National Service Framework for Diabetes

One Year On
## Contents

Foreword from Dr Sue Roberts, National Clinical Director for Diabetes 1

Section 1: Expectations 2
   Introduction 2
   National Action 3

Section 2: Local Action – Organisational Steps in the First Year 6
   Local diabetes networks and local leadership 6
   Local baseline assessment and audit 7
   Workforce skills profile and supporting frontline staff 7

Section 3: The Next Two Years and Beyond 8
   National targets 8
   Systematic retinopathy screening programme 8
   Diabetes registers 9
   Systematic treatment regimens 10

Section 4: Conclusion 11

Annex A: Diabetes NSF Standards to be Reached by 2013 12
Foreword

Diabetes is a chronic, progressive disease that affects 1.3 million people in England. There may be as many as another million people who have it but who are not aware they have it and the number of people being diagnosed is increasing every year. Unless diabetes is managed effectively, it can lead to complications that may result in kidney failure, blindness and foot amputation. Diabetes is also a major risk factor for coronary heart disease and stroke.

The cost of diabetes is huge – an estimated 5 per cent\(^1\) of all NHS expenditure. But the cost to people’s quality of life – and their life expectancy – can be equally heavy. However, with appropriate support, not only in terms of drugs and treatments, but also structured education and advice, people with diabetes can manage their condition so that the effect on their lifestyle is minimised.

Services for people with diabetes have in the past been variable – pockets of excellence are common, but that excellence is not universal. The National Service Framework for Diabetes sets out how, working together, everyone throughout the whole healthcare system can ensure that the best diabetes care and support is available to all no matter who they are or where they live. As Alan Milburn (then Secretary of State for Health) said in his introduction to the National Service Framework for Diabetes Delivery Strategy, “Our goal is to make the best practice already offered in some places the norm.”

When I was appointed as National Clinical Director for Diabetes, I realised that there was a huge task to be done. In my visits to events organised by the Strategic Health Authorities, involving the whole range of people working in diabetes care, including people with diabetes themselves, I have been encouraged at the progress that has already been made. This report describes that progress, and the next steps. We are not there yet – it is after all a ten-year programme – but I know that with the support of healthcare professionals, organisations such as Diabetes UK and people with diabetes we will see the transformation in diabetes services envisioned by the National Service Framework become a reality.

Sue Roberts
National Clinical Director for Diabetes

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Section 1: Expectations

Introduction

1. The National Service Framework for Diabetes: Standards, published in December 2001, set out a vision of diabetes services which:

   • leads to fewer people developing diabetes and better care for those who have it

   • is centred around the needs of people with diabetes, developed in partnership with healthcare staff, equitable, integrated and focused on delivering the best outcomes for the person with diabetes

   • offers care that is structured and proactive, providing people with the support they need to manage their own condition

   • is encapsulated in 12 standards, 32 key interventions (a summary of the standards is shown in Annex A).

2. The National Service Framework for Diabetes: Delivery Strategy, published in January 2003, set out the organisational steps that could help the NHS to reach the targets for diabetes in Improvement, Expansion and Reform: the next 3 years and the National Service Framework (NSF) standards over the next ten years. In the first year Strategic Health Authorities (SHAs) working with Primary Care Trusts (PCTs) could:

   • set up a local diabetes network, or similarly robust mechanism, which involves identifying local leaders and appointing and resourcing network managers, clinical champions and a person(s) with diabetes to champion the views of local people

   • review the local baseline assessment, establishing and promulgating local implementation arrangements with a trajectory to reach the standards

   • participate in comparative local and national audit

   • undertake a local workforce skills profile of staff involved in the care of people with diabetes and develop education and training programmes with the local Workforce Development Confederation.

3. This report describes the progress made in the first year, nationally and locally, to achieve these first steps.
National Action

4. There have been a number of national actions put in place to support the NHS to deliver the NSF targets and standards. In the first year the Government’s commitments included the appointment of a National Clinical Director for Diabetes, and setting up a programme of implementation in the Modernisation Agency.

5. **The National Clinical Director for Diabetes**, Dr Sue Roberts, was appointed in March 2003 and she has already begun to establish a programme to oversee the implementation of the NSF by:
   - supporting NHS clinicians and managers in reaching the standards and delivering the targets
   - ensuring clinical commitment through professional leadership at national level
   - ensuring that emerging new knowledge is effectively disseminated through modernisation plans
   - advising Ministers and officials in the Department of Health on priorities and progress, working with the NHS Modernisation Agency, the National Institute for Clinical Excellence (NICE), the Commission for Health Improvement (CHI) – and the Commission for Healthcare Audit and Inspection (CHAI) when it is established in 2004 – and other bodies to support delivery.

6. The National Clinical Director for Diabetes will have visited all Strategic Health Authorities by the end of April to meet the main stakeholders, get a picture of the issues on the ground, and share the local vision and programme for improving life for people with diabetes. Feedback from these visits helped to inform the assessment of NHS progress set out in section 2 of this report.

7. **The NHS Modernisation Agency** programme has been set up to support local NHS staff and their partner organisations in improving services for patients by focusing on four key areas:
   - improving access – helping to provide fast and convenient services
   - raising standards of care – improving the quality and safety of the patient’s experience
   - supporting local improvement – building local capacity
   - spreading good practice – helping everyone share their knowledge and learning.

8. The National Diabetes Support Team (NDST), part of the NHS Modernisation Agency, was established to support local healthcare services to achieve these aims. Working with the National Director, the NDST has already established a national diabetes network of healthcare professionals through which they are sharing regular communications of good practice and fact sheets. There is also a website under development, which will be available later in the spring.

9. The NDST is supporting the National Director in her series of SHA visits, which is helping to shape the future work of and relationship between the NDST, SHA leads and local diabetes leads.
10. Other national initiatives achieved so far are:

11. A national Diabetes Workforce Group has been established to develop workforce planning and development, under the umbrella of the Long Term Conditions Care Group Workforce Team (CGWT). All workforce issues relating to diabetes are now being channelled through this group, which has prioritised a number of objectives for the coming year including developing skills for diabetes facilitators, network champions and commissioning leadership, scenario planning of various service models, initiating learning sets for workforce planning, developing an education & training strategy, and exploring prescribing issues.

12. The first phase of occupational standards for diabetes commissioned by the CGWT is due to be completed during 2004 following rigorous piloting during the spring and summer. Retinopathy standards, which are being adopted as national occupational standards across England, Wales, Northern Ireland and Scotland, are also due to be published in 2004. The electronic tools which Skills for Health are developing to use with these occupational standards will enable fast, accurate workforce skills profiles of staff to be built.

13. Devon and Cornwall Workforce Development Confederation (WDC) have tested a disease-based approach to workforce planning for diabetes. This report has been shared with other WDCs and diabetes leads at the national CGWT conference as well as the national workforce planning tools project. The Diabetes Workforce Group has made specific recommendations to the Workforce Numbers Advisory Board relating to future staff requirements.

14. The Diabetes Information Strategy, which was published at the same time as the Delivery Strategy, contained a number of strands of work. Progress has been made in a number of areas of which the following can be noted:

- Data requirements to support the NSF standards have been reflected in the National IT Programme NHS care records Output-Based Specification. This means that when the NHS care record comes on line it will support the implementation of the NSF standards by providing direct care for children and adults with diabetes, patients having access to their own records and care plan, practice-based registers of people with diabetes and coronary heart disease, screening for people with diabetes and clinical decision support for health professionals. Continuing liaison with the National Programme will ensure the new NHS care record will fully support the high-quality care required by people with diabetes.

- Diabetes datasets development, which will define minimum standards that should be recorded and maintained within clinical systems, is progressing and all the datasets are planned to have Information Standards Board approval by the end of 2004.

- The National Clinical Audit Support Programme has developed a dataset and put a technical infrastructure in place to begin the collection of comparative diabetes clinical audit data by April 2004.

- NHS Direct Online has a continuing programme of development information on diabetes and has developed web pages in the section known as the ‘NHS Direct Online Health Encyclopedia’.
15. **Research** – The NSF committed the UK National Screening Committee (NSC) to advise the Department of Health by 2005 on the most effective policy for screening for Type 2 diabetes. A Task Group was established in April 2003 to provide the evidence on screening to the NSC. There are a number of strands to the research evidence, described below, which will be incorporated into a systematic review of the benefits and cost-effectiveness of early diagnosis of Type 2 diabetes. It is expected the advice from the NSC will be submitted to the Department by late 2005.

16. Research is being commissioned to supplement other ongoing work on screening for Type 2 diabetes in England and abroad. Five new research projects will define groups at high risk of diabetes, especially in deprived or ethnic minority communities, and the optimum strategies for screening in the community. The Department of Health is also funding a pilot programme under the auspices of the NSC – The Diabetes Heart Disease and Stroke Prevention Project (DHDS). This is a pragmatic study in primary care to identify the prevalence of diagnosed Type 2 diabetes and coronary heart disease and to screen for undiagnosed diabetes. This study is being carried out in 9 PCTs, and 27 intervention practices (3 from each of the 9 PCTs) have been identified to participate in the project.

17. A project team has been established to co-ordinate the project and facilitators have been appointed. A Project Advisory Group, made up of key stakeholders, including Diabetes UK, has been established to oversee the development of the project. The project team has set up a website to ensure good communication with the public and those participating in the pilot (www.nelh.nhs.uk/screening/diabetesproject/home.htm). Each of the practices involved in the project is now offering opportunistic and targeted screening.
Section 2: Local Action – Organisational Steps in the First Year

18. The Delivery Strategy expects PCTs to use the funds made available in baseline allocations to build the capacity of their health communities to reach the NSF standards, and outlines a number of organisational steps PCTs can take in the first year to:

- set up a local diabetes network
- review the local baseline assessment, establishing and promulgating local implementation arrangements with a trajectory to reach the standards
- participate in comparative local and national audit
- undertake a local workforce skills profile of staff.

Local diabetes networks and local leadership

19. The Delivery Strategy suggests that clinically led, managed diabetes networks, involving people with diabetes, are one of the means of providing a structure for service planning and delivery, promote seamless care and support staff by targeting resources where they are most needed. Usually they cover a ‘natural’ population. It is also good practice to design accountability arrangements to ensure that decisions are implemented. Where networks exist it is helpful for a dedicated network manager, a clinical champion(s) and leader(s) among people with diabetes to be identified to lead change.

20. Feedback from the National Director’s SHA visits has shown that, although organisation of services for people with diabetes at PCT level is well advanced and valued, there is more work to do to establish networks at a level coterminous with other secondary healthcare. It is encouraging that there is an awareness amongst those involved with diabetes care of the necessity and willingness to work at such a level but the development of networks is at an early stage for most health communities. Some networks set out to appoint network managers but where diabetes is not seen as a priority by the PCTs this is less successful.

21. Strategic Health Authority diabetes leads have an important role to play in encouraging PCTs to build an infrastructure which will deliver the NSF standards. The SHA visits by the National Director have helped to develop more awareness about the merits of diabetes-specific networks and the NDST will follow up progress by meeting with SHA diabetes leads three to four times a year to support their work.

22. Particularly encouraging is the fact that Diabetes UK, with the help of Department funding, has established a user support programme that will begin to enable people with diabetes to participate in service planning and become patient champions.
Local baseline assessment and audit

23. The Delivery Strategy suggests that, in order to establish capacity to achieve the standards, PCTs may want to review their local baseline assessment and establish arrangements for promulgating local implementation. A suitable web-based tool – DiabetesE – has been made available free to all PCTs as part of NpfIT which will support review of baseline assessments, give feedback, help to shape an action plan to improve and help with benchmarking and with team building.

24. Feedback from the SHA visits by the National Director has shown excellent progress in some areas but many PCTs have yet to begin this work.

25. Participating in comparative local and national audit is also an essential step and national audit is due to begin in April 2004 as explained in section 1.

Workforce skills profile and supporting frontline staff

26. The Delivery Strategy outlines a number of local workforce actions that could be taken to facilitate the implementation of the NSF standards. These include undertaking a workforce skills profile of staff involved in the care of people with diabetes, developing education and training programmes with Workforce Development Confederations, developing new skills, knowledge and training on new roles. The SHA events attended by the National Director identified local developments building on national initiatives outlined in section 1, although general progress on completing workforce profiles was still required.
Section 3: The Next Two Years and Beyond

National targets

27. The Delivery Strategy outlines two critical national diabetes-specific targets that were contained in Improvement, Expansion and Reform: the next 3 years, the planning and performance framework for 2003–2006, which sets the priorities for the NHS over the next three years. The targets are outlined below:

- By 2006, a minimum of 80 per cent 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 per cent coverage of those at risk of retinopathy by end 2007.
- In primary care, update practice-based registers so that patients with coronary heart disease (CHD) and diabetes continue to receive appropriate advice and treatment in line with NSF standards and, by March 2006, ensure practice-based registers and systematic treatment regimens, including appropriate advice on diet, physical activity and smoking, also cover the majority of patients at high risk of CHD, particularly those with hypertension, diabetes and a body mass index (BMI) greater than 30.

28. The Delivery Strategy also suggests steps to help the NHS achieve these targets by 2006. These are:

- To deliver the first target, PCTs will need to put in place a systematic eye screening and treatment programme, including recall.
- To deliver the second target, PCTs will need to update diabetes practice-based registers using them as the basis for systematic treatment regimens with advice and treatment in line with the Diabetes NSF standards.

29. Revenue funding to deliver the national targets and to begin to make progress in delivering local priorities across the standards has been included in the general allocations to PCTs. Capital funds of £27million have also been available from 2003 to 2006 to help purchase digital cameras that are essential in delivering the national target on retinopathy screening. Progress in these areas is as follows:

Systematic retinopathy screening programme

30. Early detection of sight-threatening diabetic retinopathy and treatment with laser therapy is effective in preventing visual impairment. The National Institute for Clinical Excellence (NICE) guidance on retinopathy screening and early management recommends participation in a formal screening programme. Whilst many people with diabetes receive regular retinal screening, there are wide variations in policies, practice and the quality of screening provided. Progress towards the target for screening for diabetic retinopathy is being monitored by quarterly PCT-level activity data, data that is then aggregated to SHA level. These SHA level summaries can then be compared to the planned trajectories.
of performance put in place to ensure transition from the current level of screening to the target of 80 per cent being offered, expected in 2006, followed by 100 per cent in 2007. We expect to be able to assess current performance on this target at Q4 2003/04 when an accurate figure for the number of diabetics on registers will be available.

31. Local delivery is being supported by a UK National Screening Committee (NSC) programme, carried out with professional organisations and Diabetes UK, to set quality assurance standards, monitoring criteria and specifications for information and professional development resources during 2003/04. A Project Advisory Group, consisting of key stakeholders, has been established to oversee the development of the national programme, and a support team is in place to advise the NHS on all aspects of the programme. A website has been created (www.nscretinopathy.org.uk) to provide information and advice on the programme. Nationally agreed prices and a contracted list of suppliers for digital cameras and related software have been negotiated which will result in considerable savings to the NHS.

32. Following discussions between the NSC, the NHS University (NHSU) and the Changing Workforce Programme, a learning and accreditation programme for retinal screeners has been accepted as one of the first programmes to be developed by the NHSU. An assessment package for current screeners and a training package for new screeners are being developed leading to the award of a Certificate and Diploma in Retinal Screening. In addition, the national support programme is developing a number of resource tools including e-learning and web-based assignments.

33. Quality Assurance Criteria and standards for the programme have been developed. Advice has been issued on setting up a retinopathy screening service and the costings that may be involved.

**Diabetes registers**

34. Most people with diabetes spend only a few hours in contact with healthcare professionals each year. The rest of the time they manage their diabetes themselves. Supporting people to manage their own diabetes is therefore at the heart of empowering people with diabetes, improving their experiences of services and improving their health outcomes. Delivering this support relies upon the establishment of effective registers. Without an effective register, it will not be possible to identify those with poor diabetes control (an indicator of those who have the highest risk of complications) nor those with newly diagnosed diabetes.

35. By 2006 all people with diagnosed diabetes should be identified in an up-to-date practice-based register. This should be a collaborative effort involving primary care and specialist services. A comprehensive and up-to-date register will provide the cornerstone of care and the basis for call and recall, clinical care, prevention, continuous quality improvement, monitoring and clinical audit. All registers must meet the requirements for confidentiality and security. Extending diabetes registers to include those at increased risk of diabetes will facilitate effective interventions, including through structured education programmes, diet and physical activity, which will also help deliver the standards and goals in the NSF for CHD. Practice-based diabetes registers can therefore be developed in primary care along the same lines as, and integrated with, the virtual CHD and stroke registers.

36. Access to health records will help people with diabetes manage their care in partnership with health and social care professionals. Care planning is at the heart of a partnership approach to care and a central part of effective care management. The outcome of this process is a personal diabetes record and agreed care plan that contains the clinical record of care, treatment and management (including test results), and is held by the person with diabetes and used by them and the diabetes team.
37. Central systematic collection of data on the establishment of registers is carried out on an annual basis and will be available for the first year in the summer. However, the NDST and Diabetes UK will be providing support and guidance on the development of care plans in the next few months and intend to hold a national conference to spread good practice. Progress on providing people with diabetes with the capacity to view and interact with their electronic records is detailed in section 1 (para 14).

**Systematic treatment regimens**

38. With the assistance of diabetes registers PCTs should, by 2006, ensure systematic treatment regimens are in place for people with diabetes. Ultimately, at the heart of these will be regular reviews, which will be based on a diabetes record and a care plan developed and agreed jointly between the person with diabetes and a member of the diabetes team. The *Delivery Strategy* outlined a number of key elements to this process: a named contact, regular review and advice and information through structured education.

39. To underpin the care planning approach, which is a vital part of the provision of structured treatment regimens advocated by the NSF, the Department of Health and Diabetes UK have been supporting several patient education models for people with diabetes. For Type 1 diabetes, the DAFNE (Dose Adjustment for Normal Eating) programme, including relevant staff training and other materials, are available at a cost of £11,770 to all diabetes services who may wish to offer DAFNE. For further information please contact Gillian Thompson (gillian.thompson@northumbriahealthcare.nhs.uk). For Type 2 diabetes, the newly diagnosed module of DESMOND (Diabetes Education and Self-Management for Ongoing and Newly Diagnosed) programme was piloted in 15 PCTs in early 2004. Further modules for ongoing education are soon to be developed. Further details are available from Marian Carey (marian.carey@uhl-tr.nhs.uk).
40. The *Delivery Strategy* was the first of the new light touch NSFs. Rather than milestones in the first year it identified optional steps that PCTs could take to support the delivery of two targets by 2006 and the standards by 2013.

41. The *Delivery Strategy* emphasised the need for local communities to agree local priorities in deciding the next steps to achieve the NSF standards. It explains:

   'Reaching the NSF standards by 2013 will be an overarching goal of PCTs but there will be significant differences from one place to another in the starting point for implementation. Local plans will need to reflect local priorities, building on these as capacity expands.'

42. In keeping with this philosophy PCTs are expected to set themselves challenging, measurable targets that will result in tangible service improvement from 2003–4. These targets needing to:

   • be determined on the basis of local needs and service capacity
   • be challenging
   • be underpinned by information and workforce developments
   • be costed and resourced
   • have measurable outcomes
   • be owned and agreed by the local health and diabetes communities.

43. At the end of the first year national programmes supporting delivery have been put in place and are beginning to deliver results. The pace of change locally is more varied. In the next year the National Clinical Director with the NDST will identify a programme of work which will focus on further developing local leadership and organisational development, knowledge management and the communication and sharing of good practice.
Annex A: Diabetes NSF Standards to be Reached by 2013

**Prevention of Type 2 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.

**Identification of people with diabetes**

*Standard 2*

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

**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.

**Clinical care of adults with diabetes**

*Standard 4*

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

**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.

**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 healthcare 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.