Department of Health

Improving Diabetes Services: The NSF Four Years On

The Way Ahead: The Local Challenge

Report from Dr Sue Roberts National Clinical Director for Diabetes, for the Secretary of State for Health

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Contact details	Laura Ladd Diabetes Policy Team Room 408 Wellington House 133–155 Waterloo Road London SE1 8UG http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/Diabetes/fs/en
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1 Foreword

The Diabetes UK award for outstanding contributions to improving diabetes care is named after H G Wells – the author of *The Invisible Man*. For many years diabetes was the 'Invisible Condition' and the people who had it were, for the most part, also invisible or at least undiagnosed. As recently as 2003 in the introduction to the Diabetes National Service Framework (NSF) Delivery Strategy[1] it was acknowledged that there was a 'missing million' of people with undiagnosed diabetes.

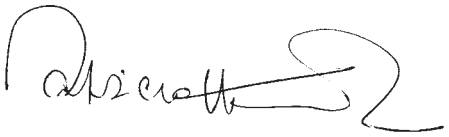
That has changed. It is now widely accepted that diabetes is a major, and growing, threat to the health of people in England. The costs to individuals, the NHS and society as a whole are big and getting bigger. With the majority of the increase in those diagnosed having Type 2 diabetes, the government has responded with joined up strategies to reduce the chances of people getting this eminently preventable condition. Policies on weight reduction and increased exercise have an important part to play in preventing diabetes but must be matched with support for early diagnosis and treatment.

The Quality and Outcomes Framework, part of the new GP contract, has led directly to the diagnosis of many of the 'missing million'. In the last year alone over 100,000 more people have been diagnosed and are now receiving the information, care and advice that will enable them to manage their condition more effectively and reduce the risks of the many complications that accompany diabetes.

The increasing numbers being diagnosed, however, do present a considerable challenge to healthcare professionals in providing high quality care for each individual. The focus on providing care at a time and location most suitable for users also means working across the traditional boundaries between primary and secondary, or rather, specialist care. There is a growing number of primary care and specialist teams working in an integrated system that enables every professional to contribute to their fullest. In this way people with diabetes have rapid access to the right care, at the right time, from the right person.

1 DH, 2003, Diabetes NSF Delivery Strategy

It is heartening to see that this fourth report into delivering the Diabetes NSF standards[2] contains so many examples of where the challenges of increased diagnosis and improving services are being successfully met. I am sure that these are just a small sample of the many innovative ways of delivering improved diabetes services, supporting effective self management and patient centred care, within the diabetes community. However there is still much to be done before the variations in treatment and outcomes that the NSF highlighted are eradicated. I am confident that the diabetes community increasingly have the skills, to add to their commitment and enthusiasm, to deliver that step change.



Patricia Hewitt
Secretary of State for Health

2 DH, 2002, Diabetes NSF Standards

2 Introduction

It is now nearly five years since the Diabetes NSF was launched and nearly four since the Delivery Strategy laid out how the Standards were to be achieved by frontline staff. In that time, and within a changing healthcare environment, considerable progress has been made. The challenge to local organisations, however, is to ensure that the restructuring of both services and NHS organisations, when combined with the increased demand for diabetes services, does not overwhelm the system and that commissioners and providers are still focused on delivering high quality, patient centred care. Local services are in a much better position to do just that because of the developments over the past year.

There is now much more detailed data and information on diabetes care which can be broken down to present an accurate picture of what local services are providing and where the gaps are. The last year has also seen the development and widespread availability of a number of tools to enable commissioners and providers to develop and deliver effective services. These data and tools together provide a powerful impetus for change and improvement.

The information now available to support commissioners and providers includes both service audits and suggestions on how local services can be measured. The National Diabetes Audit is now the largest annual audit of diabetes services in the world, recording anonymised information on the health and well being of nearly 700,000 individual patients. At the end of the audit period in 2006, 220 primary care trusts, 4,972 individual practices, 81 hospitals and 197 paediatric units were registered. The data they are submitting provides a wealth of information on the care that people are receiving. With the PBS diabetes prevalence model[3] integrated into the National Diabetes Audit not only can the care people are actually receiving be seen, but also any gap in provision. This allows care to be better targeted at those sectors or groups where under provision is in existence.

In addition to the National Diabetes Audit data, there are now:

- Quality and Outcomes Framework (QOF) data on diabetes outcomes in practices

3 Yorkshire and Humber Public Health Observatory

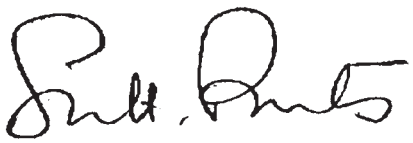
- Diabetes E data on PCT self-assessment of diabetes services
- Hospital Episode Statistics (HES) data on the impact of diabetes on secondary care
- Better metrics to support measuring improvement
- Specific local data from a variety of sources.

All of these, when used together, can provide a much more rounded picture of diabetes prevalence, existing care, gaps and ways of measuring improvement than ever before. This report is an important resource for members of the diabetes community to promote and improve diabetes care.

However, having the information available is only part of the solution. Commissioners and providers must be able to use all that data to support their planning process. To that end, a number of tools, guides and reports have been produced that will enable high quality services to meet the specific needs of the local community. The Commissioning Toolkit[4] produced by the Department of Health and the National Diabetes Support Team in partnership with the Primary Care Diabetes Society, Diabetes UK, Association of British Clinical Diabetologists and the Yorkshire and Humber Public Health Observatory was developed in response to the need voiced by local services for support in the commissioning process. It has been an outstanding success, and warmly welcomed by the diabetes community.

In addition to this, a wide range of other guidance has been produced by the Department of Health and the National Diabetes Support Team, ranging from a Patient Education Toolkit[5] to support evaluation of local programmes to a guide to improving foot care[6] for people with diabetes that has been downloaded more than 10,000 times. A full list of all the support material for the diabetes community is at Appendix A.

Taken together, the wider and more detailed information on diabetes, combined with practical guidance on how to deliver improved care, provides a rich seam of resources for all the diabetes community to access. I am confident that they will use all their considerable expertise and experience to ensure that work to deliver a world class diabetes service in England continues.



Dr Sue Roberts
National Clinical Director for Diabetes

4 DH, 2006, Diabetes Commissioning Toolkit
5 NDST, 2006, How to assess structured diabetes education: a tool kit
6 NDST, 2006, Diabetic Foot Guide

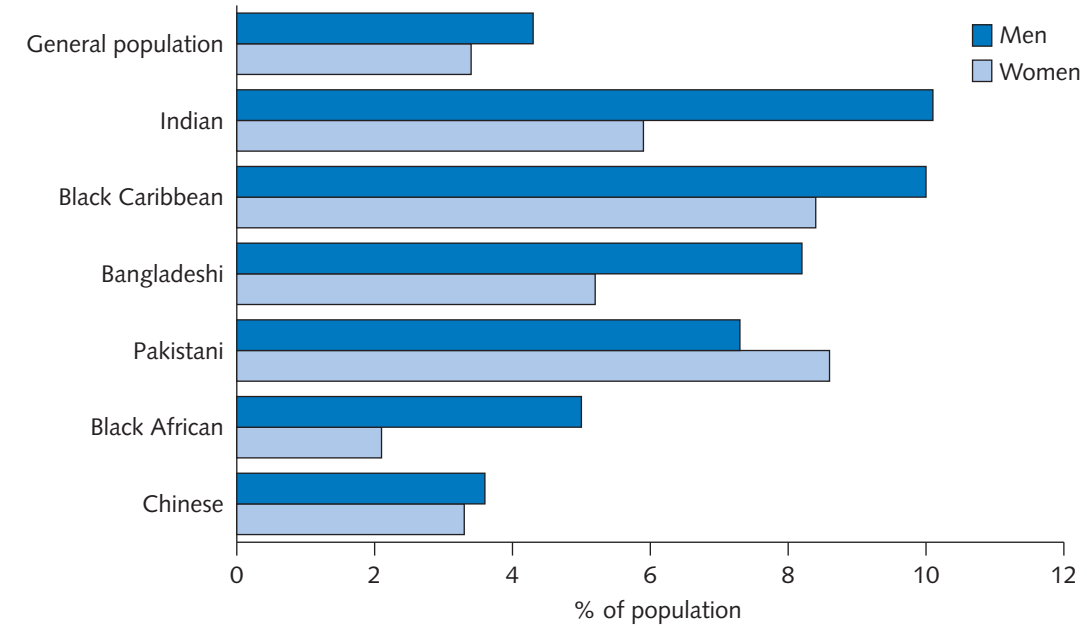
3 Preventing and identifying diabetes

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

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

Type 2 diabetes has a well documented link with diet, obesity and lack of exercise. Additionally, as Figs 1 and 2 show, both ethnicity and deprivation are major contributors to an increased risk of diabetes. Research has confirmed that a better diet, increased physical activity and modest weight loss could reduce the development of Type 2 diabetes in middle-aged adults at high risk by 58%[7]. The challenge now is to find ways of delivering these benefits in real life rather than purely research settings.

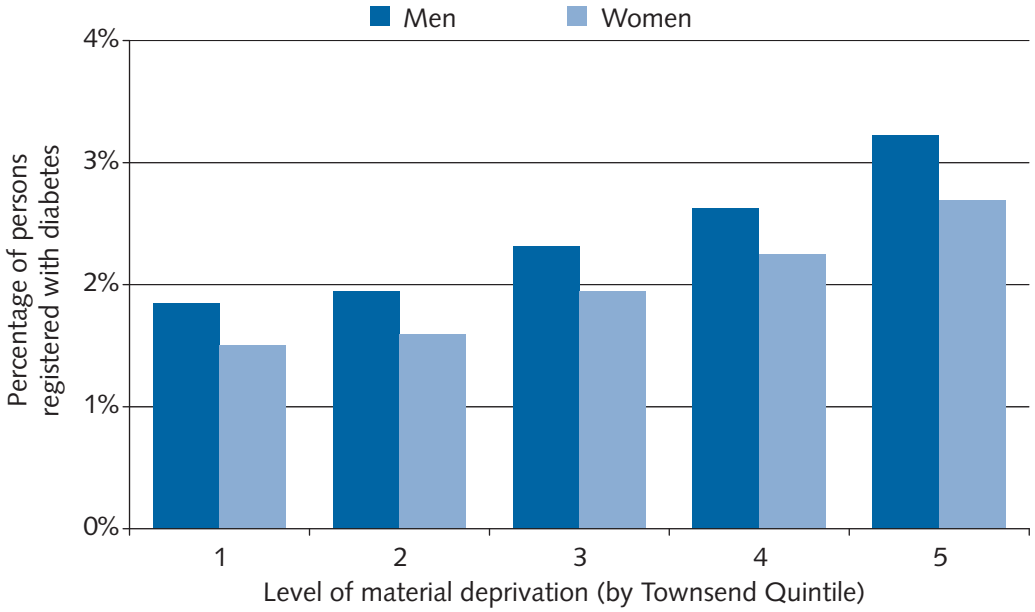
Fig 1. Prevalence of doctor diagnosed diabetes within minority ethnic group



Source: Health Survey for England 2004

7 Finnish Diabetes Prevention Study, Finland and Diabetes Prevention Program, USA

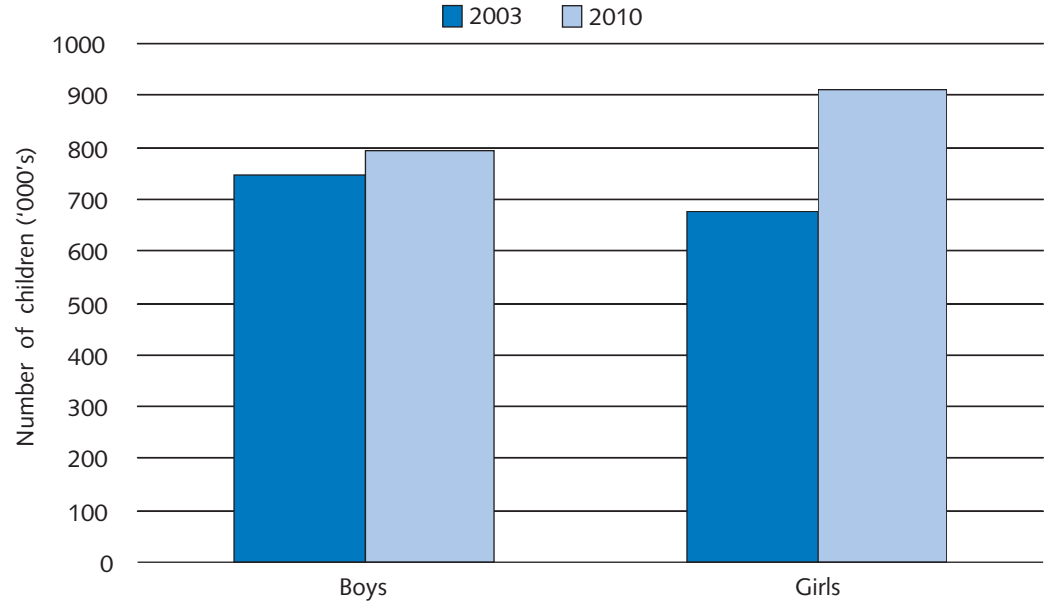
Fig 2. Material deprivation and percentage registered with diabetes



Source – National Clinical Audit Support Programme (NCASP)/National Diabetes Audit (NDA) Toolkit

It is apparent that the challenges in developing effective screening and prevention programmes for diabetes also impact on many other areas of health and social care.

Fig 3. Estimated number of obese children, 2003 and 2010



Source – 'Forecasting Obesity to 2010', Joint Health Surveys Unit, 2006

The predicted growth in child obesity is a particular challenge. We are already seeing an increase in Type 1 and Type 2 diabetes and as fig 3 shows, with obesity increasing, there are implications for rising numbers of children with Type 2 diabetes.

The Department of Health has a series of Public Service Agreements (PSAs) in the overall field of prevention that will have profound effects on the diabetes community. These are to:

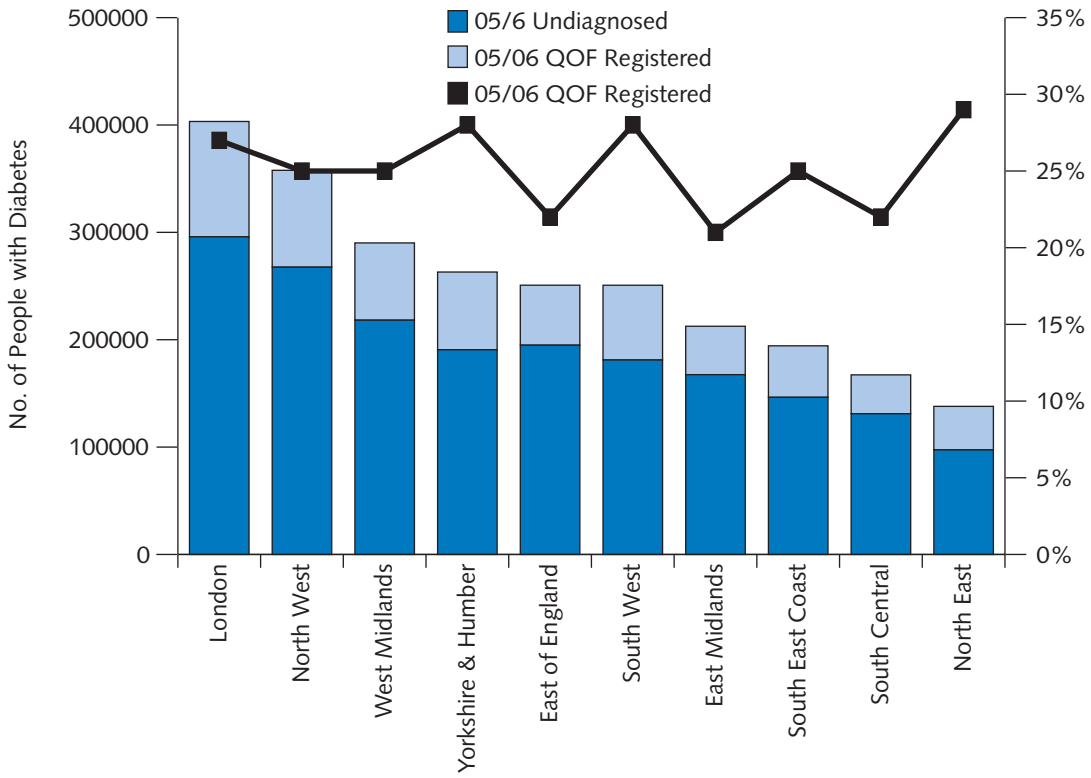
- Reduce substantially the mortality rates from the major killer diseases by 2010.
- Reduce inequalities as measured by life expectancy at birth by 10% by 2010.
- By 2010 increase life expectancy at birth in England to 78.6 years for men and 82.5 years for women.
- Halt the year-on-year rise in obesity among children under 11 by 2010 in the context of a broader strategy to tackle obesity in the population as a whole.
- Enhance the take-up of sporting opportunities for 5–16 year-olds so that the percentage of school children in England who spend a minimum of two hours each week on high quality PE and school sport within and beyond the curriculum increases from 25% in 2002 to 75% by 2006 and to 85% by 2008.
- By 2008, increase the take-up of cultural and sporting opportunities by adults and young people aged 16 and above from priority groups by increasing the number who participate in active sport at least 12 times a year by 3% and increasing the number who engage in at least 30 minutes of moderate intensity level sport at least three times a week by 3%.

These targets have been well supported by the two major White Papers that focused on the role of prevention in improving the nation's health. Both *Choosing Health*[8] and *Our health, our care, our say*[9] recognise that primary prevention, with individuals becoming more responsible for becoming and staying healthy, is a vital part of any health and social care strategy.

8 DH, 2005, Choosing Health: Making Healthy Choices Easier
9 DH, 2006, Our health, our care, our say: A new direction for community services

These broader policy initiatives have been supported on the ground by the Quality and Outcomes Framework (QOF). This rewards general practices for each person on their registers as well as for 17 other indicators of good practice for each person. This has seen over 100,000 more people diagnosed with diabetes in the last year alongside improvement in all the other diabetes QOF indicators.

Fig 4. Registered people with diabetes and estimated undiagnosed non-registered cases (YHPHO prevalence model) by SHA



Source: QOF 2005/6

There is no doubt that diagnosis rates are increasing and the 'missing million' is now more likely to be a missing half-a-million. With more than 100,000 people newly diagnosed last year, the estimated diagnosis rate is now more than 80%. Diabetes prevalence is not equally distributed around the country, however, with ethnicity, deprivation and age being important influencing factors. As fig 4 shows, some Strategic Health Authorities have a much higher incidence than others and also more success in diagnosing those cases that they have. This shows that all Strategic Health Authorities still have work to do to find the undiagnosed people with diabetes in their area.

A number of services have found innovative ways of working that focus on supporting those at risk of diabetes and identifying those who already have it.

Case study 1 – Screening vulnerable communities in Bradford and Airedale

Health workers from Bradford and Airedale PCT have been working with practice nurses and GPs in partnership with Astra Zeneca to raise the profile of diabetes in South Asian communities. They are particularly keen to raise awareness of the importance of diabetes screening and how people can reduce their risk by making changes to their lifestyle.

A series of information sessions were held in the community, followed by screening for risk factors for cardiac diseases and diabetes. Anyone identified as being at risk was referred to the practice nurse at their own surgery for advice, support and medication if necessary.

Diabetes lead Louise Butterfield said: "Many people with diabetes have had it for between nine and 12 years before it is diagnosed and many of them will have started to develop complications. However the good news is that if it is spotted early, you can greatly reduce your chances of any serious health problems."

A press release was sent out to local newspapers to publicise the awareness and screening events to as many people as possible. The release also included details of common symptoms of diabetes.

For more information contact: stuart.gabbitas@bradford.nhs.uk

Case study 2 – Diabetes Prevalence in Sefton

Diabetes prevalence information is being used in Sefton PCT to identify people with diabetes who have not yet been diagnosed.

The work was started by Southport and Formby PCT as part of the Health Foundation Leadership Programme, which supports closer working between primary and secondary care.

It was established that the recorded incidence of diabetes was 3.93%, while the predicted prevalence was 5.21%. This is 4,740 patients diagnosed, compared to 6,264 who are predicted to have the condition. This left potentially 1,524 patients undiagnosed.

The information used to generate these statistics came from the Quality and Outcome Framework and the PBS Prevalence Model. The results were broken down by practice and put in a short, easy-to-read document that was shared with all local practices.

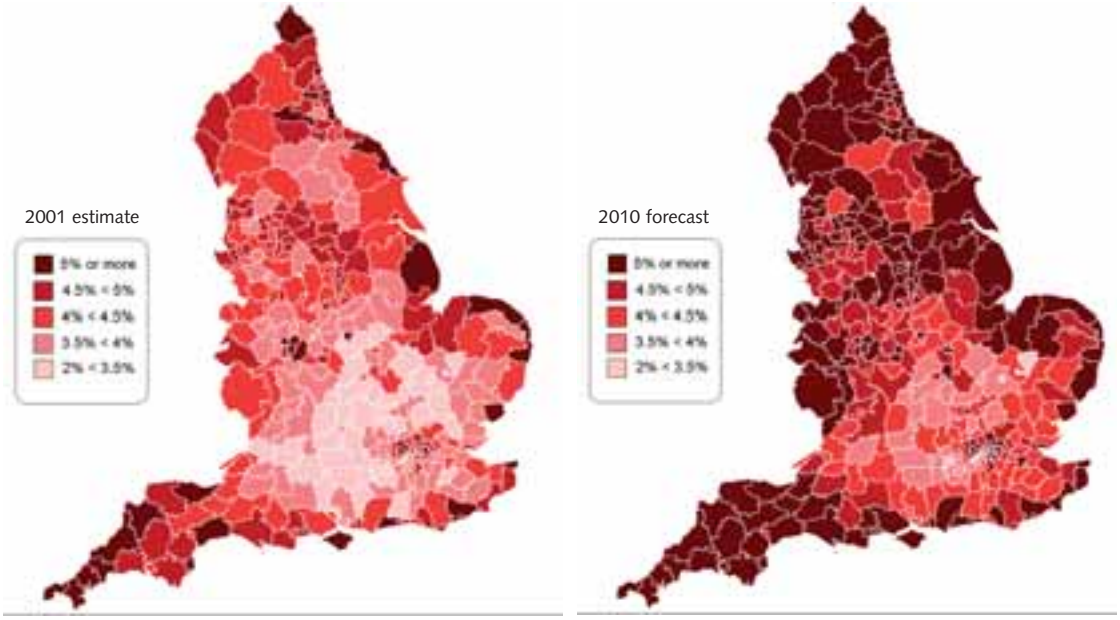
A year later, the percentage of patients diagnosed with diabetes had increased to 4.09%.

The booklet has now been updated and practices are still working on identifying more patients with diabetes.

Specialist Registrar in Public Health Dr Ifeoma Onyia said: "The fact that these patients have been identified and placed on the diabetes registers means that they will benefit from the high quality care encouraged by the quality and outcomes framework."

For more information contact: Ifeoma.Onyia@seftonpct.nhs.uk

Fig 5. Forecast increase in prevalence of diabetes



Source – PBS Diabetes Prevalence Model

These maps illustrate the estimated and forecast geographical pattern of diabetes prevalence by local authority in 2001 and 2010. The maps show that rates are highest in coastal areas with generally older populations, and inner city areas with high levels of socio-economic deprivation and high proportions of black and South Asian populations. Despite the majority of London Boroughs having relatively young populations, their rates are high because of their deprivation and ethnicity profiles. Comparison of the maps for the two time-points illustrates the combined effect on diabetes prevalence of the anticipated national increases in obesity prevalence and the ageing of local populations.

The forecast increase in prevalence between 2001 and 2010 is 15% across England. However, it is estimated that two thirds of diabetes can be prevented.

Case Study 3 – Weight Management in Redcar and Cleveland

A new weight management service in Redcar and Cleveland is producing encouraging results for people at risk of developing diabetes. The aim of the service is to target overweight and obese people before they develop chronic health problems.

The weight management service is separated into four stages:

Stage 1 – Basic intervention:

- Population based opportunistic lifestyle and physical activity recommendations and advice
- Signposting to services

Stage 2 – Weight Management Service:

- For clients with BMI 25-29kg/m^2
- For clients with BMI 30-39.9kg/m^2 without co-morbidities
- Trim and Slim delivered by Health Trainers, healthcare assistants, Sure Start nutrition team, leisure centre staff
- Weekly/monthly weigh-in, nutrition and lifestyle information, physical activity, data collection
- Delivered in a variety of easily accessible settings in a 12 week programme

Stage 3 – Weight Management Service:

- Delivered one-to-one by dieticians
- For clients with BMI 30-34.9kg/m^2 with co-morbidities

Stage 4 – Specialist Weight Management Service:

- Delivered by the multidisciplinary team, including a GPwSI, physiotherapist, psychologist and dietician
- For clients with BMI ≥ 40kg/m^2 or BMI ≥ 35kg/m^2 with significant co-morbidities

The service was set up as a result of the creation of an obesity strategy in 2003. Since its inception the data has shown some weight loss, with a small number of clients achieving 5kg weight loss in six months. Other outcomes are also improving. Weight Management Service Lead Fiona Taylor said: "The service is in its early development, however, we are very encouraged as are the clients as resting heart rates are improving, assessments show increased exercise tolerance and there is evidence of a decreased dependency on medication."

The service is being fully evaluated by Teesside University.
For more information contact Fiona Taylor: f.taylor@leedsmet.ac.uk

Prevention in the workplace

Major employers, and the NHS is the largest in England, are also becoming aware of the benefits of providing information and advice to their staff. The statistics show that sickness absence costs:

- The UK economy more than £12billion a year;
- Employers £495 a year in direct costs for every worker employed. Indirect costs are probably considerably more (CBI 2005 statistics).

With the prevalence of diabetes set to rise to 5% of the population by 2010, it makes good economic sense to provide information on health risks and facilities to support healthy living.

Case study 4 – Awareness in the Workplace

Solihull Care Trust targeted its own staff in a diabetes awareness campaign. Staff were invited to visit the Trust's headquarters to find out more about diabetes risk and prevention. Those who took part received blood pressure, glucose and carbon monoxide level tests.

Diabetes Business Support Manager Caroline Harrison said: "The event was well attended and raised awareness with staff. As a result, some colleagues were advised to see their GP."

The campaign was also taken to the wider community with a Collection and Awareness Day. This was run by the Community Diabetes Team in partnership with diabetes service-users. They gathered at a local supermarket to collect money, hand out leaflets and provide information on local diabetes services.

For more information contact Caroline Harrison:
caroline.harrison@solihull-ct.nhs.uk

4 Empowering People With Diabetes

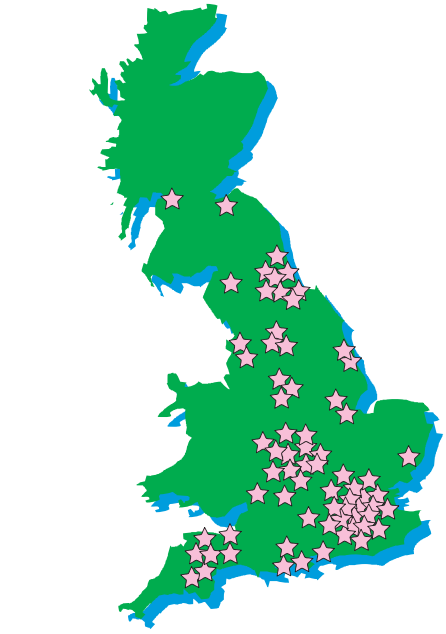
Standard 3: All children, young people and adults with diabetes will receive a service which encourages partnership in decision-making, supports them in managing their diabetes and helps them to adopt and maintain a healthy lifestyle. This will be reflected in an agreed and shared care plan in an appropriate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

Engaging people with diabetes in their own care is a core part of the NSF delivery strategy. It is encouraging to recognise the steady increase in the quantity and quality of patient education now being delivered. The expanding number of sites offering DAFNE (Dose Adjustment for Normal Eating) and DESMOND (Diabetes Education and Self-Management for Ongoing and Newly Diagnosed) programmes, accompanied by the determination of people who have developed local programmes to meet the established criteria, means many more people with diabetes have access to good quality structured education. The *Structured Patient Education Toolkit* produced by the National Diabetes Support Team and Diabetes UK has now been downloaded over 1,800 times, enabling people to work towards meeting those criteria.

Initiatives to target hard to reach groups such as black and minority ethnic communities and those with special needs are also supporting a more empowered and involved diabetes community.

Fig 6. The increase and spread of diabetes structured education programmes

The DESMOND New Diagnosed Programme in May 2006



- 80 PCTs taking part
- Training team of 15 working in 3 regions
- 300 educators trained since 2003

DAFNE Education Centres

- 56 centres by March 07

There is still substantial evidence that not every person with diabetes is either aware of the need for structured education or training or can access it. The Diabetes UK *State of the Nations* report[10], examining diabetes care amongst its members in 2006, found that, in England:

- 49% of adults were aware of education courses
- 29% of children and young people were aware of education courses
- 36% of adults found the course offered was at the wrong time or place
- 20% of trusts provided a 24 hour telephone helpline
- 47% of trusts provided education for children and young people.

Although the same report found that most trusts reported some kind of structured education for people with Type 1 and Type 2 diabetes, this does not give an indication of its quality. It is vitally important that education programmes meet the criteria set out by NICE and by the *Structured Patient Education Toolkit*.

10 Diabetes UK, 2006, Diabetes: State of the Nations 2006

The case studies below set out some of the approaches to patient empowerment adopted by local services.

Case study 5 – Reaching Diverse Communities in Hackney

Bilingual lay educators perform diabetes group education for many different minority ethnic communities in Hackney, one of which is the large Turkish community. GPs and practice nurses are encouraged to refer patients with diabetes, whose first language is not English, to the education groups.

The project was kick-started by money from the Neighbourhood Renewal Fund and provides the following programmes in a variety of languages:

- DESMOND – for newly diagnosed Type 2 diabetes
- X-pert – for Type 2 diabetes
- BICEP – Barts and Homerton Intensive Carbohydrate Education Programme – for Type 1 diabetes

Educational resources have also been produced:

- Leaflets – on blood glucose, travel, insulin, foot care, complications, diet and much more, in English and Turkish
- Audio CD – an introduction to Type 2 diabetes in Turkish and Bengali (Sylhetti)
- DVD – A Guide to Diabetes in Turkish
- Patient held records – English and Turkish
- Diabetes Identification Cards

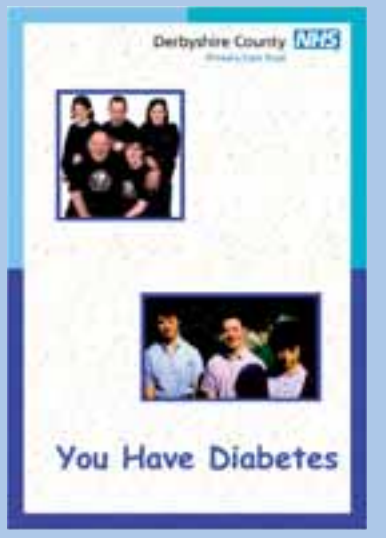
All of the resources are available from the diabetes centre's website at: http://www.diabetes-resources.org.uk/

Diabetes specialist nurse Anna-Marie Jesson said: "The production of sustainable resources enables the wider community of healthcare professionals to reach out to patients who may be excluded from care due to lack of a common language. Anecdotally, attendance at clinics has been higher, and patients are happier with the service than previously."

A member of the Turkish community said: "I found it very useful, because I didn't know much about diabetes, but now I have a knowledge and I know how to prevent me and my family getting diabetes."

For more information contact: Anna.Jesson@homerton.nhs.uk

Case study 6 – Learning Disabilities Support



An information pack for people with learning disabilities who have diabetes has been developed in Derbyshire County Primary Care Trust (PCT). Created by a Diabetes Specialist Nurse and a Learning Disabilities Nurse, it contains a booklet called "You Have Diabetes".

"You Have Diabetes" contains information on:

- What diabetes is
- How it is treated
- Healthy living
- Going to the clinic
- Other tests

The booklet is written in simple accessible language and contains lots of pictures. Readers are guided through it by a character, who also has a learning disability, called Sam.

There is also a booklet for carers called "Understanding Diabetes", explaining the essentials of the condition from a carer's perspective.

Lead Community Diabetes Specialist Nurse Michelle Denyer said: "There is a need for educational materials for all with diabetes and this publication has been written specifically for those with learning disabilities using pictures and text. Along with other resources this has been well received by people with learning disabilities and their carers."

The booklet for people with learning disabilities can be downloaded here: www.diabetes.nhs.uk/downloads/derbyshire_carers_info

The booklet for carers can be downloaded here: www.diabetes.nhs.uk/downloads/derbyshire_learning_disabilities_booklet

For more information contact: Michelle.Denyer@derbyshirecountypct.nhs.uk

Care Planning

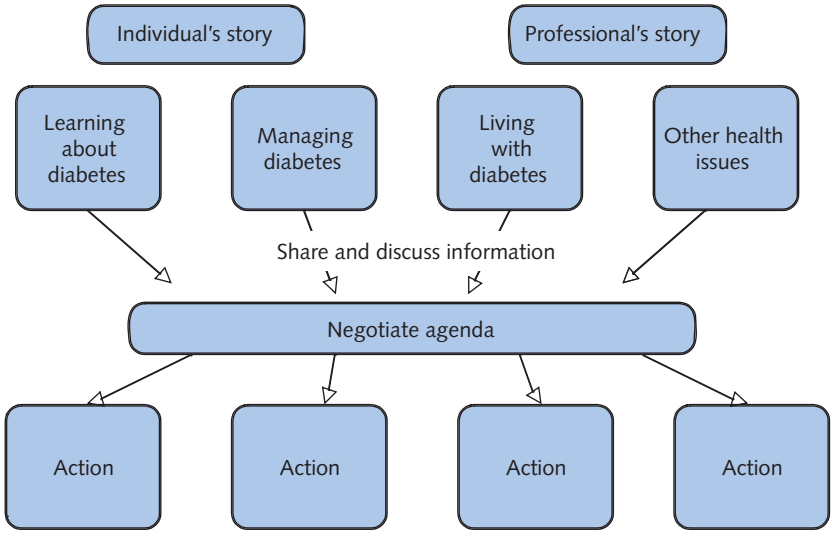
The principle of patient empowerment has been clearly set out by the National Service Framework and its delivery strategy. The challenge now is to translate this into actions that will support empowerment by putting people with diabetes at the centre of their care.

Developing and supporting care planning systems that encourage full patient involvement in the design and implementation of their own care is vital. A joint Department of Health and Diabetes UK working group on care planning has produced a report, *Care Planning in Diabetes,* to provide a policy context and proposals for implementation. This can be found at: http://www.diabetes.nhs.uk/downloads/care_planning_in_diabetes_report.pdf

Care planning is underpinned by the principles of patient-centredness and partnership working. It is an ongoing process of two-way communication, negotiation and joint decision-making in which both the person with diabetes and the healthcare professional make an equal contribution to the consultation. It differs from the 'paternalistic' or 'healthcare professional-centred' model of consulting, traditionally applied in acute settings.

The working group has developed a model for effective care planning based on the vision set out in the Diabetes National Service Framework and the Matrix report *Good care planning for people with long term conditions*[11] commissioned by the NHS Modernisation Agency. The model draws on research in clinical practice, psychology and education to set out a process of negotiation and shared decision making between the healthcare professional and the person with diabetes. Where appropriate, family members or carers should be involved in this process.

Fig 7. Care planning working group report: December 2006



11 www.networks.nhs.uk/uploads/2005_Jun/matrix_care_planning_report.pdf

Case study 7 – Communicating Better

A new project in Bolton is helping people with diabetes to set the agenda in consultations with healthcare professionals. Agenda Cards are part of a piece of work being carried out by Bolton Primary Care Trust (PCT) and the Design Council's Red Team. The aim is to empower people with diabetes and improve communication.

Agenda Cards, developed through interactive workshops, cover six aspects of life with diabetes:

- Progress and Change
- Food and Eating
- Medication and Treatment
- Emotions and Feelings
- Health
- Relationships

In each category there are several cards with different statements on each, which can be used to convey feelings, concerns or priorities. For example, in the Medication and Treatment section there are five cards:

- I forget to check my feet
- Sometimes the medical terms confuse me
- Taking my medication is difficult
- I worry about my eyes
- My blood test results are confusing

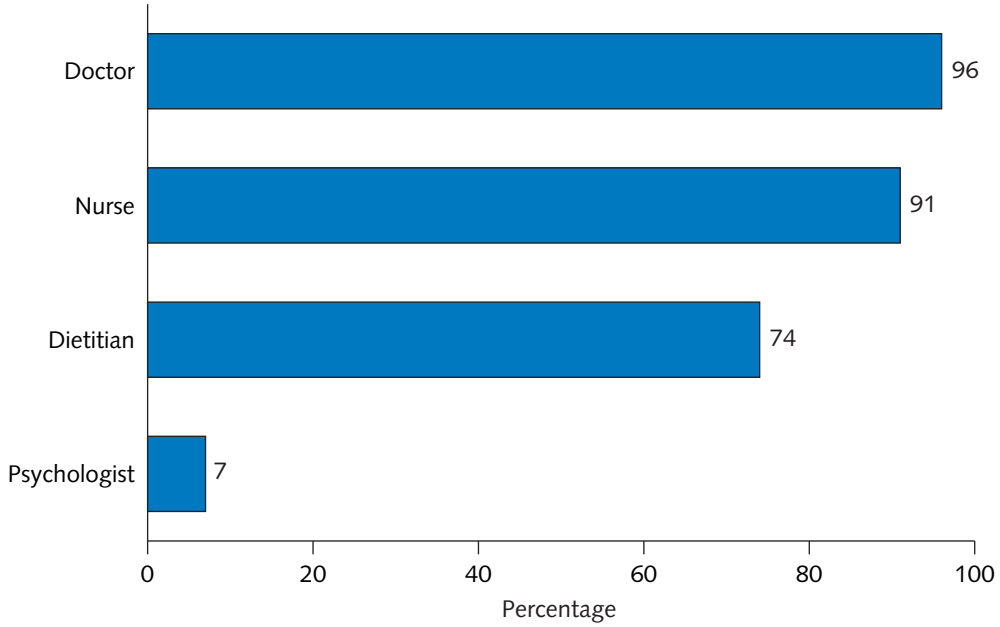
Consultant Nurse Jane Pennington, who has been involved in piloting the cards, said: "I have worked with patients who used them and it makes a world of difference. This has enabled people to talk about sexual difficulties. They don't even have to say it, they can just get the card out. As health professionals we always think we can talk to everyone, but sometimes people can't say those words. It's a revelation."

To view the Agenda Cards and find out more, visit:
http://www.bolton.nhs.uk/BoND/card_front.aspx?card_type=1

Psychological Support

One of the major gaps in developing proper patient empowerment and improved self-management is psychological support to promote behaviour change. As shown in fig 8, the Diabetes UK *State of the Nations* report provided evidence that for children and young people who have a particular need for psychological support, only 7% had access to such support. The Diabetes Workforce Strategy Group, supported by Skills for Health, is currently working on identifying the range of psychological support required, and how this can be provided by the diabetes workforce.

Fig 8. Professionals seen by children and young people at specialist clinics

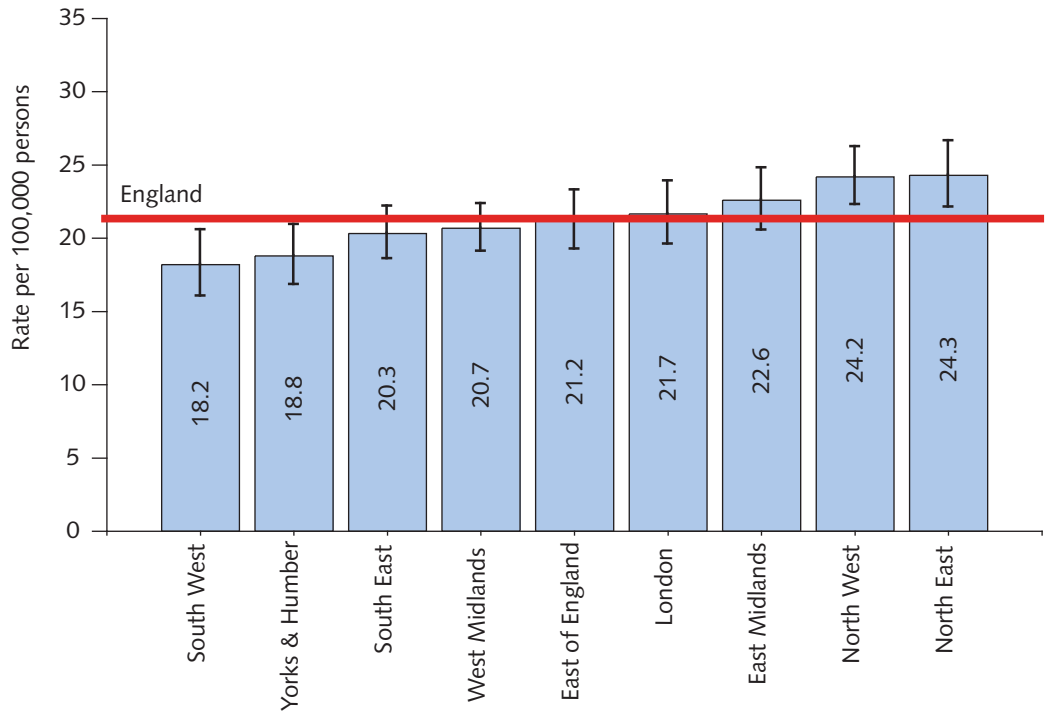


Source – Diabetes UK 2006 Members survey

Assessing Improvement

To determine the effectiveness of patient empowerment it is important to have a means of measuring it. Currently, a broad indication of the effectiveness of strategies to support self management, especially at times of illness and stress, is provided by the rate of admissions for ketoacidosis (see fig 9). The Healthcare Commission Diabetes Service Review, to be released later this year,[12] will provide more detailed evidence, but PCTs might usefully review their own local data as a starting point for measuring how effective their empowerment strategies are.

Fig 9. Emergency hospital admissions with primary diagnosis of diabetic ketoacidosis and coma



Source – Compendium of Clinical and Health Indicators (NCCHOD). Indirectly age and sex standardised rates per 100,000 population with 95% C.I.s, all persons.

12 www.healthcarecommission.org.uk/_db/_documents/Diabetes_Assessment_Framework_find.pdf

5 Clinical Care for Adults with Diabetes

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

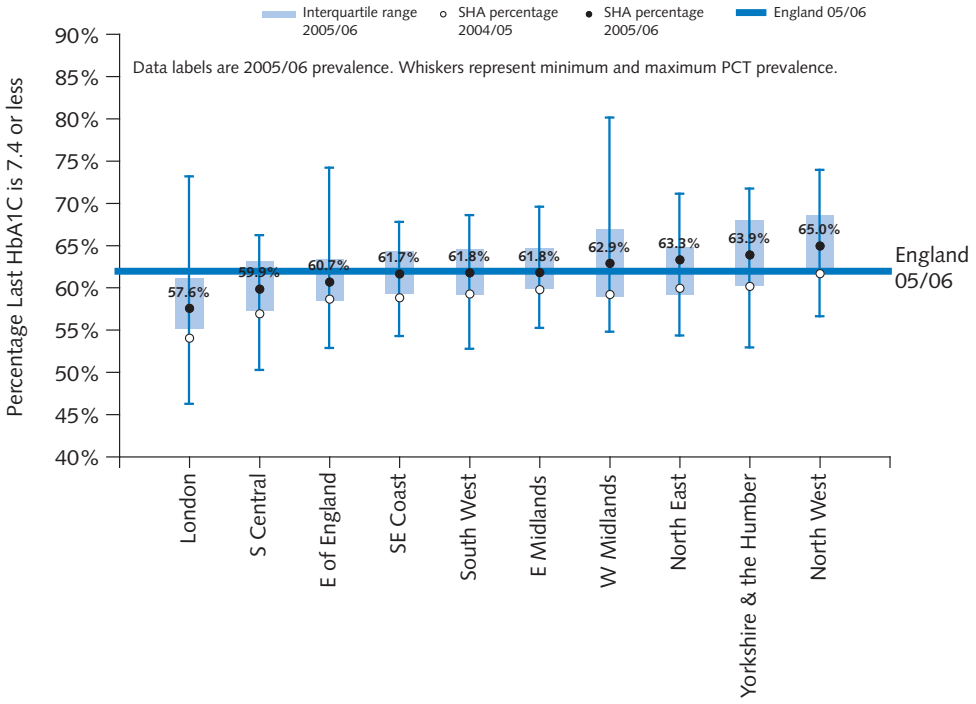
The Quality and Outcomes Framework (QOF) has been a success in identifying and recording a wide range of indicators of the routine processes and outcomes for people with diabetes. It has also demonstrated considerable improvement in the care that people with diabetes are receiving.

The Yorkshire and Humber Public Health Observatory has produced an analysis of what the QOF data means for diabetes. Apart from the increase in diagnosed prevalence from 3.5% to 3.6%, an additional 100,000 diagnosed, the analysis provides much more detailed information about the other indicators. It can be seen at:
http://www.yhpho.org.uk/viewResource.aspx?id=721

Services can benchmark their diabetes care through three indicators: HbA1C (a measure of glucose control), blood pressure, and cholesterol levels. Figs 10 to 12 demonstrate, for each of these clinical areas:

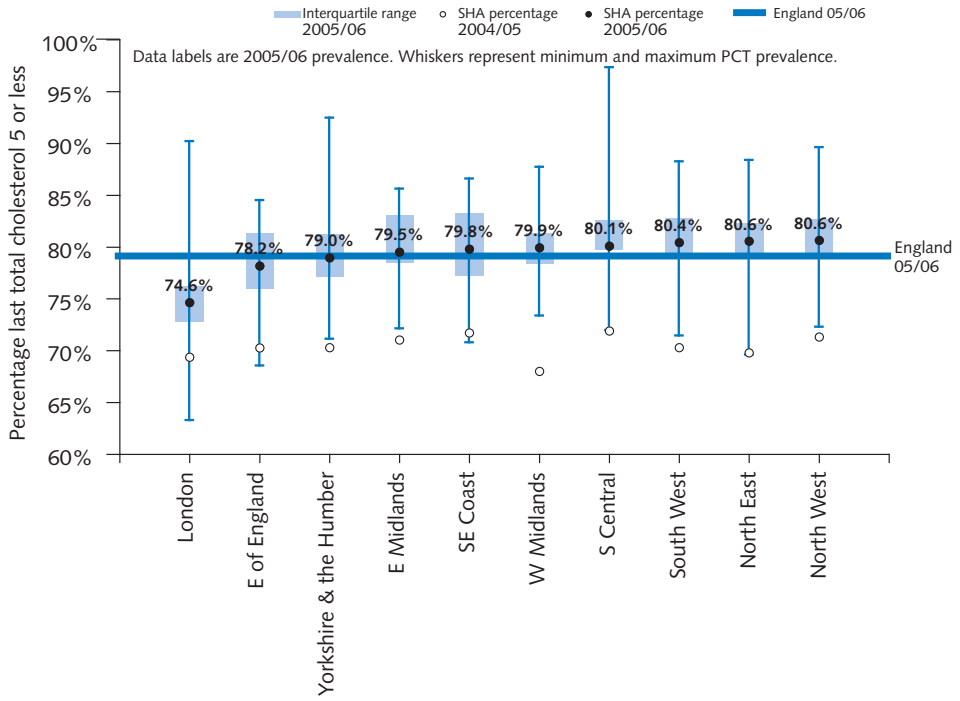
- The difference between each strategic health authority
- The improvement within each strategic health authority, shown by the filled and unfilled circles, between 2004/5 and 2005/6
- The variation amongst PCTs within each SHA. A long line through the circles shows a large variation, and a short line shows a small variation

Fig 10. Percentage of GP registered population diagnosed whose last HbA1c was 7.4 or less, by SHA 2004/05 and 2005/06



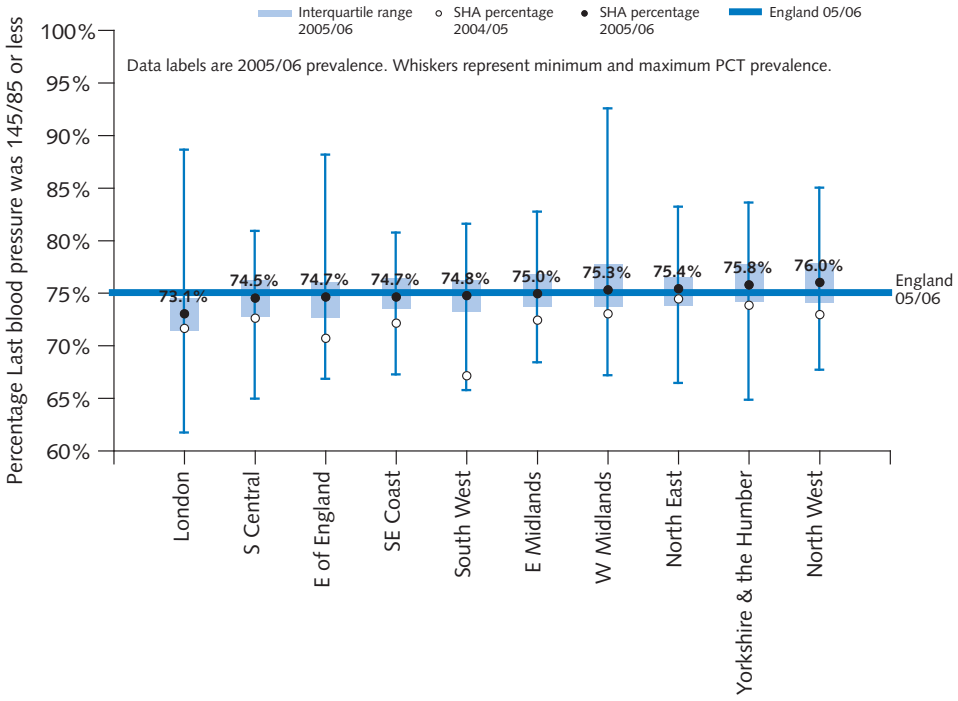
Source: HSCIC, CFID (using Quality & Outcomes Framework data)

Fig 11. Percentage of GP registered population diagnosed whose last blood pressure was 145/85 or less, by SHA 2004/05 and 2005/06



Source: HSCIC, CFID (using Quality & Outcomes Framework data)

Fig 12. Percentage of GP registered population diagnosed whose last measured total cholesterol within previous 15 months was 5 or less, by SHA, 2004/05 and 2005/06



Source: HSCIC, CFID (using Quality & Outcomes Framework data)

There have been improvements over the last year but there remains a lot to do. It is significant, for example, that within each SHA there are differences between the primary care trusts which need to be addressed. The focus now needs to be on the 20-40% of people who are not achieving good results and who could be at a higher risk of complications in future years.

Fig 13. Achievement against QOF indicators

	Measuring	Improving Outcomes
QOF Indicator	Achieved	Achieved
HbA1c	97%	62%
Blood Pressure	98%	75%
Cholesterol	95%	79%

Source: 2005/6 QOF data

Fig 13 shows that measurement of these key indicators is excellent[13], but that there is still work to do on improving outcomes. There needs to be a greater focus on ensuring that people with diabetes are encouraged to develop the skills, knowledge and above all motivation to improve their care in partnership with professionals.

13 It is recognised that a small but variable number of people are excluded by practices as part of their contract.

What is particularly encouraging is the increasing recognition that services need to be tailored to the needs of the patient, and that the individual circumstances of different communities and groups must be properly addressed if effective diabetes care is to be provided. The one-size-fits all model is still in existence but is becoming increasingly rare.

Making sure that people understand their condition and the medicines they are taking to control it is a big part of delivering effective clinical care. Recent research outlined in *The Diabetes Information Jigsaw*[14] revealed that there are still some gaps in understanding:

- More than a third of people do not know they will have the condition for life
- Half don't know it can reduce life expectancy
- 32% don't realise heart disease is a common complication
- 18% don't realise poor management could result in amputations
- 60% of pregnant women with diabetes do not realise that poor control could result in stillbirth or a baby with congenital malformation

A lack of knowledge about diabetes can also result in poor medicine concordance. The report found that:

- 65% of people do not take their medication as prescribed
- A third do not understand what their medicines are for or how to take them
- 57% don't ask questions in consultations because they feel there is not enough time
- 25% don't understand what their medicines are for even after asking, as they don't think the nurse or doctor sees a benefit in telling them.

The report concludes that because of this failure to both understand the impact of diabetes and adhere to medicine regimes, one in five people are suffering from preventable complications.

14 Association of the British Pharmaceutical Industry (ABPI), Diabetes UK and Ask About Medicines, 2006, The Diabetes Information Jigsaw Report

Case study 8 – Medicines Management for Minority Communities

People with diabetes who do not speak English have been involved in a new project in Gloucester to improve knowledge of their medication. A Diabetes Specialist Nurse (DSN) has been employed to lead the medicines management project in Barton, Tredworth and White City.

All patients with diabetes who do not speak English from one practice were identified and invited to clinics. The clinics were single-sex to cater for the cultural needs of some of the patients. Two Gujurati clinics and one Bengali clinic were held, supported by translators and a Hindi-speaking GP, Shanta Nair.

Each patient was encouraged to bring all their medicines with them and each one was reviewed in turn. The patient wrote down the name of the drug, what it was used for and when to take it, in their own language. The English name was also written, to encourage patients to compare this name to the one on each box of tablets. A copy of this sheet was then scanned into the patient's records for future reference.

DSN Suzy Allard said: "A lot of the patients came in with carrier bags with lots of boxes in. Often they'd have four different boxes, each with the same medication in."

She added: "The clinics were very well received. I have seen patients since with the sheet and they now know what their medications are for."

For more information, contact Suzy Allard on: suzy.allard@glos.nhs.uk

Case study 9 – Rapid-Access Clinic

A Diabetes Nurse Practitioner-Led Rapid Access Clinic has been set up by Brent PCT as part of the Integrated Diabetes Pathway. The aim is to improve care for people with diabetes in the area.

In each locality of the PCT, a diabetes nurse practitioner runs a clinic, working closely with the consultant physician. GPs can also telephone their local consultant with any specific queries.

Patients do not need an appointment and are referred for:

- Blood glucose stabilisation
- Frequent hypos and/or hyperglycaemia
- Titration of anti-hyperglycaemics, including insulin
- Difficulty with insulin delivery devices and blood glucose meters

The clinic was set up because patients were waiting a long time for specialist clinic appointments and often simply needed reassurance they were doing the right thing. There were frequently minor concerns about pens and blood glucose meters that could not be answered at the GP surgery. The clinic is in the early stages of development at the moment but is already quite popular.

Lead Diabetes Nurse Practitioner Nina Patel said: "This service has proven very successful. We are finding that as GPs get to know of the service they are sending patients to these clinics. Sometimes patients are willing to travel some distance if they can be seen on a particular day. For example, someone living in Kilburn is happy to go to Wembley clinic if they can be seen that day."

For more information contact Nina Patel: nina.patel@brentpct.nhs.uk

Case study 10 – Increasing Capacity in Secondary Care

A collaborative, practice-based diabetes clinic has been set up by Adur, Arun and Worthing Primary Care Trust (PCT), involving a practice nurse and a Diabetes Specialist Nurse.

Patients with Type 2 diabetes are seen by the practice nurse and a diabetes specialist nurse as part of a shared approach. Medication is reviewed and if necessary altered. Lifestyle counselling is also given. This means that more patients, who wouldn't necessarily be referred to secondary care, can receive specialist care in the community.

Consultant Nurse, Sara Da Costa said: "The principles of this service redesign are improving earlier access and care for patients, and increasing clinician skills in diabetes management in primary care."

There are currently three DSNs employed by Adur, Arun & Worthing teaching PCT, working alongside practice nurses in 31 of the 32 practices. The clinic means that patients are seen by specialists earlier than usual, resulting in more treatment options and potentially improved outcomes. An audit of these clinics has revealed that of the HbA1Cs that have been repeated, 85% have fallen.

Practice nurses have reported they are developing their diabetes knowledge and skills through the clinics, and patients enjoy having continuity of location and care staff.

Sara said: "These clinics have increased capacity in secondary care, which we have used to increase our phone triage and provide assessment and discharge planning on our admissions ward. The former has reduced attendances to Accident and Emergency, and the latter has reduced length of stay. It's had a huge impact."

For more information contact Sara Da Costa on: 01903 205111 or email: sara.da-costa@wash.nhs.uk

Reducing variation in the use of Insulin Pumps

It is important that treatment for diabetes fits the patient, and there are alternatives to the standard insulin delivery methods. Alternative diabetes treatments are available for Type 1 diabetes, including Continuous Subcutaneous Insulin Infusion (CSII), better known as pump therapy. NICE published guidance on the use of CSII in 2003, but there is great variation in uptake of this. The joint Department of Health/Diabetes UK Insulin Pumps Working Group is simultaneously publishing a report[15] outlining what needs to be done to address this, featuring a range of practical suggestions and information about delivering a CSII service. It includes information on commissioning and providing services as part of a comprehensive diabetes service for adults and children, how to obtain supplies and what needs to be done to improve education and training.

15 Insulin Pump Services: Report of the Insulin Pumps Working Group, DH, March 07

6 Clinical Care of children and young people with diabetes

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

Standard 6: All young people with diabetes will experience a smooth transition of care from paediatric diabetes services 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.

Although there is much focus on the growth of Type 2 diabetes amongst adults, there is also a significant increase in the number of children and young people diagnosed with Type 1 and other variants of diabetes. In the UK, we have the highest number of children diagnosed with diabetes in Europe, and still have a way to go to increase the number of children attaining good diabetes control.

Diabetes has a significant medical impact on children and young people. Of those with Type 1 diabetes, some 30-40 per cent will develop microalbuminuria, leakage of small amounts of a protein, albumin, into the urine, which is an early warning of kidney damage. 25 per cent or more may require laser treatment for retinopathy, a disease of the retina that is usually caused by diabetes. Diabetes can also have implications for other areas of their activities and development, such as school attendance and full involvement in extra-curricular activities such as trips and sports. There can also be consequences for social and family life as well as overall psychological wellbeing.

Despite some excellent examples of local progress, services for children with diabetes and their families are still well below standard in many areas. The Department of Health is committed to addressing this, and set up a joint working group with Diabetes UK to examine the issues for children and young people and outline what needs to be done to improve their care. This work has now been completed, and the forthcoming report of its work will clarify the standards that need to be met, and make suggestions for key outcomes to support quality commissioning and provision. This report also provides a substantial policy context, placing diabetes care within a holistic approach to improving the social and health outcomes for children and young people.

Case study 11 – Child-led Consultations

Since 2003, diabetes services for children in Dartford and Gravesham have been streamlined and, as a result, outcomes for young people are improving. The service, based at Darent Valley Hospital, brings an holistic approach to caring for children with diabetes.

There are three main clinics:

- Weekly consultant-led multi-disciplinary "one stop" clinic
- Monthly nurse-led, consultant supervised, multidisciplinary annual review clinic
- Three-monthly transition clinic.

Paediatric Diabetes Consultant Dr Alok Gupta said: "The multi-professional clinics are a one-stop shop so you get the complete package in one go and uniform advice. You don't have to go from one room to another getting conflicting advice."

A key part of the weekly clinics is the set-up of the appointments. It is very informal, with the child choosing where they sit. The consultation is then led by the child. Diabetes is not mentioned until the child talks about it. The children can also keep in touch with Dr Gupta by text, email and phone.

Through this approach, an improvement in outcomes has been achieved year-on-year.

For more information visit:
http://www.dvh.nhs.uk/page.asp?node=565&sec=Children_and_young_people

Contact Dr Gupta via the Children Diabetes Team secretary Julie Hudson:
julie.hudson@dag-tr.sthames.nhs.uk

The needs of children and young people with diabetes are a complex mix of clinical care, social support and psychological engagement. Their care is not just a case of adult care writ small. There are good examples where the specific needs of children and their parents or carers are being identified and catered for. Diabetes UK research confirms that 95% of children and young people have access to specialist help between clinics, with nurses playing the biggest part in delivering this care.

Case study 12 – Making the Child the Boss

A paediatric diabetes clinic in Guildford is putting children in charge of their diabetes right from the start.

The clinic, based at the Royal Surrey County Hospital, is run by a consultant paediatrician with a special interest in diabetes and a paediatric Diabetes Specialist Nurse, Nicola Ward.

At diagnosis each child is brought into the hospital for a day – and overnight if they wish. Every child is offered a choice between multiple daily injection therapy and twice daily insulin. Nicola tells them about the different types of treatment.

She said: "When you give them a choice they run with it better and respect you for respecting them. I make the child the 'boss' right from the day of diagnosis with the aim of empowering them to be the 'boss' of their diabetes."

Children are regularly visited at home between clinic appointments. The result of this is improved HbA1c levels anecdotally.

The clinic also provides a 24 hour helpline, so worried parents/children can get in touch.

For more information, contact: Nicola.ward@royalsurrey.nhs.uk

Case study 13 – Information for Teenagers

A booklet written by people with Type 1 diabetes for teenagers newly diagnosed with the condition has been produced by East Suffolk Diabetes User Group.

The booklet is separated into three sections:

- **What is Type 1 diabetes and how do I manage it?** This covers diagnosis, prevention, complications and hypos.
- **Can I still lead a normal life?** This covers activities and lifestyle, including sex, alcohol, smoking, holidays and diet and sport as well as driving, pregnancy and depression.
- **Useful contacts and information:** This covers clinic attendances, unused medicines, needles and sharps, useful websites, glossary, useful contacts and simple advice for keeping in control

The booklet is written in the style of a magazine, presented clearly with pictures and quotes from people with diabetes. It was developed by a group of people of all ages and backgrounds with diabetes.

User Group Chair Geraldine Tipping said: "A school found the information very helpful when taking a pupil with Type 1 diabetes on a school trip, and similarly a Brownie Group was grateful for information. A colleague and I held a display at the town hall which was open to the public and we had an enormous response."

All GP practices have been sent copies of the booklet and it is also being used at the James Padget Hospital in Great Yarmouth.

For more information contact: Geraldine.tipping@arch.suffolkcc.gov.uk

Transition

Moving between children's and adults' services can still be difficult, but there have been major attempts to address this. The Department of Health/Diabetes UK joint working group will be looking at this issue, and in the meantime there are many good examples of good practice.

Case study 14 – Transition from Children's to Adult Care

Transition from paediatric to adult care in Salford is being catered for by a Young Persons Diabetes Team (YPDT). The team offers a One Stop Shop approach, enabling young people with diabetes to access services under one roof at one appointment.

The service, aimed at 16–25 year-olds, is delivered by a multi-disciplinary team made up of:

- Consultant diabetologist
- Adult Diabetes Specialist Nurse (DSN)
- Paediatric DSN
- Dietician
- Podiatrist
- Healthcare assistant

Involving both paediatric and adult staff means that youngsters transferring into or out of the YPDT retain some continuity in the staff they see. The clinic is held in the evening, resulting in high attendance rates.

The team at Salford believe that young people with diabetes should be seen as a separate group to adults, as evidence indicates that the incidence of adverse events is higher in this age group. A survey of young people who had transferred to the YPDT indicated it works well.

A leaflet called *'Moving On'* highlights what young people can expect from adult services when they transfer at 25 years old.

Paediatric DSN Sue Greenhalgh said: "Overall the young person's service and our transition arrangements run well. However, we are constantly reviewing our practice and trying to find ways of improving the service."

For more information contact: Sue.Greenhalgh@CMMC.nhs.uk

7 Managing diabetic emergencies and care of people with diabetes in hospital

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.

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.

Certain groups are more likely to need specialist intervention – in particular children and young people, pregnant women, newly diagnosed people with Type 1 and those with a genetic variant of diabetes. In many circumstances this will be planned and may or may not be delivered within a hospital. Despite the focus on self-management, however, some will still have episodes requiring specialist care that can only be delivered in a hospital. In addition to planned inpatient care, some people with diabetes access emergency care on a more frequent basis. This might mean more visits to accident and emergency departments or more calls upon the ambulance services.

Case study 15 – Researching diabetes ambulance callouts

The East Anglia Ambulance Trust (EAAT) carried out some research on the extent to which people with diabetes used their services. They found that 65% of users had used the service more than once and that 48% had done so within the previous 12 months. Preventing the repeat call has the potential to prevent up to 1,500 calls to the emergency services per year in East Anglia.

The study suggests that many patients with diabetes are either not receiving or not retaining the education they require and are not able to sufficiently control their diabetes or self treat when suffering a diabetic attack. The survey reported that 54.9% of respondents stated they had not received any specific hypoglycaemia education in the last year.

Annual responses made by the East Anglia Ambulance Trust (EAAT) to patients suffering from a diabetic emergency

EAAT calls	Emergency response proportion	Estimated monthly responses by EAAT	Total estimated annual response by EAAT	Estimated number of out of hours responses
Hypoglycaemia	85%	173	2078	97+
Hyperglycaemia	15%	61	731	42+
Total diabetic emergencies		**234**	**2809**	**583**

The EAAT study found that:

- 85% of responses to diabetic emergencies are for hypoglycaemic attacks
- 51% of the respondents were responsible for 78% of the emergency calls
- 56% of respondents have good warning signs of low blood sugar
- 28% of respondents did not know the cause of their attack
- 80% of respondents had had diabetes for over 10 years
- 55% of respondents stated they had not received specific hypoglycaemia education within the last year.
- Two-thirds of patients are treated at home by the ambulance service
- 65% were repeat callers, 48% calling more than once within the last year
- On 60% of occasions the patient's GP was informed
- On 20% of occasions patients could not remember a copy of any documentation being left with them when the ambulance crew left

Case study 15 – Researching diabetes ambulance callouts (cont)

Steve Mortley, Project Manager, said "As a result of this research we decided to appoint a nurse to do some follow up contacts and that has seen some real reductions in the number of calls from people with diabetes. I am sure that there are important lessons to be learnt from this initiative."

For more information contact: steve.mortley@eastamb.nhs.uk

People with diabetes have a disproportionate impact on NHS specialist and emergency services because of the complex nature of their condition and the associated complications, from heart and renal disease to foot ulcers. The resources needed to provide the multi-skilled and multi-disciplinary teams to tackle such complexities are considerable.

The way that the workforce and other resources are organised is central to the care that people with diabetes receive. Local networks that develop robust models of care and joined up care pathways are a key element of this. Integrated care pathways have recently been studied in conjunction with admissions due to diabetic ketoacidosis (DKA). The research found that the introduction of integrated care pathways can reduce DKA admissions and improve the management of diabetes[16].

..nothing could quite match up to the nurse I had when recovering from ankle surgery who refused to give me glucose powder dissolved in water when I had a low blood sugar because "you're diabetic and sugar is bad for you"…

…Without having my own alarm clock to wake me up to test, I was also dependent on them for that. It is what I really hate about being in hospital – feeling so disempowered….

…I woke with a pounding headache at 6.30am and checked the blood glucose log sheet to find that no tests had been done. A quick test with my own meter revealed 2.1…..

…relying on hospital staff to test my blood sugar frequently made me feel uneasy..

16 Waller, S., Delaney, S., Strachan, MW., 2007, Does an Integrated Care Pathway enhance the management of diabetic ketoacidosis? Diabetic Medicine 2007 Feb 12

For many people with diabetes the care they receive in hospital and from the ambulance services is second to none, but this is not always the case. There is evidence of people who have successfully self managed their condition for years having their medication taken away from them, who have not been allowed to eat when they wanted to avoid a hypoglycaemic event, who have been in hospital for one condition with their diabetes not recognised, or being undiagnosed before they went into hospital and leaving the same way. The quotes on the previous page are some examples of the experiences of people with diabetes in hospital.

Approximately 10 per cent of hospital budgets are spent on the care of people with diabetes. Improving the care they receive, in particular reducing both admissions and length of stay, therefore has real potential to enhance the lives of patients and save valuable resources.

Case study 16 – Reducing Emergency DKA Admissions

Diabetes staff in Cornwall are working in conjunction with a pharmaceutical company to reduce hospital admissions due to Diabetic Ketoacidosis (DKA).

DKA places a large financial burden on the NHS in terms of hospital admissions, but most cases are preventable by better management or earlier diagnosis. In Cornwall, blood ketone testing is now being used with the aim of improving the care of people with diabetes, reducing hospital episodes and freeing up financial resources.

In the initial pilot in a small area of Cornwall, people with diabetes who had a history of DKA and recurring hospital admissions were given a dual glucose and ketone testing meter. They were also given a personalised traffic light system protocol, giving advice about what to do if ketones are raised. This system is drawn up with a Diabetes Specialist Nurse (DSN), giving specific doses of insulin to take, relating to the test result.

The service, now being rolled out across the county, has reduced DKA hospital admissions among this high risk group in the pilot area.

Lead Diabetes Nurse Caroline Kysh said: "It's about improving patient care and empowerment as well as recurring hospital admissions."

The project is being run in conjunction with pharmaceutical company Abbott, whose role is to provide the meters and educational support material and services for clinicians and patients.

For more information contact: caroline.kysh@rcht.cornwall.nhs

Case study 17 – Hospital Admission Management Database

A new database at Bristol Royal Infirmary is supporting improvement in the care of inpatients with diabetes-related foot complications. Set up by the podiatry department, the database means that when a patient is admitted to the hospital, for any reason, the podiatry department will receive an email.

The system was set up because people were being admitted for reasons other than their foot complications, missing their podiatry appointments and getting lost in the system.

Podiatrist Edyth Dougan said: "The system gives us the opportunity not only to follow these patients up, but to alert staff on the wards to the foot care needs."

The success of the system has led to it being expanded to include the Diabetes Nurse Specialist team's patients.

For more information contact Edyth Dougan: Edyth.dougan@ubht.nhs.uk

8 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.

The St Vincent Declaration, agreed in 1989 and adopted by the UK and other European governments, was an agreement to work to improve the prevention, identification and treatment of diabetes. It set out a number of aspirations for improving diabetes care, one of which specifically addressed the needs of women with diabetes who become pregnant. The aim was to:

Achieve a pregnancy outcome for women with diabetes that equates with that of women without diabetes.

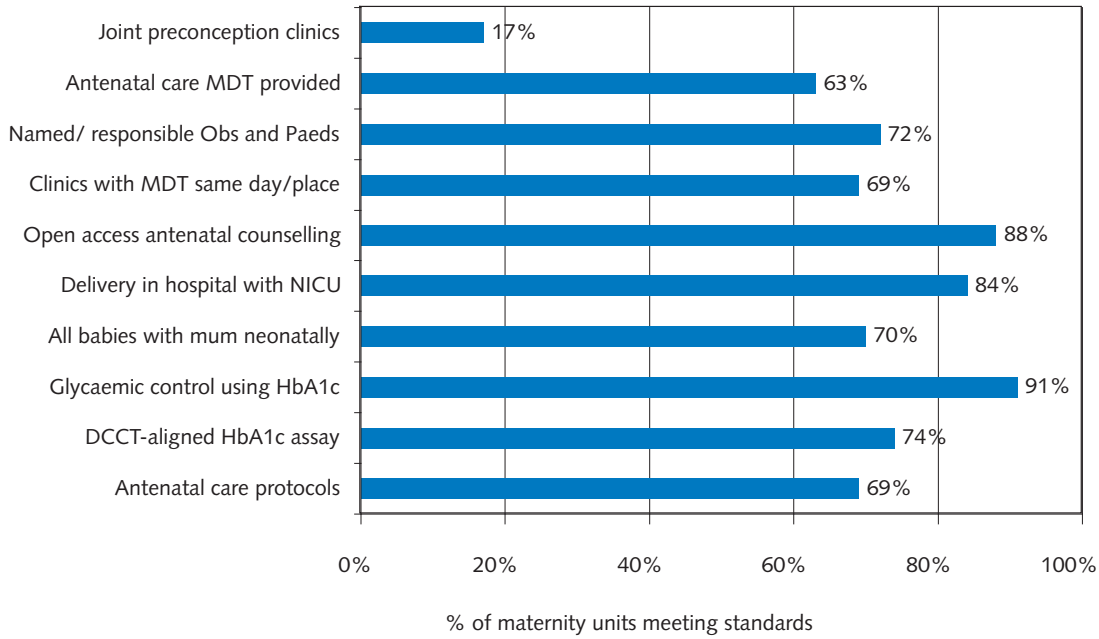
The latest research by the Confidential Enquiry into Maternal and Child Health (CEMACH) confirms that there is still some way to go before such an aspiration is reached.

CEMACH Programme 2002–2007 [17]

- Babies of women with diabetes are
  - Five times as likely to be stillborn
  - Three times as likely to die in their first months of life
  - Twice as likely to have a major congenital anomaly
- Nearly 1 in 3 mothers with diabetes have Type 2 Diabetes
- Two thirds of women with diabetes are separated unnecessarily from their babies at birth

17 www.cemach.org.uk

Fig 14. Percentage of maternity services meeting standards



Source: Confidential Enquiry into Maternal and Child Health (RCOG, 2004). Data from 213 maternity units.

Fig 14 shows how many maternity units are meeting standards for women with diabetes. Although the data is encouraging in some areas, clearly there is room for improvement in others. It is also important to note that the outcomes for women with Type 2 diabetes are very much the same as for Type 1, and an increasing number of women of child bearing age are being diagnosed with Type 2 diabetes. When coupled with evidence that women from communities more likely to get diabetes often have larger families, this demonstrates how important it is for maternity and diabetes services to be able to respond to the needs of women with diabetes.

Case study 18 – A Multi-Disciplinary Approach to Pregnancy

Outcomes for pregnant women with diabetes are improving in Norfolk thanks to a hardworking multi-disciplinary team.

The Norfolk and Norwich University Hospital Diabetes in Pregnancy Team consists of:

- Diabetes specialist midwife
- Named Diabetes Specialist Nurse (DSN) for Pregnancy
- Diabetes Consultant with additional consultant support on alternate weeks
- Obstetric consultant
- Specialised dietetic support

Pre-pregnancy care is delivered at the diabetes centre with 4-6-weekly appointments with a diabetes specialist nurse and 3-4-monthly doctor appointments. Women can also see the specialist midwife at this stage.

Consultant Rosemary Temple said: "To achieve a good outcome, it is essential women are well prepared for pregnancy with best possible glucose levels at time of conception and in the first few weeks of pregnancy."

In 2004/5, 71% of women with Type 1 diabetes received formal pre-pregnancy care compared with 38% nationally. In that time 79% of women with Type 1 diabetes attending the antenatal clinic had HbA1c ≤7.5% at booking, with 56% at ≤7%. By 12 weeks gestation, 72% of women had HbA1c ≤7%, compared to 35% nationally.

There is a weekly combined clinic with an emphasis on teamwork, in particular with high risk patients who have not achieved tight glycaemic control and women with diabetic complications. Women also have contact numbers for the DSN and midwife.

Between 2002 and 2004, admissions to the Neonatal Intensive Care Unit (NICU) have dropped from 48% to 15%.

For more information contact Rosemary Temple:
rosemary.temple@nnuh.nhs.uk

9 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 long term complications of diabetes, if it is not well managed, can be devastating. The risks of heart disease, stroke, kidney failure, blindness and amputation are much increased by having diabetes.

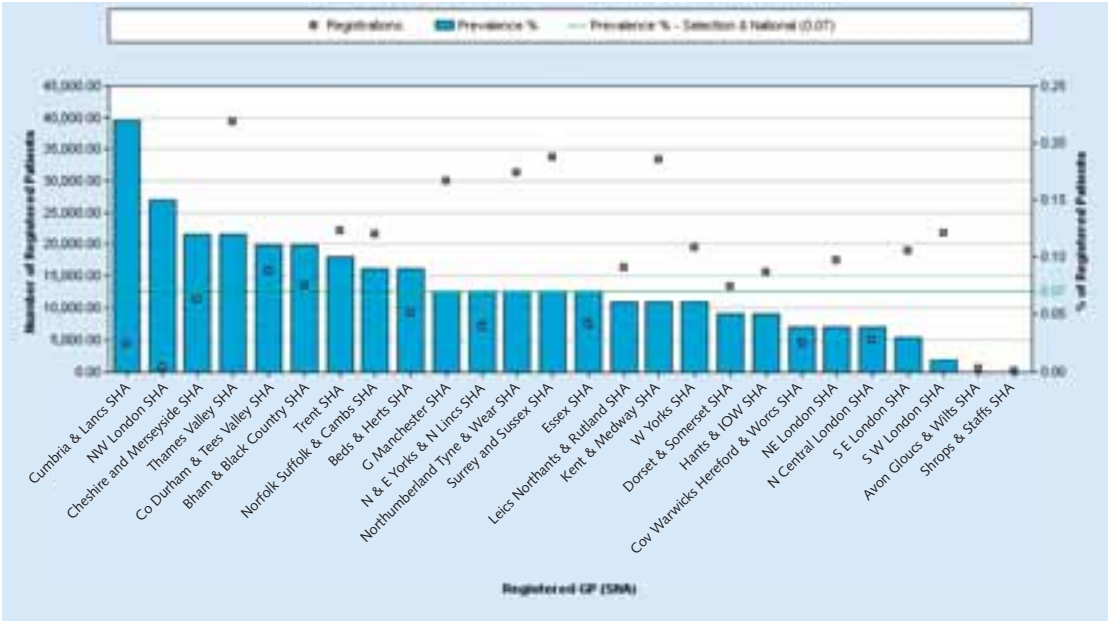
- Adults with diabetes have heart disease death rates about two to four times higher than adults without diabetes
- The risk for stroke is two to four times higher among people with diabetes
- Diabetes is the single largest cause of blindness in people of working age
- Diabetes is the most common cause of non-traumatic lower limb amputation
- Impotence may affect up to 50 per cent of men with longstanding diabetes
- Diabetes has become the single most common cause of end stage renal disease
- 24 per cent of people admitted to hospital with Myocardial Infarction (MI) have diabetes – and their outcomes are much worse than those without diabetes
- Hospital lengths of stay for people with diabetes are 20 per cent higher than for those without diabetes – systematic care in hospital can reduce this by half

Early diagnosis and regular, effective monitoring and self-management can do much to delay if not prevent many of these complications.

Coronary Heart Disease is one of the most significant complications of diabetes, and improving the outcomes for people with diabetes who have Acute Coronary Syndromes (ACS) is vitally important. Research associated with the Myocardial Infarction National Audit programme (MINAP) has shown that treatment with diabetic medication was associated with a lower early mortality for patients with ACS presenting with blood glucose > 11 mmol. As these patients are likely to have diabetes it suggests that all patients presenting with this blood glucose level, whether diagnosed as having diabetes or not, should receive immediate diabetes appropriate treatment.

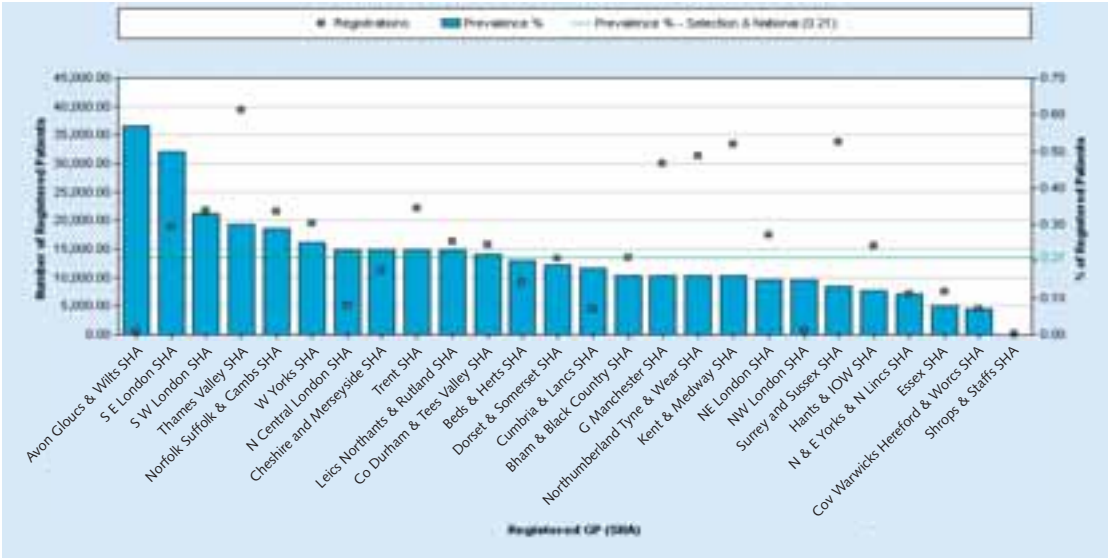
The prevalence of different diabetes-related complications still varies significantly between strategic health authorities, as shown by the National Diabetes Audit 2004/5. Figs 15 to 17 show prevalence of major amputations, renal failure and myocardial infarction. (Note that some of the variation will be as a result of selective data collection and reporting, as the figures in the graphs are based on the data received by the National Diabetes Audit).

Fig 15. Major amputation prevalence per SHA (old boundaries)



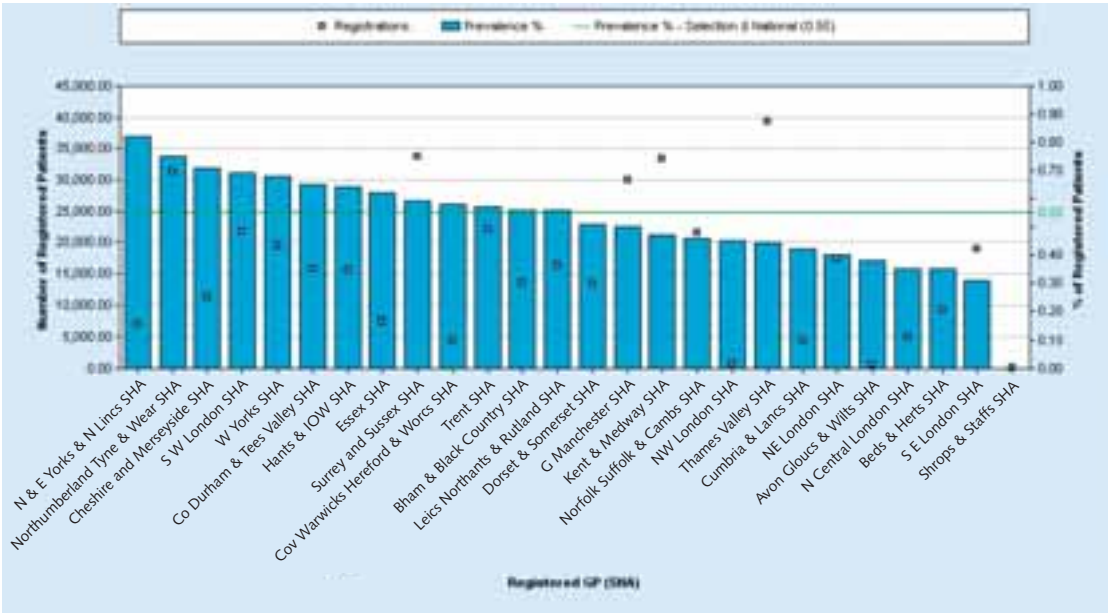
Source: National Diabetes Audit 2004/5.

Fig 16. Renal failure prevalence per SHA (old boundaries)



Source: National Diabetes Audit 2004/5.

Fig 17. Myocardial Infarction prevalence per SHA (old boundaries)



Source: National Diabetes Audit 2004/5.

Case study 19 – Using Software to Highlight Complications

Dorset PCT is developing a new piece of software that links to the GP computer system and flags up people with or at risk of cardiovascular disease and diabetes.

The programme uses existing practice data to highlight people and stratifies them according to their cardiovascular risk. Where data is missing it substitutes the Health Survey national population statistics. Those at high risk, including people with diabetes, can then seen by a practice nurse for further assessment and proactive management.

At the moment, three practices in Dorset are involved in the pilot, totalling 10,000 patients.

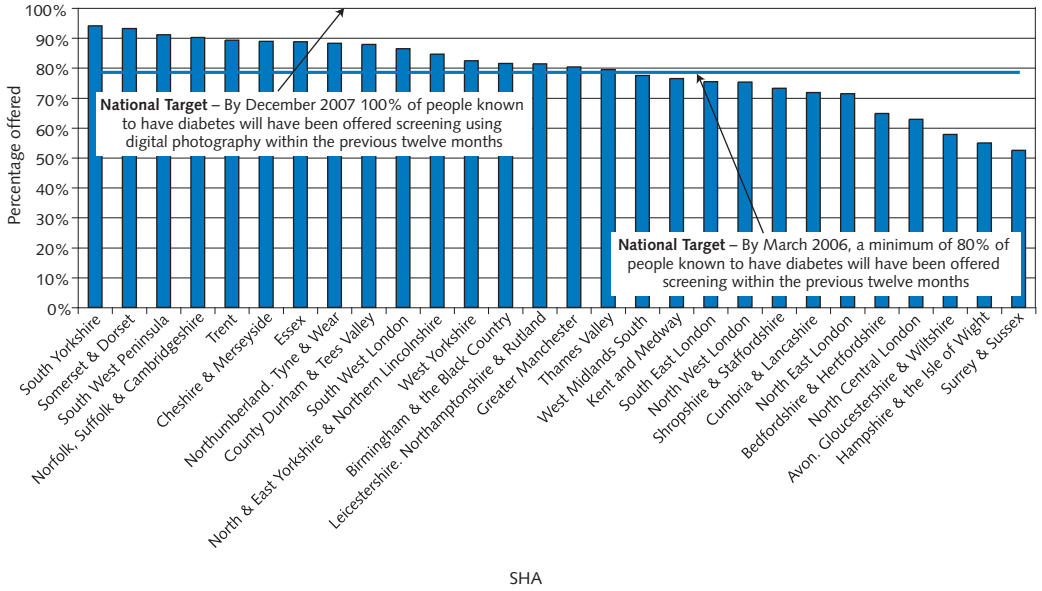
Specialist Diabetes Nurse Peta Fenn said: "The next step is to develop computerised diabetes and primary prevention cardiovascular disease care pathways to link to the software, as my colleague Sharon Ford has done for the secondary prevention of coronary heart disease."

For more information contact: peta.fenn@dorset-pct.nhs.uk

Eye complications

Within 20 years of diagnosis nearly all patients with Type 1 and around 60 per cent of those with Type 2 diabetes have some degree of retinopathy. By April 2006, the 78.4% of people with diabetes had been offered retinopathy eye screening, very nearly achieving the 80% goal set out in the Diabetes NSF Delivery Strategy. This is an real achievement, particularly since more than 400,000 more people have been diagnosed with diabetes since the aim was first established.

Fig 18. Percentage of people with diabetes offered retinopathy screening 2005/06 (by old SHA boundaries)



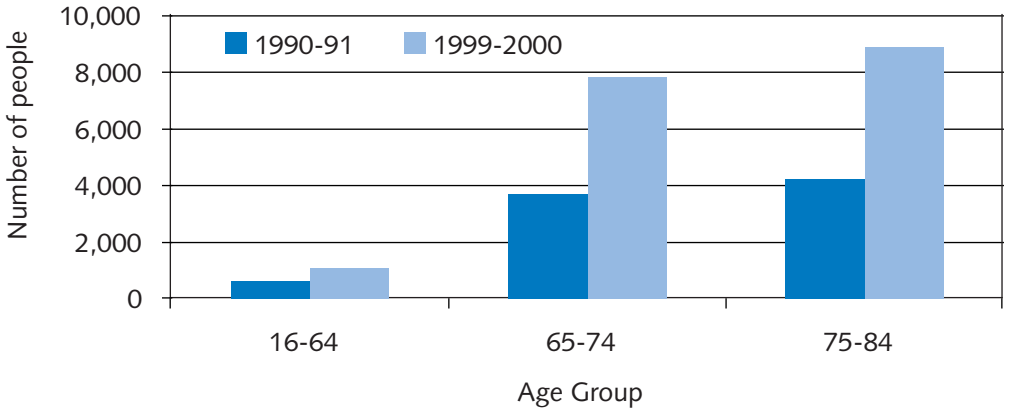
Source: Local Delivery Plans 2005/6.

There is still more to do, however, as fig 18 above shows that there is still tremendous variation across the country in the delivery of retinopathy screening.

Previous research[18] has confirmed that diabetes is still the most common cause of blindness in working age people – and nearly doubled between 1990/91 and 1999/2000 (shown in fig 19). These figures, collected before the introduction of the National Screening Programme, reflect the increased prevalence of diabetes and also show the potential cost to the service as well as the people involved.

18 Bunce, C., Wormald, R., 2006, Leading causes of certification for blindness and partial sight in England and Wales, in BMC Public Health 2006, 6:58

Fig 19. Increase in blindness registration among people with diabetes in England and Wales prior to the National Screening Programme.



Source: Bunce, C., Wormald, R. (2006), Leading causes of certification for blindness and partial sight in England and Wales, in BMC Public Health 2006, 6:58.

Case study 20 – Retinal Screening in Nottingham

Nottingham Diabetic Retinopathy Service (DRS) was established in September 2006 and now provides a community-based digital photographic service. The DRS uses six screening sites to provide 1,900 screening appointments per month for a diabetes population of 24,000. There is currently no waiting list for screening, grading or treatment.

There is a central call and recall system to manage the delivery of screening area by area, using Primary Care Trust (PCT) data. Patients and primary care teams can be notified by letter and telephone when appointments are missed.

Staff providing photographic screening and slit lamp examinations use notebook computers to manage workflow and information. This enables flexibility and ensures the service is mobile. It also means patients can view the images when they are captured.

If a patient needs to be referred to a consultant ophthalmologist he or she is booked directly into the dedicated weekly clinic. Urgent cases can be dealt with within days of photography.

The DRS is progressing well, but there are still plans for the future.

Dr Tasso Gazis said: "The future will bring refinement of the grading process as staff gain more experience and old images become available for comparison. We also plan to use secure e-mail to reduce the cost and improve the speed of information delivery to Primary Care teams."

For more information visit: www.nottinghamretinopathy.co.uk

Services for older people

As diabetes is such a complex condition, the role of multi-disciplinary teams in supporting and caring for patients is essential. By combining the skills, knowledge and experience of the many professionals involved in diabetes care and integrating that with the day-to-day experience of the person with diabetes, a holistic system of care can be developed.

A key part of meeting NSF standards is to establish systems to deliver care when and where people need it. For many this will mean a local practice or diabetes centre but for some, particularly older people, even this could be difficult. In order to improve the availability and standards of care, outreach systems need to be developed that recognise the needs and restrictions, either cultural or physical, of people accessing diabetes services.

Case study 21 – Educating Care Home Staff

Care home staff are being given the opportunity to learn about diabetes thanks to a project in Cumbria.

A nurse-educator and a dietitian have been working alongside residential and nursing care home staff to provide diabetes training. They developed the programme with the support of Cumbria-based diabetes health professionals, following an audit which highlighted the prevalence of diabetes in nursing and residential care homes in East Cumbria.

In the space of two years the training has been delivered to 50 nursing and residential care homes in the area. More than 300 members of staff have received certificates of attendance.

The course covered all aspects of diabetes care for managers, nurses, carers and catering staff, including:

- Hypoglycaemia
- Blood glucose monitoring
- Dietary issues

Each home was also given a file containing diabetes information along with a named diabetes link nurse who can offer induction training and support to new and existing staff.

Nurse Educator Diane Heeley-Creed said: "We felt that it was important to progress this work and we delivered training that was tailored to the needs of each individual home and its staff. We received an excellent response from the staff in residential and nursing homes in the area who were very committed to this project."

The project was awarded the Arun Baksi Award for Team Innovation in Diabetes Care at the 25th Isle of Wight Diabetes Conference.

Case study 22 – Better Care for Older People with Diabetes

Older people with diabetes are receiving a better standard of diabetes care in Sefton Primary Care Trust (PCT).

The diabetes community team developed a structured care process for those housebound or in care homes. The aim was to provide an at-home annual review, using the skills of the specialist diabetes team, district nurses and senior staff in care homes. Two Diabetes Nurse Practitioners (DNPs) were employed, whose objectives were:

- Identify all those diagnosed with diabetes that are housebound or in care homes
- Create awareness and understanding of the new DNP service
- Manage annual review for those identified
- Manage diabetes control and medication review to optimise treatment
- Manage early interventions in newly diagnosed
- Manage referral to, and liaison with, wider diabetes management team and other social support and health professionals
- Educate and support patients and their carers, including care home staff, to increase empowerment, satisfaction and quality of life
- Progress towards a wider nurse practitioner role

The result of this service is an increase in direct referrals to the DNP service, as well as improved diabetes skills and knowledge in care home staff.

In the first year of the service, HbA1c rates have improved, with 68% of the target population with a rate of 7.4% or less. All of them received an annual review, as opposed to just 58% before the service was set up.

For more information contact: koonlan.chan@seftonpct.nhs.uk

10 Supporting the Diabetes Community

As diabetes communities work locally to improve standards of care, the NHS is also changing. Historical patterns of commissioning and delivery are being replaced by a new culture where the independent and third sectors are valued partners in the NHS.

National Diabetes Support Team

The National Diabetes Support Team (NDST) has been a key player in this new way of working. It has worked with frontline staff to establish and improve networks, has developed a number of tools and guides for the diabetes community and ensured they are seen by as wide an audience as possible through its website, publications, conferences and other events. The NDST website has had more than 1.5 million hits in the past year with in excess of 100,000 reports and guides downloaded.

Support for commissioning

The way that services are commissioned is pivotal to improving diabetes care. The commissioning process should be grounded in a comprehensive needs assessment that takes into account all the elements that deliver effective care. This includes not just a broad brush analysis of prevalence based on factors such as age, gender, ethnicity and deprivation but also identifying specific factors such as pregnancy and genetic disorders such as Maturity-Onset Diabetes of the Young (MODY). Meeting these identified needs is likely to be a complex pattern of interdependent providers, with those providing day-to-day care working in partnership with specialist care. Guidance on how to commission effective, high quality services is available from the *Diabetes Commissioning Toolkit*, which can be found at:
http://www.diabetes.nhs.uk/downloads/commissioning_toolkit_diabetes.pdf

Diabetes Networks

The structure of the NHS itself is also evolving. Strategic Health Authorities and Primary Care Trusts are now fewer in number but are more broadly based and representative organisations. The NHS is also now looking at the way services are provided locally to ensure that people can access the right care. On the provider side we are seeing an increasing focus on larger, more specialised units that can offer a full range of the most advanced practices and technologies for when care needs to be delivered in a hospital setting. This is matched by the drive to deliver more community based services at the time and place that people want them. These changes mean that Diabetes Clinical Networks – a core element of planning diabetes care – could play an increasingly important role in supporting the commissioning of services.

Networks have the ability to bring together people from all elements of the multi-disciplinary support that people with diabetes might require, as well as the people who use the services. This provides them with a unique insight into what providers need to deliver. With the support of the NDST, networks have improved their range of activities and involvement, interacting with other service developments and improvement initiatives in the NHS. Five of them, for example, are involved in the Integrated Service Improvement Programme (ISIP) demonstrator sites, which are looking at how to develop more effective and efficient models of care.

Workforce

The reconfiguration of service delivery will require service providers to look at innovative ways of working, based around developing a new integrated skills base. Much work on identifying and working through new competences for diabetes healthcare professionals has already been done by Skills for Health and these are available at www.skillsforhealth.org.uk

Knowing what competences your workforce needs, however, is just a part of the planning process. It needs to be supported by systems which enable different configurations of staff and skills to be properly graded and costed. The NDST is developing the "Torbay Model", which supports the workforce planning process in just such a way, to enable it to be more widely used.

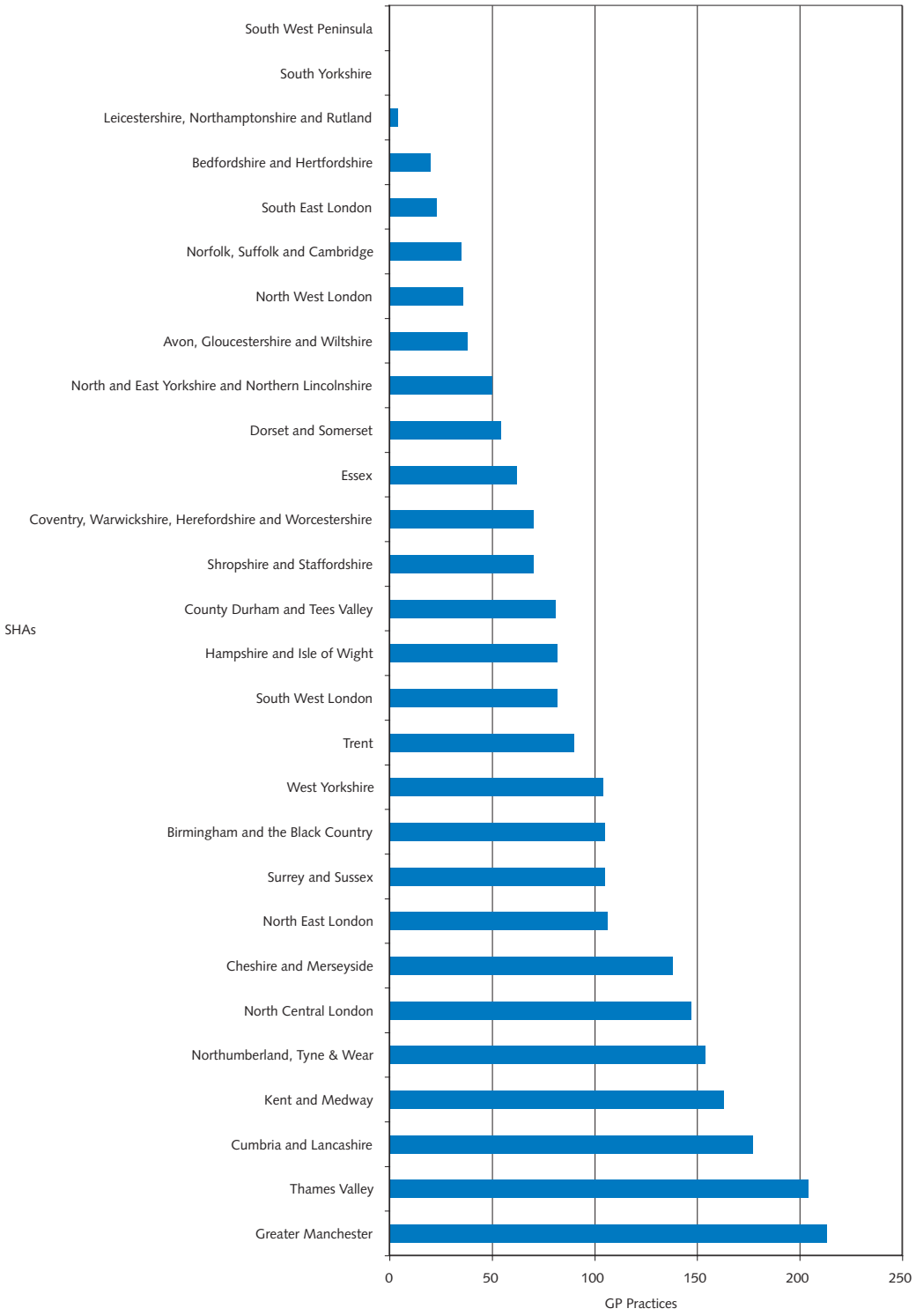
Information and audit

The amount of accurate information about diabetes services that is becoming available is increasingly useful for the diabetes community. Work by the NDST, Yorkshire and Humber Public Health Observatory, Healthcare Commission, National Diabetes Audit, Information Centre for Health and Social Care, Diabetes UK and the Diabetes Retinopathy Screening Programme is enabling commissioners, providers and users of services to examine in much greater detail than before what services are needed in a locality, what their performance is like and ultimately whether or not they are improving.
The available information now includes:

- *Key Facts*, which summarises much of the existing information on prevalence, diagnosis, financial and human costs of diabetes in England
- *Better Metrics*, which provides guidance on some straightforward measures that can be used to measure and benchmark local service improvement
- *National Diabetes Audit Annual Report*, which provides a detailed analysis on the state of diabetes services across a wide range of activities
- Quality and Outcomes Framework data, analysed specifically to extract the diabetes measurements both nationally, by SHA and by PCT
- Quarterly data on progress towards the diabetes retinopathy screening targets
- Diabetes prescribing costs and volume analysed by SHA

Fig 20 shows how many practices submitted data to the National Diabetes Audit in 2005/6 (using old SHA boundaries).

Fig 20. Number of practices that submitted data to the National Diabetes Audit in 2005/6 by SHA (old boundaries)



Source: National Diabetes Audit 2005/6.

Links with broader DH initiatives

Several policy initiatives support more broadly the themes of the Diabetes NSF and Delivery Strategy. Building on the principles of *Choosing Health* and *Our Health Our Care Our Say*, healthcare professionals working in diabetes have been actively progressing ways of delivering local, patient centred care. This has been supported by the development of Long Term Condition demonstrator sites by the Department of Health that will trial a new direction for community services by testing the benefits of integrated care supported by advanced assistive technology. The demonstrators will support individuals with longer-term and complex health and social care needs through the creation of multidisciplinary teams at PCT and local authority level. The teams will develop integrated care plans and, where appropriate, advanced assistive technology will be deployed in the home to support the provision of care.

Care Planning

Care Planning in Diabetes[19], a joint DH, Diabetes UK and NDST publication, explores the key role that effective patient engagement and consultation contributes to empowering patients and improving knowledge and self-management. By ensuring that the principles of care planning are embedded within commissioning and provider systems, and by encouraging partnership working between healthcare professionals and patients, the diabetes community can make real progress in improving diabetes care.

Advances in pharmaceuticals and medical technology

Advances in drugs, devices and assistive technology are a significant factor in how people with diabetes are treated. Major pharmaceutical and medical advances, from islet transplantation to more sophisticated forms of insulin, are enabling people with diabetes to live more easily with the condition rather than suffer from it. These advances are also supported by the greater availability of high quality structured patient education through DAFNE, DESMOND and other programmes.

At a national level the Department of Health, the voluntary sector and the NDST have worked together to provide support to frontline staff in improving diabetes care. The challenge now is to use these tools, and experience shows that the diabetes community is more than up to doing the job.

19 www.diabetes.nhs.uk/downloads/care_planning_in_diabetes_report.pdf

Appendix A

This section lists all the Department of Health and National Diabetes Support Team (NDST) publications produced in 2006 at the request of the local NHS to support local delivery. For details of all NDST publications, visit www.diabetes.nhs.uk

To order any of these products email: NDST@prolog.uk.com or tel: 08701 555455 quoting the reference number.

Diabetes and the Healthcare Commission	Mar-06	NDST021
QOF	Mar-06	NDST022
Primary Care Commissioning	Mar-06	NDST023
Foot guide	Apr-06	NDST024
PCT Reconfiguration	Jun-06	NDST025
Beyond Boundaries: a guide to diabetes network	Jun-06	NDST026
Turing the Corner: Improving Diabetes Care	Jun-06	DH Ref: 273641
The Psychological Impact of Diabetes	Jul-06	NDST027
Preventing Diabetes	Jul-06	NDST028
Levels of Care: A New Language for Service Planning and Design	Aug-06	NDST029
Diabetes and Pharmacy Services in England	Aug-06	NDST030
Patient Education Tools Project – toolkit	Aug-06	Available online
Bolton Diabetes Journey	Oct-06	Web based only
NICE and Diabetes: A summary of relevant guidelines	Jul-06	NDST031
(Beyond Boundaries) NDST network guide supplement: system reform and commissioning	Jul-06	NDST032
PBR September update	Dec-06	NDST036
Improving the care of women with diabetes	Oct-06	NDST033
Commissioning toolkit	Oct-06	available online
(Beyond Boundaries) NDST network guide supplement: User Involvement	Nov-06	NDST034
(Beyond Boundaries) NDST network guide supplement: Structured Patient Education	Nov-06	NDST035
Care Planning in Diabetes	Dec-06	DH Ref: 278401

Appendix B

In the preparation of this report many members of the diabetes community put forward examples of practice to be featured as case studies. Unfortunately they could not all be featured in the main body of the document, however, the writers of this report would like to extend their thanks to all who sent information for consideration.

Links to further examples of diabetes practice can be found below:

Empowering people with diabetes:

- Volunteer telephone support for people with diabetes in Norfolk: http://www.diabetes.nhs.uk/Infopoints/Empowering_Patients.asp
- Exercise on referral for people with diabetes: http://www.diabetes.nhs.uk/downloads/DOROTHEA070606.pdf
- Patient and public involvement information from Lambeth: http://www.diabetes.nhs.uk/downloads/lambeth_ppi_toolkit.pdf

Clinical care of adults with diabetes:

- Eye screening and treatment services in East Anglia: http://new.edp24.co.uk/content/news/story.aspx?brand=EDPOnline&category=News&tBrand=edponline&tCategory=news&itemid=NOED23%20Aug%202006%2018%3A19%3A34%3A137
- Diabetes education for care home staff: http://www.diabetes.nhs.uk/Infopoints/Care_Home_Staff.asp
- New skills in Primary Care in Tameside and Glossop: http://www.diabetes.nhs.uk/downloads/TGPCT_initiation_insulin_GP.pdf http://www.diabetes.nhs.uk/downloads/TGPCT_insulin_initiation_guidelines.pdf

Clinical care of children and young people with diabetes:

- Children's Support Group set up in Widnes: http://iccheshireonline.icnetwork.co.uk/0100news/0100regionalnews/tm_headline=getting-to-grips-with-diabetes&method=full&objectid=17995532&siteid=50020-name_page.html
- Booklets for young people in Waltham Forest: http://www.walthamforest-pct.nhs.uk/Services/diabeteschildrens.htm

All the data used in this report will be made available on the NDST website in the near future.

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