams.

**Phoenix NHS Stop Smoking Service**

This Lincolnshire-based service has focused on the needs of people with problems such as asthma, diabetes and Coronary Heart Disease (CHD). It provides clinical support for people from 100 sites across the county.

It was identified that to start with, staff from acute care were very rarely referring patients to the project. Phoenix NHS developed a hospital resource guide to build better relationships with the acute sector. When piloted the guide was very well received. The service is now supported by all staff from primary and secondary care in Lincolnshire and it is supported by all three of the area’s PCTs.

Referrals to the service have increased dramatically in the last year and should contribute to all three Lincolnshire PCTs achieving their Department of Health targets which in turn will support Trent Strategic Health Authority achieving theirs.

In particular, referrals and consequently smoking quits with pregnant smokers have been described as ‘astonishing’ by project staff. It is thought that when published the figures will show a 200% increase of pregnant smokers quitting. There is also a predicted large increase in quit rates for heavily dependent smokers too.

Phoenix NHS Stop Smoking Service means that more smokers are offered easier, on site access to smoking cessation support and a majority of these clients are the most heavily dependent presenting with one or more illnesses that will get worse by continuing to smoke.

**Retinopathy**

Diabetic retinopathy is the leading cause of blindness in working age adults. This is preventable with effective screening and timely treatment.

The target, specified in the Priorities and Planning Framework 2003 – 2006 (PPF), is “by 2006, a minimum of 80% of people with diabetes to be offered screening for the early detection (and treatment if needed) of diabetic retinopathy as part of a systematic programme that meets national standards, rising to 100% coverage of those at risk of retinopathy by end of 2007”.

Data from Local Delivery Plan Returns show that 78.4% of people with diabetes have been offered screening for diabetic retinopathy, slightly below the target of 80% for 2006 specified in the PPF.
Great progress has been made and more people with diabetes offered screening for retinopathy than ever before and to higher standards. We recognise that the speed of progress is variable across the country and there is a range of action in hand to support the NHS in reaching the 2007 target.

We are looking for assurances that all programmes have a range of quality features in place to enable digital photography by December 2006 at the latest, where this is not yet implemented. This includes having appropriately trained screening staff, identified clinical leads, annual invitation to screen, participation in full quality assurance, call and recall based on a single list so we can be confident that by December 2007 we can offer screening to all people with diabetes that fully meets national standards.

Local delivery is also being supported by the UK National Screening Committee (NSC) programme, carried out with professional organisations and Diabetes UK. Information on the screening programme can be found at http://www.nscretinopathy.org.uk

The final and largest part of the £27 million allocated to support the purchase of digital cameras and related equipment for diabetic retinopathy screening was allocated to SHAs last year (£5m in 03/04, £9.6m in 04/05 and £12.4m in 05/06).

No single approach to the model of screening programme has been prescribed. This is because local circumstances such as population and service distribution varies. The aim is for services to be easily accessible to all people with diabetes. In developing their screening schemes PCTs will wish to respond to local needs. Regardless of the option chosen, national standards must be met.

Screening for diabetic retinopathy each year forms a key part of routine care for people with diabetes and it is vital that they and their carers understand why it is being done and the risks associated with failing to be screened.

It is important that once someone has been identified as having sight threatening retinopathy they are referred for treatment as early as possible.
One-Stop Triage and Laser Clinic in Hull

The concept of the one-stop triage and laser clinic for the assessment and treatment of diabetic retinopathy was developed with two main aims:

- To facilitate the prompt assessment of people with potentially sight threatening diabetic retinopathy
- To avoid unnecessary referrals into already overcrowded ophthalmology clinics, improving efficiency and cost effectiveness.

This means that patients with sight threatening retinopathy can now be seen and treated in one hospital visit compared to previous multiple visits. This minimises anxiety and time to treatment for the patients. The one-stop clinic has dramatically improved the time to assessment and treatment of patients with retinopathy and has enabled the Hull and East Yorkshire Retinal Screening Service to meet the Quality Assurance Standards set out by the National Screening Committee in July 2005 for the timely consultation of screen-positive patients.
3 Picking up the pace

With building blocks to support measuring improvement in place and changes to the NHS designed to improve the delivery of care on their way it is time for diabetes services to pick up the pace of improving services. The existing disparities in care provision that were one of the fundamental reasons for the introduction of the NSF standards still exist.

Although there are many examples of excellent care focused on engaging users in a true partnership allied to integrated multi-disciplinary teams there are still many examples where this is not so.

The key to good services for long term conditions

Engaged empowered patient

Supportive, organised system

It is obviously welcoming to see good examples but these must not blind us to the reality that some care is still not organised to the highest standards no matter the commitment and experience of individual health care professionals.

Of particular importance is the need to have effective patient education that meets NICE guidelines\(^6\) and meets the Department of Health criteria in place. This needs to be supported by psychological and psychosocial support integrated into all the other aspects of care provision. It is important to reflect that the online Diabetes Dialogue\(^7\) carried out last year found these were exactly the elements that the contributors


\(^7\) [http://www.hansardsociety.org.uk/node/view/476](http://www.hansardsociety.org.uk/node/view/476)
considered important. It is not good enough to provide education that informs people it is about transforming the cultural relationship between an empowered patient and their healthcare professional.

**Supporting people**

**The Engaged and Empowered Patient**

*Emotional and Psychological Support*

The Diabetes Dialogue 2005 and Diabetes UK State of the Nations Report 2005\(^1^8\) highlighted the fact that people with diabetes were still experiencing problems accessing psychological support with many people feeling that the provision of emotional support was a significant gap in diabetes services, particularly for children, young people and parents.

Although diabetes is not inevitably associated with psychological difficulties, it may result in additional psychosocial vulnerabilities, depending upon factors such as coping skills, support and individual resilience. These can include: eating problems, social isolation, fear of intimacy and difficulties with future life decisions, fear of stigma, depression and anxiety, separation issues, low self-efficacy and other threats to ‘self’ development and low sense of perceived control.

The long-term implications and life threatening nature of this condition makes the psychological and social challenges particularly complex especially among children and young people.

**Essex Strategic Health Authority**

Essex Strategic Health Authority is leading on a new project looking at the mental health implications of diabetes. A small team has begun to explore the challenges involved for those people with existing mental health problems who develop diabetes and those who develop mental illness after being diagnosed with diabetes. It is planned that the project will provide valuable insight into the development of diabetes services which are inclusive and accessible to all those who need them.

Chris Birbeck said that “the needs of people with diabetes and mental health issues are under-represented within current diabetes service provision. It is essential that we work together to ensure that the key issues for this group are identified and incorporated into future service developments.”

The guidance issued by the Children’s and Young People’s Diabetes Services Working Group\(^1^9\) will address the provision of psychological support for both children and their


parents or carers from diagnosis to ongoing support. This will be published in the Autumn of 2006.

Psychological interventions to improve self-management and facilitate adjustment to the daily demands and life-long implications of diabetes are an important part of the multi-disciplinary package of care necessary to manage diabetes effectively. Defined, psychological interventions could improve engagement with treatment, coping, and blood glucose levels, providing a cost-effective way of enhancing self-management and quality of life.

It is recognised that that there is poor access to specialised psychology and psychiatry services in some areas. The development of such services, fully integrated into other aspects of diabetes care, is an essential component of delivering improved diabetes care.

The Diabetes Workforce Executive Group is identifying potential models of care through which psychological support to people with diabetes can be delivered.

The aim of this work is to provide advice and guidance on the most effective options for service delivery to those responsible for commissioning psychological services.

**Self care**

A system based on individual self care, set in the context of a well-structured, properly planned organisational framework, is at the heart of the Diabetes NSF. This approach to providing effective care has informed the work of the diabetes team from the outset. The recently published Department of Health document “Supporting people with long term conditions to self care: A guide to developing local strategies and good practice” demonstrates that this philosophy is now central to government plans for the whole NHS.

The document focuses on four key areas:
1. Skills and training
2. Information
3. Tools and devices
4. Support networks

In diabetes, we consider that all these strands of self care are important. The Department of Health believes in the importance of adopting a systematic, rigorous approach: setting standards and quality indicators and facilitating training and quality

assurance. It is important to be as intellectually rigorous in these areas as in developing a medical intervention.

**Skills and training**

Structured education and care planning are complementary ways to support self management, one underpinning the other.

**Patient Education**

The vital contribution that diabetes education makes towards enabling effective self care is widely recognised. Unless people are actively informed about their condition and given the necessary skills they need to make the best choices about the way they live their lives with diabetes, they cannot self care to the maximum they would wish. This is at the heart of the management of all long term conditions. This central role is recognised by the work put into developing the Department of Health criteria.21

This was reinforced in January 2006 by Ministers reinstating the NICE Health Technology Appraisal No 60 – Guidance on the use of Patient Education Models for Diabetes. The Ministerial funding directive places a legal obligation upon Primary Care Trusts to implement the recommendations.

Over the years a number of structured education programmes have been developed by enthusiastic and committed staff who recognised the need for some form of user support. Many of these were developed in isolation from other programmes and were designed to meet the needs of local communities. The Type 1 Education Network now exists to bring together various local programmes and to provide support and information to enable them to effectively meet the needs of those with Type 1 diabetes. This includes supporting them in meeting the established criteria.

To provide further support for local education programmes, the Department of Health, working in collaboration with Diabetes UK (DUK), is producing additional guidance to help local coordinators assess whether the education programmes they are delivering meet the criteria. This guidance will be available in the summer of 2006.

In addition to local education programmes, there are two nationally developed patient education programmes that do meet criteria for structured education. If required, these can be commissioned by PCTs for use in their local area. They are:

- **DAFNE (Dose Adjustment For Normal Eating)** for Type 1 diabetes
  
  http://www.dafne.uk.com/

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DESMOND (Diabetes Education and Self-Management for Ongoing and Newly Diagnosed) for Type 2 diabetes http://www.desmond-project.org.uk/

DESMOND had 50 PCTs with educators trained to deliver the DESMOND Newly Diagnosed course at the end of April 2006. A further 20 PCTs are currently in negotiation and could be accommodated for training before the end of 2006.

Following one DESMOND course in West Cumbria, attendees were asked to post their comments on the course:

‘Learned a lot more about what can happen with diabetes’

‘An excellent course...very informative and well worth coming to’

‘All new diabetic patients should have the chance to attend such programmes’

‘A very informative and worth while presentation and an aid to taking ownership of one’s diabetes....A five star approach’

Results of a feasibility trial in which 80% of patients offered a DESMOND course attended the programme is being produced and a randomised controlled trial (RCT) is well advanced. An evaluation of DESMOND for those from BME (black and minority ethnic) groups will be available in Autumn 2006.
The Expert Patients Programme (EPP) which provides individuals with long term conditions with the skills and support to manage their condition complements the diabetes specific courses discussed.

### Anne’s Story

“‘It’s one of the best things that’s ever happened to me,’” says Anne Smith, talking about her involvement in the Expert Patients Programme. Since taking part two years ago Anne, who has been diagnosed with diabetes for nine years, has lost two and a half stone in weight, her insulin dose has been more than halved and her HbA1c has reduced.

East Midlands-based Anne says the course, which aims to help people manage chronic/long-term conditions more effectively themselves, has completely changed her outlook on life. She said: “Before the course I was Anne Smith: diabetic, arthritic and couldn’t hear properly. I am now Anne Smith, I have diabetes and arthritis and if you think I didn’t hear you, I probably didn’t! I’ve turned my life around.”

As a result of this change, Anne decided to train as an Expert Patients Programme (EPP) tutor and now helps support others as they manage their own medical conditions. She said: “When I tutor it and I go to the reunions I’m amazed at how I feel. It’s a big rush because people improve so much. Everybody gets something out of it.”

### Care Planning

A joint Department of Health, Diabetes UK Care Planning working group was established in June 2005 with a remit to assess what needs to be done to enable local services to provide care planning for people with diabetes as outlined in the Diabetes NSF. This includes:

- Defining care planning
- Highlighting good practice
- Identifying gaps where more work needs to be done
- Agreeing a programme for national implementation
- Defining a programme of research and development.

Work is now underway to produce a care planning guidance document for frontline NHS services. The group expects to report before the end of 2006.

### Information

Many services are producing high quality information for patients.
Tools and devices – Assistive Technology

For people with diabetes using various technical devices to support their control is commonplace. In fact it would be impossible for people to monitor their condition and adjust their treatment accordingly if it were not for the assistance of items such as blood glucose monitoring equipment and insulin pens. Just as new drugs come onto the market so companies and healthcare professionals are exploiting new IT methods and technologies to enhance people’s ability to take control of their diabetes and support self care. The development of insulin pumps is an example where new technology has transformed people’s ability to look after themselves with the minimum intervention from healthcare professionals.

There is no doubt that just as the pace of technological change has accelerated so will the pace of using mobile ‘phones, texting, the internet and wireless systems to support people with diabetes in self care.

Promoting self care is one of the most cost-effective interventions of managing diabetes. The Wanless Report 2002 noted that for every £100 spent on self care £150 can be saved by the NHS overall. Technology will increasingly play a key role in enabling and promoting self care as remote monitoring, reminder services and e-clinics come into

South Wiltshire’s New Diabetes Pack

A handbook of core diabetes information and a record of diabetes care has been launched by South Wiltshire PCT Diabetes Network to be given to every adult with diabetes. Included are sections on the nature of diabetes, dietary information, physical activity pointers, foot care tips, the members of the diabetes team and how to access diabetes services.

In addition there is a section for personal patient-specific information on diabetes treatments, objectives, consultations, test results and a record of topics discussed which is designed to be the patient’s hand-held record of diabetes care.

There is also further information that can be added to the pack covering:

- Treatments prescribed,
- Home monitoring techniques,
- Smoking,
- Alcohol,
- Driving,
- Family planning,
- Diabetes complications,
- Sick day rules.

Salisbury District Hospital Diabetes Consultant Martin Smith said: “I think this is a really valuable initiative. It means people will be able to make an informed decision as to how to manage their own diabetes.”

The full handbook is available on the NDST website at:
their own. Technology can create opportunities to achieve a more positive and cost-effective clinical outcome in ways often more acceptable to the individual, as well as helping to address impending capacity challenge created by increases in long-term conditions.

However, we must be sure that these new technologies are quality assured, are truly benefiting patients, not just simplifying life for healthcare professionals and that patients receive the appropriate education to ensure that they are used in the most beneficial way.

**Blood Glucose Testing Strips**

For instance blood glucose testing strips prescribed in general practice cost the NHS more than £130 million a year, nearly a third of the total spend on primary care prescribing for diabetes. There is evidence that there is potential over-use of these testing strips due to a lack of understanding about their purpose in good management but further work is required to quantify it. Key research is being carried out to determine the best way to use this technology.

Blood glucose monitoring strips help support good blood glucose management as the use of blood glucose testing strips is not a stand-alone intervention but is part of a complicated self-management intervention which includes patient education.

**Remote monitoring**

**Salford PCT – Pro-Active Call Centre Treatment Support (PACCTS)**

The PACCTS (pro-active contact centre for treatment support) study provides an information communication and technology platform to investigate whether proactive contact centre-based communication between healthcare professionals and patients with Type 2 diabetes can enable better self-management and control of glucose.

A randomised controlled trial in which patients were telephoned according to a protocol with the frequency of calls proportional to the last HbA1c level was popular with patients. They felt more in control of their diabetes as a result of PACCTS, and had formed strong relationships built on trust, with call-centre staff.
The OwnHealth project

Two PCTs in Birmingham are to be the first in the UK to implement a community self care project in which patients with diabetes and other long-term conditions will receive regular telephone support at home by trained community nurses.

The project which will be run by UK Pfizer Health Solutions in conjunction with NHS Direct, will cover North and East Birmingham PCTs, and will be aimed at patients with diabetes, long-term heart failure and cardiovascular disease.

Patients will be phoned at home by their own ‘care manager’, a specially-trained nurse, at set appointment times. Every patient will have one care manager, and will know them by name.

The case managers will use specifically designed software to help patients develop care plans that support them to be directly involved in managing their own conditions. A total of ten care managers will be involved, one for each practice in the scheme, and they will be employed by NHS Direct.

Patients with diabetes, long-term heart failure and cardiovascular disease will be recruited in four areas around Birmingham: Kingstanding, Oscott, Washwood Heath and Bordesley Green, where there are higher concentrations of people with chronic health problems.
Support Networks

Peer Advisors in Somerset

People with diabetes have been successfully supporting each other thanks to an NHS Live Project run by Weston Health Area Trust and North Somerset PCT. The project was based on a similar programme run on the Isle of Wight. The patient-led Peer Advisor Group has been a learning experience for patients, health professionals and facilitators involved.

So why have peer advisors?

They are ideally placed to reinforce advice and to provide reassurance and support to patients with diabetes. Patients and carers relate to others who are in the same situation.

They provide an empowered patient voice on committees and forums – NHS or voluntary – with their factual knowledge as a patient and the confidence gained from the programme to argue their case persuasively.

They are effective trainers for future courses.

They will create a network of advisors – local and national.

One patient taking part in the programme said: “I would like the additional knowledge gained for my own benefit, and then I hope to be able to use this deeper understanding to help others. In this way, perhaps new patients will not feel as isolated and lonely as I certainly did when diagnosed.”

A member of staff involved with the programme said: “Attending the sessions as a facilitator has given me an in-depth insight into the disease and the patients’ concerns. This is transferable to my job. My lasting thought is that they are ‘people with diabetes’ and not just ‘diabetic patients’.”

The project is now looking to the future, hoping to develop this model for other long-term conditions.
Supportive Organised Systems

Whilst individual teams need to be organised to support patients, teams themselves need to work together if people with diabetes are to receive the best care.

Laurie Pike Health Centre

Laurie Pike Health Centre is located in the Aston Ward of Birmingham serving an ethnically diverse, inner city population high in deprivation and unemployment.

The practice operates out of modern, well maintained, purpose built premises offering a full range of services to patients, including:

- Diabetes Clinic including access to Chiropody and Dietetic Services, Hypertension Clinic including ECG monitoring and 24 hour blood pressure recording if appropriate, Cardiovascular Clinic to include ECG monitoring if appropriate, Asthma Clinic/COPD Clinic, Specialist Dermatology Clinic, Maternity, Child Health, Travel Health Clinic, Minor Surgery, Sexual Health Services, Physiotherapy, Mental Health, Substance Misuse, Smoking Cessation, Warfarin Monitoring, Phlebotomy.

- The Laurie Pike Health Centre has developed and evolved to include a “one stop” approach with chiropody and dietetic services running alongside clinics; depth of experience and knowledge within the nursing team, coupled with a commitment to ongoing training to maintain and update skills.

Organising co-ordinated services is not enough in itself; it is also important to actively seek out where improvements might be made.

HbA1c in North Northumberland

HbA1c levels in North Northumberland are improving thanks to the positive problem seeking of joint work between practice teams and the specialist service. Records for all patients with a HbA1c result greater than 7.4% were jointly reviewed in two practices and a tailored plan developed for each.

Some patients were seen by the practice team to tease out the problem or increase medication. Some were referred to insulin start groups if HbA1c persisted to be high, some were referred to specialist care and others were seen by Diabetes Specialist Nurses in the community.

The result of this programme is that 45% of HbA1c results have dropped by 1%.
Networks

The important contribution that effective clinical networks can bring to improving the care of people with diabetes is recognised in the NSF Delivery Strategy. By developing operational links between healthcare professionals and managers working in both primary and secondary care, across health and social care, as well as people with diabetes, beneficial synergies in identifying priorities and targeting resources can emerge.

However, effective networks do not necessarily appear by themselves. They need the commitment, drive, enthusiasm and practical support of all those responsible for delivering diabetes care and users of the services they provide. This often means that tensions between the different components of the health and social care community have to be overcome with recognition that personal and parochial interests have to be put aside in the interests of improving diabetes care across a whole locality. This is not always easy as people often hold strong views about the importance of their own particular service or area and can resist what is often perceived as “giving up” any autonomy or individual decision making.

Here the role of the Diabetes Network Manager can be crucial in explaining the benefits that effective networks can produce and influencing decision makers, both manager and clinicians, to become positively engaged with new ways of delivering diabetes care. Their job is not an easy one and the role of the National Diabetes Support Team (NDST) in providing both start up resources to local organisations to employ network managers and the continuing support provided by the network of Regional Programme Managers has been invaluable.

Apart from their contribution to effective organisational partnerships networks also have a role to play in supporting healthcare professionals. This includes those both directly involved in the network and in the wider diabetes community. They have organised training days around specific elements of diabetes care as well as providing personal development opportunities. This has included work around leadership and organisational development for people in their locality.

However there is still some confusion over the role of networks – how they should operate, what they should do and how they should do it. To provide some clarity to all of those questions the NDST is producing a Guide to Diabetes Networks. It will contain not only simple guidelines on the role of networks but also practical examples of how they have worked and what they have achieved.

Ultimately the improved care for people with diabetes that networks can deliver will only be achieved with the full commitment, energy, imagination and innovation of all.
those health and social care professionals in the diabetes community working in partnership with service users. A copy of the network guide will be available on the NDST website: www.diabetes.nhs.uk

**Networks in Action**

The network encompassing Shropshire County and Telford and Wrekin PCTs has responsibility for taking forward diabetes care across Shropshire. It meets quarterly and is accountable to professional executive committees of both PCTs and the Acute Trust.

Between 2003 and 2005 the network has worked on many projects, resulting in the following achievements:

- Development of a set of 15 clinical guidelines
- Baseline assessment of services conducted
- Newly diagnosed patients provided with Diabetes UK information packs
- Group-based education provided
- Review of nursing services implemented across Shropshire
- Funding for paediatric diabetes nurses provided.

**Specialist Services**

The role of specialist services within diabetes communities is pivotal. Although it is recognised that the majority of care will be provided in the primary sector it is no mistake that each diabetes network is shaped around the local specialist service. It is impossible to develop the integrated care envisaged within the White Paper, Our Health, Our Care, Our Say or have effective diabetes networks without the full engagement of diabetes specialists. To enable the voice of the specialist community to be heard the Special Services Liaison Group (SSLG) has been established. This is composed of consultants from Diabetes UK and the Association of British Clinical Diabetologists (ABCD). It provides a forum within which consultants can discuss issues relevant to specialist diabetes services with the National Clinical Director. The group is currently working to clarify the present and future multi-faceted role of the consultant diabetologist and the multidisciplinary team and to address the issues raised for diabetes services by NHS system reform.

This group, in partnership with the NDST and the King’s Fund, has developed a pilot training programme to assist specialist consultants to support the development and change of their own services, whilst maximising their contribution to the growth of

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22 http://www.kingsfund.org.uk/
capacity and quality in services outside their centres. The pilot programme ran in two phases in March and May 2006, and was fully subscribed. Further information about the work of the Specialist Services Liaison Group can be found at: http://www.diabetes.nhs.uk/Work_areas/Specialist_Services_Liaison_Group.asp

**Diabetes Scoping Project**

The Department of Health has recently commissioned the Diabetes Scoping Project which is a survey of the roles, responsibilities, working practices and job satisfaction of Consultant Physicians with a special interest in Diabetes.

A number of consultants have been interviewed and the following six themes have emerged from a preliminary analysis of the data:

- Role of the Consultant Diabetologist
- Integration with general medicine
- Team working
- Relationships with GPs
- Relationships with PCTs
- Recruitment and training

Further analysis is ongoing, and the final report will incorporate additional data and integrate responses to the Scoping Project’s presentation and ensuing discussions at the Diabetes UK conference, 30th March 2006.

The Diabetes Programme Team is keen to work with all the professions working in the multidisciplinary team. The NDST supports the Diabetes Inpatient Specialist Nurses discussion forum on the internet and good relations have been established with RCN Diabetes Nurse Specialist Group and the Consultant Nurses Group. Dieticians, podiatrists, and psychologists all provide an active contribution to current initiatives to improve diabetes care.

**Knowledge Management**

When working to improve any system of healthcare, processes for disseminating knowledge and information about what works when planning and implementing improvement are vital. There are numerous examples of people in one part of the country designing ways to enhance the services they deliver only to find out later they have replicated work already done by others elsewhere. They have spent a lot of time reinventing the wheel. It is against this background that the need to establish an effective knowledge management system became an essential part of delivering the NSF standards.
The focus for the diabetes Knowledge Management system is the web site www.diabetes.nhs.uk. This contains a wealth of material from all over the world about improvements in diabetes care and treatment. The site holds documents, Factsheets and breaking diabetes news, as well as forums for healthcare professionals to exchange views and ideas. It gets an average of 100,000 hits a month with more than 1,000 documents downloaded. The NDST has also set up a system that allows hard copies of Factsheets and reports to be ordered over the phone or by email. Through the Infopoint pages people can let others know how they have improved their own local services which can be invaluable when others are looking at the same area of work. A regular diabetes email briefing is produced containing updates on diabetes news and has 1600 direct subscribers and is cascaded to thousands more.

Both robust evaluation and anecdotal evidence confirm that the website and the other resources provided by the NDST are highly thought of by the diabetes community. They are seen as significant contributors to the professional knowledge of healthcare professionals and thus the improved care of people with diabetes.

“The web site in general and the Infopoints, Factsheets and other resources are a fantastically useful resource for anyone working in diabetes.” said Bernie Stribling, Network Coordinator for Leicestershire, Northamptonshire and Rutland SHA. “I also work with the Renal NSF and we want to model our Knowledge Management system on the excellent diabetes one.”

**Workforce**

Without a dedicated workforce, there would be no diabetes care, and how that workforce is organised can have a real impact on people with diabetes. Through workforce projects and competence development, the advantages of this area of work are being felt in many areas.

Phase 1 of the Diabetes National Workforce Competence project was completed in autumn 2004 and we know that these competences are being used by local health communities to undertake development of the workforce in a variety of ways. A significant focus of our work in 2005 has been on supporting the implementation of these competences and the sharing of good practice across health communities.

Phase II of the Diabetes National Workforce Competence project is now underway and we aim to have this completed in summer of 2006. Once completed there will be an entire suite of competences to support the delivery of diabetes management and the development of models of care.
Further information on the projects developing National Workforce Competences and National Occupational Standards is available at: www.skillsforhealth.org.uk

General information on workforce initiatives in diabetes can be found on the NDST website: www.diabetes.nhs.uk

There continue to be a variety of innovative approaches to developing the workforce such as:

**Care Technicians in Norfolk, Suffolk and Cambridge**

The Diabetes Care Technician (DCT) role was piloted by the Changing Workforce Programme in the Greater Peterborough health system from 2003-2004, in response to a shortage of professionals available to manage the increased numbers of people being diagnosed with diabetes.

In October 2004 Norfolk, Suffolk and Cambridge Strategic Health Authority launched a mainstreaming programme with the objective of supporting the sustainability and transferability of the DCT role. Different sites within the SHA have used the DCTs in different ways, some based in primary care, some in secondary and some mobile. In many cases the DCTs are releasing time of more senior staff, enabling them to spend more quality time with patients.

Some activities DCTs have been taking part in:

- Providing education on lifestyle management – weight, smoking, exercise, foot screening, visiting people with diabetes in care homes, recording blood pressure, height and weight, home visits, spending time with patients

- There are now 17 DCTs working across the SHA. They are recorded as having provided a good service, released registered staff and contributed to improved recruitment and retention.
New roles in Leicester

Innovative work by Sabera Khan, a Diabetes Eye Nurse at Leicester Royal Infirmary, has been praised by Lilly and honoured with an award at the recent Abracadabra event.

The position was created in 2004 at the Leicester Royal Infirmary to provide a more comprehensive service to patients who were attending the hospital for assessment and treatment of diabetic retinopathy. She is an ophthalmic trained nurse with a specialisation in diabetes care, working alongside the ophthalmologists in the eye department and the Diabetes Team in the hospital.

She said: “I am very pleased that this new innovative service has been recognised worthy of an award. I hope to maintain this service for patients requiring the individualised care and support, alongside the supportive network that we have established between the Diabetes and Ophthalmic Units.”

The role of the Diabetes Ophthalmic Nurse includes the following:

• To be available for multilingual advice and support if required.
• To provide expert care, advice and support to patients.
• Providing diabetes care for a population with many risk factors.
• Identify patients with poor diabetic control.
• To carry out eye tests including Fluorescein Angiography to facilitate same day laser treatment if necessary.
The Electronic Patient Record

One of the key aims of ‘Connecting for Health (CfH)’ (the name of the NHS programme on information technology) is to develop an electronic patient record. This will have enormous benefits in ensuring that all the relevant information for each individual is readily available wherever and whenever they are seen, improving safety and ensuring that the inaccuracies and problems related to the current paper based system become a thing of the past. It will also enable patients to have easy access to the important features in their own health record.

To achieve this it is essential that all the features of good care can be recorded electronically and all in the same way so that information can be transferred accurately as well as confidentially between different parts of the system. It soon became apparent that the five different regions of the CfH programme (‘Clusters’) were all developing in slightly different ways. So CfH divided up the 50 most common conditions between different parts of the country so that only one group was working on each, and this work would then be shared with everyone else to ensure national consistency. (These programmes are called ‘Do Once and Share’ (DOaS)).

The Diabetes Do Once and Share project completed its first stage in January 2006. It worked in a unique way ensuring that all the work, even though it seemed very technical to begin with, was developed by groups in which 50% of the participants were people with diabetes and their carers, and 50% were healthcare professionals. In the past the diabetes record has usually only recorded the physical health of patients. But people with diabetes at the workshop told us that there were many other aspects of life which were important and affected their health and how well they could look after themselves.

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Brent Teaching PCT

Brent Teaching PCT has developed an electronic web based tool, which enables the skills of the current workforce to be mapped against the diabetes competences.

The Diabetes Online System (DOS) is a web based, self-assessment tool which uses competences to:

- Enable individuals to plan their future development
- Enable organisations to provide better multidisciplinary training across the sector
- Support the improvement of services for people with diabetes in the community

Staff log onto the system and carry out a self-assessment of their current skills against the target level agreed for their staff group. It is easy to complete and takes approximately 15 minutes.

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http://www.connectingforhealth.org/
So the Diabetes DOaS proposals include the idea that the record should give equal weight to five dimensions of care including knowledge and health beliefs, behavioural aspects including self-management and life style, emotional aspects, and social aspects as well as clinical care. Further work is planned, linking to other related conditions and other groups who are proposing to include a wide range of issues determining health.

Involvement of large numbers of people with diabetes was crucial to the success of the outcome for most people as these comments illustrate.

### Patient

‘Excellent – I hope it was as beneficial to clinicians as it was for me’

‘Helped motivate me and made me more positive and optimistic’

### Carers

‘I found that the professionals listened to me more than I thought they would’

### Healthcare professionals

‘Workshop design conducive to all people to participate’

‘Good interaction between healthcare professionals and patients. Valuable insight into patient experience of the service’

*This work can be found at [http://homepage.mac.com/marksmith2/DOaS/](http://homepage.mac.com/marksmith2/DOaS/)*

### Building partnerships

Just as local diabetes services need effective partnership working at a local level so there is a need to establish similar partnerships at a national level with a range of stakeholders. There is a need to understand what we each have in common but also recognition of the different perspectives and goals that each possess. A full appreciation of this leads to mutual respect and honesty where differences do not become barriers to understanding.

The opportunities for developing national partnerships are seemingly endless as diabetes touches upon so much of the healthcare world but there are four key elements. These are:

- Service users
- Healthcare professionals
- Healthcare organisations
- Independent sector.
Each of these has a number of separate organisations operating on a national level that needs to be effectively engaged with. Successful partnerships have been built with all of these elements over the past year leading to joint working on a number of initiatives to improve diabetes care.

**Diabetes UK**

This year has seen the working relationship between Diabetes UK, the Department of Health and the National Diabetes Support Team grow even closer. Diabetes UK is actively involved and joint chairs several Departmental Working Groups and the Regional Programme Managers (RPMs) from the NDST and Diabetes UK continue to work together in a spirit of partnership. The NDST has attended a number of DUK regional events and RPMs from both organisations have undertaken joint training.

Our goal is the same – to improve the lives and services of those people living with diabetes. This is best achieved by sharing our knowledge and resources and continuing to work together in a spirit of co-operation and mutual understanding.

**NICE**

There are a number of important reviews of guidance currently happening or expected in 2006.

A ministerial funding directive came into effect in January 2006 to accompany the NICE Health Technology Appraisal – Guidance on the use of Patient Education Models for Diabetes – Health Technology Assessment 60 placing a legal obligation upon Primary Care Trusts to implement the recommendations.

NICE has also recently consulted on the review of its Type 2 diabetes guidance which will amalgamate several related pieces of Type 2 guidance and health technology assessments. A similar review of all related Type 1 guidance is scheduled for 2008. Further details can be found on the NICE website www.nice.org.uk

NICE has recently announced a review of NICE Technology Appraisal Guidance No.57, on the use of continuous subcutaneous insulin infusion for diabetes. It anticipates that it will start in approximately one year.

**Health Foundation**

In 2005 the Health Foundation launched a new scheme on Shared Leadership for Change. Leadership development tends to focus upon individuals but, to have sustainable improvement, leadership qualities need to be spread across the whole team.

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24 http://www.diabetes.org.uk/home.htm
25 http://www.health.org.uk/
Diabetes was selected for the Shared Leadership for Change award because the patient pathway crosses many differing organisations with services being delivered by multidisciplinary teams.

One of the six diabetes networks chosen is Newham in London.

Newham is one of the most deprived boroughs in the country. More than 100 different languages are spoken by the people who live there. So BME and deprivation issues are a big challenge to the borough, which has one of the highest diabetes prevalences in the country.

In the past Newham has been recognised for innovative work, but in getting the Shared Leadership for Change Award it is beginning to take its work to a new level. A major focus so far has been developing a strong network. The lead on this is Geetha Bala, who has led a real exploration into who is in the network and what they are there for. People are being encouraged to look at their roles and the contributions they all make.

Currently, as part of this work, the network is developing a work plan charting how it will meet the NSF standards.

The Health Foundation will be working closely with the NDST to ensure that the development each organisation is doing is complimentary and that learning can be quickly spread.

**Healthcare Commission**

**Patient Survey**[^26]

The Healthcare Commission has been working closely with the NDST and the Department of Health to develop a National Patient Survey for people with diabetes and a Service Improvement Review to assess the quality of diabetes services.

The National Patient Survey of People with Diabetes is the first to be carried out on a specific long-term condition and was developed in discussion with people with diabetes and healthcare professionals. The survey will be carried out by PCTs later this year.

**Service Improvement Review**[^27]

The Healthcare Commission will be assessing the quality of healthcare services for people with diabetes later this year. Diabetes was selected as the first long term condition to be reviewed. The review will focus upon how the NHS supports people to look after their own diabetes.


[^27]: http://www.healthcarecommission.org.uk/InformationForServiceProviders/ReviewsAndInspections/SecAAArea1/fs/en
The review will also look at how services are organised working across the whole patient pathway to support self-management including the provision of structured education, how people have been supported in managing their diabetes whilst in hospital and whether they have been included in agreeing a care plan.

The review will draw upon data that is already collected for monitoring purposes. But some ‘bespoke’ data collection will be necessary as well. The National Diabetes Patient Survey will be a key element to the Service Improvement Review.

**Wider Partnerships**

Apart from national partners such as National Institute for Health and Clinical Excellence (NICE) and the Healthcare Commission whose range covers more than diabetes, partnerships have been developed with a number of diabetes specific organisations. The National Diabetes Support Team (NDST) has actively worked with the National Diabetes Audit (NDA) to promote both engagement with it and its contribution to diabetes care. Joint work has been carried out by the Department of Health, NDST and Yorkshire and Humber Public Health Observatory (YHPHO) to promote their prevalence model and develop key facts about diabetes. The NDST has worked with the Diabetes Research Networks Co-ordinating Centre to promote their work and raise their profile. They have also worked with the Type 1 Diabetes Education Network, the Royal College of Nursing Specialist Diabetes Nurses Group, the Diabetes Inpatient Specialist Nurses Group, the Association of British Clinical Diabetologists (ABCD) and the Renal NSF team.

In developing partnerships in diabetes it is impossible to ignore the role of the independent sector. Apart from their contribution to diabetes care by developing improved drugs and equipment they support a number of non-promotional initiatives at both a national and local level.

The NDST has worked with the Diabetes Industry Group in jointly organising successful conferences on networks and patient education. Links have been established with individual companies to ensure that the NDST is kept informed of forthcoming events and conferences. Insight has been gained into independent sector programmes such as Insulin for Life and MERIT and opportunities to promote the NSF Standards, explain where diabetes sits in the big picture and raise the profile of the NDST.

29 http://www.ukcrn.org.uk/drn.html
30 www.diabetes.nhs.uk/downloads/Type_1_Education_Network.pdf
4 Going the extra mile

Many people working in diabetes are already going the extra mile for those with the condition, and this report contains further help and support for them. With the current growing awareness of the risks diabetes and its complications pose to people and the NHS, everyone in local health communities including commissioners, clinicians, specialist nurses, dieticians, podiatrists, clinic staff and people with diabetes now need to ask themselves whether diabetes has the priority it deserves.

There are real signs of progress towards the NSF Standards across the country, but there is still a great deal to be done towards ensuring that service users receive the best quality of care wherever and whoever they are. As can be seen in some of the following case studies, it is working collaboratively that is proving the best way to maximise resources and opportunities to transform this vital service. Coupled with this, the Government is now focusing on long-term conditions such as diabetes, creating a responsibility to ensure that all the many strands of policy and practice affecting diabetes are successfully integrated to deliver the best care possible.

Creating opportunities

Retinopathy – target to end of 2007

We know that more people are now being offered screening and the quality of screening is improving. However, the speed of progress is variable across the country and the December 2007 target of all people with diabetes having been offered screening using digital cameras in the previous twelve months looms large. The focus from now as we move to December 2007 is to ensure that all people with diabetes are offered high quality screening that meets national standards.
**Succeeding in systematic screening against the odds**

Despite facing substantial constraints, the Bristol and Weston Diabetic Eye Screening Service (BWDESS) has been rolled out across the region thanks to the enthusiastic team work between primary and secondary care. Previously only Weston had provided digital screening and then not as part of a systematic programme.

26,000 patients from Avon, North Somerset and South Gloucestershire PCTs will be offered screening in the coming year. This activity will reduce the risk of loss of sight considerably in the area. About 7,000 of patients can be expected to have some retinopathy within the first full year of screening. If all patients attended for screening about 2,050 of the entire group would, more likely than not, need to be assessed for laser treatment in the eye clinic.

The first clinic started in October 2005 with additional clinics being held in GP practices or alternative locations, staying for a period of between one and six weeks at each. Dr Maria Macipe, a medical retina specialist, supervises the training of all screeners, the work in the grading suite and has been carrying out the grading itself until screeners were trained to do this from April 2006.

The staff have found it enormously satisfying overcoming the numerous challenges in getting established within such a short time-frame. All the screening staff were new to the role when they joined in September 2005 and needed to develop rapidly the skills to run clinics. They came from a wide range of backgrounds both within and outside the NHS, but share an enthusiasm and determination for high quality patient care.

The BWDESS is looking forward to being able to count the number of people whose sight it has helped to save by the end of 2007 and reflect on the difference this has made to the quality of their lives.
Maternity and Pregnancy

‘Pregnancy in women with Type 1 and Type 2 diabetes in 2002 – 2003’, a report published by the Confidential Enquiry into Maternal and Child Health (CEMACH) in October 2005, has confirmed that women with diabetes in England, Wales and Northern Ireland have a much higher risk of stillbirth and fetal congenital anomaly than the general maternity population, with no difference in risks between Type 1 and Type 2 diabetes. However, women with diabetes are not adequately prepared for pregnancy and women with Type 2 diabetes (who are more likely to be from minority ethnic groups) appear less able to access health care services before pregnancy. There is also concern that health professionals and women consider Type 2 diabetes to be a less serious condition.

We are committed to ensuring that risks during pregnancy for women with diabetes are minimised. The NHS should have a series of checks in place to enable women with diabetes to have healthier pregnancies including support to achieve blood sugar control; kidney, eye and blood pressure checks; scans before 14 weeks and at 16 to 24 weeks; and regular measurement of the baby.

CEMACH identified a number of steps that health professionals should be taking which could fundamentally improve the chances of women with diabetes having a healthier pregnancy. A full copy of the report can be downloaded for free31.

As a response to these findings, CEMACH has also taken the lead in developing two information leaflets for national use, the first with the Royal College of General Practitioners for the primary care team, and the second with Diabetes UK for women with diabetes. Both these leaflets focus on the importance of good preparation for pregnancy and early contact with the specialist diabetes team. The leaflets will be published in the summer.

System Reform (Year of Care)

Health Reform in England32 set out the key reforms that are taking place within the NHS, such as the introduction of a wider range of providers, stronger commissioning, and new payment mechanisms. It is crucial that the diabetes network understands these reforms and the impact that they might have for diabetes services. The NDST has appointed a System Reform Programme Manager to support the process of disseminating information to the diabetes community and ensuring that proper consideration is given to the impact of these policies on diabetes services.

31 http://www.cemach.org.uk/publications.htm or ordered directly from CEMACH
32 Health reform in England: update and next steps, December 2005
In addition to contributing to Department of Health-wide system reform policies, the Diabetes Programme Team will be leading delivery of the ‘Year of Care’ project. The commitment to test a Year of Care approach to commissioning was included in the Choosing Health White Paper, and reinforced in the new White Paper on community health services, Our Health, Our Care, Our Say.

A ‘Year of Care’ describes the on-going care a person with a long-term condition should expect to receive in a year, including support for self-management, which can be costed and commissioned. The approach involves shared decision-making between patients and healthcare professionals in the design of a package that meets the patient’s individual needs. The approach will result in more effective use of the care planning process to open up choice for patients with long-term conditions. More information on the project is available on the NDST website at www.diabetes.nhs.uk.

Payment by Results
Payment by Results (PbR) is one of a number of linked changes designed to make the NHS fit for purpose for the 21st century. These changes have the dual aim of ensuring that care is of the highest quality whilst also providing good value for money.

The aim of PbR is to provide a transparent, rules-based system for paying trusts which will reward efficiency, support patient choice and diversity and encourage activity for sustainable waiting time reductions. Further information can be found at: http://www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/FinanceAndPlanning/NHSFinancialReforms/fs/en

The National Diabetes Support Team has produced a factsheet, exploring the implications of PbR for diabetes services:
http://www.diabetes.nhs.uk/Reading_room/Factsheets.asp

The new national emphasis on commissioning provides an excellent opportunity to review current services and ensure that they are fit for purpose. Networks will have a crucial role in ensuring that diabetes services are designed and commissioned around the needs of the local diabetes population. Networks will be able to support commissioners at various stages in the commissioning process, such as agreeing a specification and appropriate quality standards.

The Department of Health will be publishing comprehensive guidance on commissioning health services in summer 2006. This guidance will be the first stage of a comprehensive commissioning framework, setting out tools and approaches that lead to high-quality commissioning.
The Primary Care Diabetes Society has set up an expert group to develop a diabetes-specific commissioning framework. The framework will link to the Department of Health work and aims to include a high-level specification for diabetes services to support commissioners.

**Structured Education**

In June 2005, the joint Department of Health and Diabetes UK Patient Education Working Group published a report on ‘Structured Patient Education in Diabetes’\(^\text{33}\). Chapter three of the report set forth key criteria for structured education programmes, intended to provide the guidance necessary to enable local services to meet the recommendations outlined in the NICE Health Technology Appraisal (HTA) and the Diabetes NSF. After the publication of the report, it became clear that local service providers would benefit from the development of further guidance, which local programme coordinators could use to measure their programmes against the criteria set forth in the NICE HTA.

As a result, two Structured Diabetes Education Development Tools are being produced: a service development tool to help local programme coordinators to assess whether the programmes they are delivering meet the NICE criteria, and an educator assessment tool, to allow diabetes educators to reflect on their current practice and to enhance their skills. Suzanne Lucas, an independent consultant specialising in diabetes services, is producing the service development tool; Professor Doug Newton, an educationalist from Durham University, is producing the educator development tool. These tools should be available in the summer of 2006.

**Research Networks**

A significant advance in supporting improved care for people with diabetes has been the establishing of the Diabetes Research Network (DRN). Its primary goal is to achieve benefits for people with diabetes, or at risk of developing diabetes, through excellence in clinical research. It will also enable Britain to continue its prestigious reputation for excellence in diabetes research.

The creation of the DRN provides a unique opportunity to establish current prevalences, to provide time trend data, to gain insights into the relative importance of established and novel risk factors and to determine new strategies for the prevention of diabetes, as well as testing new therapies.

People with diabetes, their carers and the public will be involved in deciding the research priorities and a research portfolio will be generated by investigators from different disciplines which will encompass clinical trials, including trials of lifestyle interventions, in

addition to pharmaceutical trials. It will also include epidemiological studies and health services research and will interact with basic and clinical science and translational research.

The eight Local Research Networks span the country and are based in the following regions:

- North East London (Barts and the London Hospital NHS Trust with Professors Graham Hitman and Gene Feder as clinical leads)
- South West Peninsula (Royal Devon and Exeter NHS trust with Professor Andrew Hattersley as clinical lead)
- North and East Cumbria (Newcastle Upon Tyne Hospitals NHS Trust with Professor Mark Walker as clinical lead)
- South East Midlands (University Hospitals of Leicester NHS Trust with Professor Melanie Davies and Dr Kamlesh Khunti as clinical leads)
- Eastern England (Cambridge University Hospitals NHS Foundation Trust with Professor Nick Wareham as clinical lead)
- North West London (St Mary’s Hospital NHS Trust with Professor Robert Elkeles as clinical lead)
- North West (Salford Royal Hospitals NHS trust with Dr Martin Gibson as clinical lead)
- Thames Valley (Oxford Radcliffe Hospitals NHS trust with Dr Andrew Farmer as clinical lead).

Each network has been tasked with increasing patient and public involvement in diabetes research, as well as supporting workforce development and open and transparent communication.

An average of £300–£400k will be provided to each network annually to employ dedicated research nurses and similar staff who will support clinical teams in hospitals to facilitate involvement in diabetes clinical studies. Networks will be required to work collaboratively, under the guidance of the Diabetes Research Network Coordinating Centre, to utilise this funding to its full effect, and will be encouraged to build on any existing links with clinical and research support services in their local areas.

More information is available on the DRN website at http://www.ukdrn.org/
The White Paper: 'Our health, Our care, Our say: a new direction for community services'

What this means for diabetes

The White Paper (WP) published in February provides great opportunities for people with diabetes and those who care for them.

The principles at the heart of the WP go right back to the NHS plan and are aimed to 'accelerate the move into a new era where the service is designed around the patient rather than the needs of the patient being forced to fit around the service already provided'. The emphasis is on supporting self care, promoting well being and community engagement, as well as prevention and early intervention.

For the diabetes community none of this is new. These are the principles that were outlined in the Diabetes NSF and the Delivery Strategy. But whereas it has sometimes seemed hard to move in the direction of greater self-management for patients, more care close to home, and more joined up working for staff, this is now being actively promoted as the central direction for NHS, and there will be incentives and new support both locally and centrally to help it happen.

The WP had a unique public consultation at the heart of its development, and it is good to know that the public felt that services for Long Term Conditions (LTC) like diabetes had improved considerably and the benefits of structured care are really appreciated. Obviously more needs to be done but there are now real opportunities to improve. The emphasis throughout this WP is on concentrating effort to improve services most in areas of greatest deprivation. These are the areas where diabetes is most common, where outcomes are worst and where people need most support, new resources and new ideas.

The WP is 230 pages long and packed with proposals and ideas. Many of these need to be worked out in detail and in pilots, so there are opportunities for the diabetes community to contribute to new thinking and evaluating new ways of working.

Further information can be found at:

Seizing opportunities

User Involvement

Diabetes UK has been funded to deliver a User Involvement Support Project. Over the last 18 months the project has delivered the following:

• Training days – There have been 167 people trained to date with a further 13 due to be trained. A resource pack has been produced for users as part of the training.
A document called Good Practice Guidance for PCTs and network managers has been produced. Over 3,000 copies of this guidance have been distributed by direct mailing and through the Diabetes UK regional professional conferences and requests following editorial coverage in a range of medical publications.

It has been used as a resource for a workshop with the London project managers of the National Primary Care Development Team and for a Health Foundation event for six diabetes teams from around the country. In general it has been well received.

“Diabetes is such a complex area of health involving so many related conditions that the insights gained from user involvement amongst diabetes patients are applicable across a very wide spectrum. The Diabetes UK guide to user involvement is a helpful and accessible contribution to the user involvement debate and we have distributed it to 800 voluntary, community and faith groups in the London Borough of Newham.”

Ian McDowell, Assistant Director, Newham PCT

The project ended in March 2006 and further work around user involvement is planned around engaging black and minority ethnic groups, children and young people and their parents and carers. Training for healthcare professionals and Diabetes Networks to support users on their networks is also being developed. A specific user reference group is planned to support the work of the Department of Health.

**Continuing work on network development**

Clinical diabetes networks will still be central to the success of joined up working and implementation of the Diabetes NSF. One of the core functions of the NDST is to support diabetes networks at whatever stage they are at. This means working with new organisations to help them get started, through to supporting more mature systems in growing and developing. There is financial support available, along with knowledge and communication systems and NDST regional programme managers who work closely with local teams identifying and meeting specific needs.

The National Patient Diabetes Survey and the Service Improvement Review being conducted by the Healthcare Commission will provide valuable feedback for diabetes networks to be able to review their services and build upon their existing successes.

‘Our Health, Our Care, Our Say’ provides the opportunity to review existing models of care and where they are delivered and by whom but this has to be done in the context of recognising the valuable role everyone plays, the specialist, the primary care team and the person with diabetes.
Identifying and agreeing the model of diabetes care that is then commissioned using practice based commissioning and payment by results has to be a priority for diabetes networks this coming year.

Leadership at all levels is critical to the success of a diabetes network. Support and development will continue to be a key feature with continued work on helping individuals acquire the skills to be able lead on improving services.

**Inequalities and BME**

People from black and minority ethnic (BME) communities are up to five times more likely to develop diabetes than the general population:

- Asian communities have a 5-6 fold higher risk, with ageing
- Chinese communities have a 3-4 fold higher risk
- Mauritian communities have a 6-10 fold higher risk
- African Caribbean communities have a 4-5 fold higher risk.

The reason for such high prevalence is not known, but factors which could play a part for all people where diabetes is concerned include:

- Genetic differences in how the body processes fat
- Inactivity/obesity
- Language barriers
- Poor knowledge of services
- Difficulties with transport
- Differences in willingness to seek medical help
- Social deprivation
- Lack of education and/or employment
- Poor housing.

These communities also face a 50% increased risk of heart disease and even greater risk of kidney disorders, with black and African Caribbean communities experiencing a high prevalence of hypertension, stroke and renal failure.
An on-line forum has been set up by the National Diabetes Support Team for healthcare professionals working with ethnic minorities to discuss issues and raise questions: http://www.diabetes.nhs.uk/forum/forum.asp?ForumID=5

**Children and Young People**

The Diabetes NSF sets out specific standards that diabetes services for children and young people should attain by 2013 as well as ensuring they are included in the standards that also cover adults. Information from Diabetes UK and the National Diabetes Audit tells us that despite the NSF Standards there are still inconsistencies in the provision of children's diabetes services.

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**Diabetes Education for Black and Minority Ethnic Communities in Birmingham**

A major area of work for the Heart of Birmingham teaching PCT (HoB tPCT) has been diabetes education for those communities that are at higher risk of developing the condition – black and minority ethnic (BME) communities. Diet and lifestyle are key to diabetes management, and therefore have been prioritised by the project.

The service aims to provide individual and group consultations, as defined by patient need and choice, in the most appropriate language. This may require an interpreter to be present. In the last ten years this project has grown to cover the whole of HoB tPCT.

Group education sessions take place in a variety of community settings, from local health centres and residential homes to places of worship and schools. The aim of this is to help clients access the sessions and feel comfortable in their surroundings. Individual appointments are also offered in a number of NHS premises to improve access for patients. Family members, friends and carers are welcome at the sessions and appointments to offer support.

Resources on diabetes care are available through the service and all GP practices in the Trust area have them in the most predominant languages read in the area e.g. Urdu and Punjabi. Resources in Somali and Arabic are currently in development due to recent demand. A pictorial guide to diabetes is also used to aid service-users from any background who have poor literacy.

Training is about to begin for 30 additional Chronic Disease Educators who will continue and increase the group education available, based in localities throughout the PCT.
The Department of Health, with the support of the National Diabetes Support Team and Diabetes UK, has established a Children’s and Young People’s Diabetes Services Working Group with a remit to identify what needs to be done to enable the NHS and local care services to meet the needs of children and young adults with diabetes as framed in national guidance.

The group will issue guidance that will help people to commission and deliver the services necessary to meet the standards as framed in national guidance. We anticipate that the guidance will be issued in the Autumn of 2006 and will assist PCTs to develop their children’s and young people’s diabetes services in their new structures.

To further support the work of the group, the National Diabetes Support Team has also established a Discussion Forum covering issues surrounding care for Children and Young People. This can be accessed at


The Group welcomes contributions from anyone involved in the care of children and young people with diabetes whether healthcare professionals, parents or carers as well as children and young people with diabetes. Anybody with an interest in the healthcare of children and young people with diabetes can email their comments to cyp@diabetes.nhs.uk

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**Transition Services in Blackwater Valley and Hart PCT**

A joint transitional diabetes clinic has been set up between the paediatric and adult service at Frimley Children’s Centre in Hampshire. Both paediatric and adult consultants attend the clinic, as well as paediatric and adult diabetes nurse specialists, along with a dietician and a podiatrist.

In the last year the service has been running, a smooth transition of children from one service to another has been recorded. Paediatric nurse specialist Julie Richardson said: “The feedback we’ve had from the patients is very positive. They like the fact they are meeting the adult staff before they go over to the adult service.”

In developing the service lengthy discussions were undertaken and feedback from patients and families already transferred to adult services was taken into account. A decision was taken after a lot of research to run the clinic three times a year with a view to the children having two or three appointments in the transfer process.

The bulk of the work was undertaken by the diabetes specialist nurses, who run the clinic which has been running for 14 months.
Insulin Pumps Working Group

We have established a new Insulin Pumps Working Group jointly with Diabetes UK to develop a strategy to help local services implement the NICE Health Technology Appraisal (HTA) Guidance No 57 – Guidance on the use of continuous subcutaneous insulin infusion for diabetes.

The group’s remit is:

i. To agree what needs to be done to enable local services to deliver the NICE HTA on insulin pumps for adults, children and young people.

ii. To consider other issues related to insulin pump therapy and feed into the development of further NICE guidance.

The group will issue guidance, aimed at both clinicians and commissioners, setting out what they need to have in place to meet the NICE HTA Guidance on insulin pumps. The guidance will also include advice on areas that clinicians and commissioners may wish to consider that is not covered by the NICE guidance.

We hope that the guidance will help to alleviate the inconsistencies in prescribing that currently exist across the NHS. The guidance will be issued in the summer of 2006.

Reducing length of stay – measuring improvement

Working to reduce excess length of stay for inpatients with diabetes can:

- Improve patient experience
- Help PCT and Acute Trusts deliver the (PSA) Public Service Agreement emergency bed day target through improved care for people with long term conditions
- Assist in meeting a number of the Standards in the Diabetes NSF.

The new national PSA target:

*To improve health outcomes for people with long-term conditions… and to reduce emergency bed days by 5% by 2008 (from the expected 2003/04 baseline), through improved care in primary care and community settings for people with long-term conditions*

offers tremendous opportunities for diabetes teams and networks to raise the profile of inpatient diabetes care and improve inpatient diabetes services.
Emergency bed days can be reduced in two ways:

- Keeping people out of hospital
- Getting people out of hospital once they’ve been admitted.

Each of these depends on the two pillars of integrated diabetes working outlined in the Delivery Strategy, namely:

- Supporting people with diabetes to better manage their own care
- Improving systematic care everywhere in the service.


**Models of Care**

There are many different approaches being developed to joint working between primary and specialist care:

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**Specialist support for community diabetes services**

Community diabetes services in Sheffield are being offered specialist support in a programme which places emphasis on collaboration between primary and secondary care.

A consultant and a diabetes specialist nurse from Sheffield Teaching Hospitals Foundation NHS Trust, alongside a chronic disease management nurse from the PCT, work with practices to identify which of their patients currently receiving their diabetes care at hospital could be well managed in a primary care setting. Training is also provided for the primary care scheme where necessary.

Audits in two of the participating practices showed that blood pressure, HbA1c and total cholesterol levels were generally lower when under practice care. Nurses also reviewed patients more frequently.

As a result of the programme primary care health professionals are skilled to a higher level and have ongoing support from secondary care specialists. Patients have easier access to health services to ensure that secondary care clinics can focus on the more complex cases.
Diabetes care in Mid Essex has been transformed by the development of a new Tier 2 service. HbA1c and blood pressure outcomes have seen significant improvements, along with reductions in weight and an increase in patients' activity levels.

All this came about when the Diabetes Network Group set up a model of care to meet the increasing demands for quality diabetes service. The aims of the new Tier 2 service are to provide an intermediate level of diabetes service between primary care and specialist services which includes a Multi-Disciplinary Team (one stop shop) for people with diabetes to access. All patients referred see the Diabetes Specialist Nurse, GP with Special Interest (GPwSI), Podiatrist and the Dietitian in one visit.

The weekly clinics run across the county, providing quality services in the community. And not only are outcomes improving, but patients are delighted with the new service:

“Now I know what I can do to take better control and it's working. It's great to have somewhere like this where everyone is so helpful and knowledgeable about diabetes.”

Workforce models

The National Diabetes Workforce Strategy, which is due to be launched later this year will bring together all this work into a comprehensive guide on workforce planning, design and development for networks and local health communities. The development of this strategy is being supported by the Challenges and Solutions Group. Established in 2005 this is a stakeholder group for anyone with a passion for workforce.
Torbay competence based workforce planning model

The aim of this model developed in Torbay was to generate staffing options for diabetes services across a locality using the diabetes competence framework as a basis for this.

A focus group which included people with diabetes was established to lead the work, and included representatives from a number of staff groups involved in the delivery of diabetes services. In developing the model the group began by mapping competences against the current workforce:

For each area of competence a grid was developed listing all the competences down one side with staff groups across the top.

These grids were used to capture and record which staff group(s) currently undertook that particular competence.

The time spent on undertaking each competence on an annual basis was calculated.

This process enabled the focus group to identify who currently was doing what, what was not been done (a gap), how long it was taking and then use this as a basis for planning.

From this baseline the group were then able to discuss and agree on how tasks might be re-allocated. This enabled four workforce models to be developed (in addition to the current one). These were:

• GPwSI model
• HCA model
• Pharmacy (external) model
• Gold standard model.

Each of these models showed how tasks could be re-allocated and the economic impact of doing this linked to the change in percentage of staff on each Agenda for Change pay band.

From this the group were able to identify the workforce model that would best deliver diabetes care across the locality.
Appendix A

More information about some of the case studies included in this report is available from the following sources:

Bolsover Wellness Project, p.22, Judy Derricott, judyderricott@nederbypct.nhs.uk, 01246 551158
Do Activity Stay Healthy scheme, p.23, Tracey Milton, traceymilton2003@yahoo.co.uk, 01278 432000
Apnee Sehat, p.24, www.apneeschat.com
Phoenix NHS Stop Smoking Service, p.26, Gary Burroughs, gary.burroughs@lincolnshire.gov.uk, 01522 550676
One-Stop Triage and Laser Clinic in Hull, p.28, Dr Margaret Balshaw, 01428 328541
Anne’s Story, p.34, http://www.expertpatients.nhs.uk/
South Wiltshire Diabetes Pack, p.35, Martin Smith, martin.smith@salisbury.nhs.uk
Weston Peer Advisors, p.38, Sue Stone, sue.stone@waht.swest.nhs.uk
Networks in Action, p.41, Helen Slater 01925265171 helen.slater@telfordpct.nhs.uk
Care Technicians in Norfolk, Suffolk and Cambridge, p.44, Hoagy Scoins 01223 597660 hoagy.scoins@nscsha.nhs.uk
New Roles in Leicester, p.45, Sabera Khan, sabera.khan@uhl-tr.nhs.uk
Education for BME communities in Birmingham, p.60, Emma Marcus, 0121 4652785, emma.marcus@easternbirminghampct.nhs.uk
Transition Services, p.61, Julie Richardson, 01483 782938
Specialist support in Sheffield, p.63, Ms Alison Iliff 01142 264252 alison.iliff@sheffiledn-pct.nhs.uk
Diabetes in Mid Essex, p.64, Linda Jewsbury, Linda.jewsbury@chelmsford-pct.nhs.uk
Appendix B

The following websites provide valuable information about diabetes:

Department of Health
http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/Diabetes/fs/en

National Diabetes Support Team
http://www.diabetes.nhs.uk/

National Electronic Library for Health
http://libraries.nelh.nhs.uk/diabetes/

National Screening Committee

National Diabetes Audit

Better Metrics
http://www.osha.nhs.uk/

DiabetesE
www.diabetesE.net/demo
http://www.innove.co.uk/diabetesE.htm

NHS Direct

Juvenile Diabetes Research Foundation
http://www.jdf.org/

Diabetes UK
http://www.diabetes.org.uk/
**DAFNE**
http://www.dafne.uk.com/

**DESMOND**
www.desmond-project.org.uk

**NICE Health Technology Appraisal on Patient Education**
http://www.nice.org.uk/page.aspx?o=68326