

Modern Standards and Service Models

Diabetes

**national
service
framework**

National Service Framework
for Diabetes: Standards

National Service Framework for **Diabetes**

Standards

FOREWORD

Less than a hundred years ago diabetes was a death warrant. The discovery of insulin in the 1920s was a major breakthrough. Since then, thanks to the dedicated work of scientists, researchers, doctors and nurses in this country and abroad, there have been huge strides forwards in our knowledge of diabetes and the most effective interventions to improve the quality of people's lives. It remains the case however, that whilst people can now live more normal lives there is still no cure for diabetes.

The number of people developing diabetes is increasing around the world. In England alone, there are more than a million people diagnosed with diabetes, and the number continues to grow. Diabetes is indiscriminate. Whilst the risk of developing diabetes increases with age, anyone can get it. The burden of the disease falls disproportionately on people from minority ethnic groups and those from socially-excluded groups. Type 2 diabetes is up to six times more common in people of South Asian descent and up to three times more common amongst those of African and African-Caribbean origin. Morbidity from diabetes complications is three-and-a-half times higher amongst the poorest people in our country than the richest.

Diabetes can still have a devastating impact on individuals and on their families. It is the leading cause of blindness in people of working age, the largest single cause of end stage renal failure, and, excluding accidents, the biggest cause of lower limb amputation. Compared with other European countries, Britain has a poor record of blood glucose control and blood pressure control. We have higher rates of heart attacks and strokes, foot ulcers, renal failure and nerve damage.

Across the NHS, in primary care, acute hospitals and community services there is a real determination to reduce the burden of diabetes. This document, the first part of our National Service Framework for Diabetes, sets out twelve new standards and the key interventions necessary to raise the standards of diabetes care.


The NSF aims to make best practice the norm: better support for people so they can more effectively adjust their insulin use to their lifestyle; dedicated nurses on hospital wards to reduce the length of stay in hospital and cut the number of complications; and community-based diabetes clinics to bring together at one location and at one time specialist expertise and services, including foot care and eye screening.

This NSF will target these initiatives to reach communities at greatest risk. By improving blood glucose and blood pressure control in people with diabetes, we could reduce the complications of diabetes, reducing the resulting number of heart attacks and strokes, blindness and renal failure perhaps by as much as a third. Targeted foot care for people at high risk could save hundreds of amputations a year. By detecting complications earlier, we can save sight, save limbs and save lives.

Alongside the real progress that has taken in place in some areas and for some places, there remain significant variations in the quality of care. Excellent diabetes services in one place can exist cheek-by-jowl with diabetes care elsewhere that is inadequate and unimaginative. Recognition of these challenges led the Government to initiate the development of this *National Service Framework for Diabetes*.

Achieving the goals of this NSF - reducing the burden of diabetes and the associated health inequalities as well as ensuring high quality of care wherever people live - demands real change in the way that the NHS delivers care to people with diabetes. Today we publish the national standards we expect to deliver. Next summer we will publish our delivery strategy, setting out the steps along the way. We will develop this strategy alongside health care professionals and people with diabetes. The pace of change will be challenging but achievable.

I am grateful to all those who have helped to prepare this first part of the NSF. Over time, with the support and dedication of the professionals across the NHS, we will make a major improvement in the diagnosis and care of people living with diabetes.



Alan Milburn
Secretary of State for Health



EXECUTIVE SUMMARY

Diabetes is becoming a more common condition world-wide. It can affect people of all ages in every population. Socially disadvantaged groups in affluent societies and people from black and minority ethnic communities (especially those of South Asian, African and African-Caribbean descent) are particularly vulnerable.

Diabetes can have a major impact on the physical, psychological and material well-being of individuals and their families, and can lead to complications such as heart disease, stroke, renal failure, amputation and blindness. There is evidence to show that:

- the onset of Type 2 diabetes can be delayed, or even prevented
- effective management of the condition increases life expectancy and reduces the risk of complications
- self-management is the cornerstone of effective diabetes care.

The National Service Framework for Diabetes: Standards includes standards, rationales, key interventions and an analysis of the implications for planning services. It exemplifies the approach to patient focused services set out in *The NHS Plan* and *The Expert Patient*. The standards are listed on page 5. Detailed information on the interventions can be found on the Diabetes NSF website, alongside service models and performance indicators on which we are seeking views.

The NSF has been developed with the help of an External Reference Group, which was jointly chaired by Professor Mike Pringle, then Chair of Council of the Royal College of General Practitioners, and Peter Houghton, Director of the Eastern Region of the Department of Health. There was wide involvement through a series of Topic Area Working Groups and the External Reference Group to develop a set of evidence-based proposals.

The second part of the NSF, the *National Service Framework for Diabetes: Delivery Strategy*, will be published in summer 2002 for implementation from April 2003. It will take account of the comments received on service models and performance indicators and will set out the action to be taken by local health and social care systems, milestones, performance management arrangements and the underpinning programmes to support local delivery. A Diabetes NSF Implementation Group is being set up to steer the development of the delivery strategy, and can be contacted at diabetes.nsf@doh.gsi.gov.uk or

Diabetes NSF Team
Department of Health
Wellington House
133–155 Waterloo Road
London SE1 8UG

Standards table

Standard 1: Prevention of Type 2 diabetes	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: Identification of people with diabetes	2. The NHS will develop, implement and monitor strategies to identify people who do not know they have diabetes.
Standard 3: Empowering people with diabetes	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.
Standard 4: Clinical care of adults with diabetes	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.
Standards 5 & 6: Clinical care of children and young people with diabetes	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. 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.
Standard 7: Management of diabetic emergencies	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: Care of people with diabetes during admission to hospital	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.
Standard 9: Diabetes and pregnancy	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.
Standards 10, 11 & 12: Detection and management of long-term complications	10. All young people and adults with diabetes will receive regular surveillance for the long-term complications of diabetes. 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. 12. All people with diabetes requiring multi-agency support will receive integrated health and social care.

CHAPTER 1: SETTING THE SCENE

Introduction

1. The last hundred years have seen very significant advances in our understanding of diabetes¹, and our capacity to treat it and to enable people to live longer and healthier lives. Today, with the support of high-quality health care, people with diabetes have the potential to live long lives free of the devastating complications suffered by previous generations.
2. The St Vincent Declaration, ratified by the World Health Organisation Regional Committee for Europe in 1991, set aspirations and goals for reducing the impact of diabetes. Since then, there have been significant developments with:
 - evidence that the onset of Type 2 diabetes can be delayed or even prevented
 - evidence that tight control of blood glucose and blood pressure increases life expectancy and improves quality of life for people with both Type 1 and Type 2 diabetes
 - new and improved therapies
 - evidence that supported self-care improves outcomes, with the diabetes specialist nurse playing a key role.

What is Diabetes?

3. Diabetes is a chronic and progressive disease that impacts upon almost every aspect of life. It can affect infants, children, young people and adults of all ages, and is becoming more common. Diabetes can result in premature death, ill health and disability, yet these can often be prevented or delayed by high-quality care.
4. Diabetes comprises a group of disorders with many different causes, all of which are characterised by a raised blood glucose level. This is the result of a lack of the hormone insulin and/or an inability to respond to insulin. Insulin in the blood, produced by the pancreas, is the hormone which ensures that glucose (sugar) obtained from food can be used by the body. There are two main types of diabetes: Type 1 diabetes and Type 2 diabetes.
5. In people with Type 1 diabetes, the pancreas is no longer able to produce insulin because the insulin-producing cells (β -cells) have been destroyed by the body's

¹ In this document, the term diabetes refers to diabetes mellitus.

immune system. Without insulin to move glucose from the bloodstream to the body's cells, glucose builds up in the blood and is passed out of the body in the urine.

In people with Type 2 diabetes, the β -cells are not able to produce enough insulin for the body's needs. The majority of people with Type 2 diabetes also have some degree of insulin resistance, where the cells in the body are not able to respond to the insulin that is produced.

6. Type 1 diabetes develops most frequently in children, young people and young adults. About 15% of people with diabetes in England have Type 1 diabetes². Although it is far less common than Type 2 diabetes, it is more immediately evident. The symptoms of Type 1 diabetes can develop very rapidly. These include increased thirst and urine production, weight loss despite increased appetite, tiredness and blurred vision. Type 1 diabetes is usually diagnosed as a result of the presence of a combination of characteristic symptoms plus a high blood glucose level. People with Type 1 diabetes need daily injections of insulin to survive. To prevent acute complications they also need to maintain their blood glucose within certain limits, which will require adjustments in their diet and lifestyle. Failure to take insulin can result in diabetic ketoacidosis³. If the balance between diet, physical activity levels and insulin dosage is not maintained, this can lead to hypoglycaemia (very low blood glucose). Both conditions can lead to coma and, if untreated, death.
7. Type 2 diabetes is most commonly diagnosed in adults over the age of 40, although increasingly it is appearing in young people and young adults. About 85% of people with diabetes in England have Type 2 diabetes, which in many cases could either have been prevented or its onset delayed. Glucose builds up in the blood, as in people with Type 1 diabetes, but symptoms appear more gradually and the diabetes may not be diagnosed for some years. As the blood glucose levels rise, symptoms may develop which include tiredness, frequent urination, increased thirst, weight loss, blurred vision and frequent infections. Thus, Type 2 diabetes is often detected during the course of a routine examination or investigation of another problem. People with Type 2 diabetes need to adjust their diet and their lifestyle. Many are overweight or obese and will be advised to lose weight. Some will also need to take tablets and/or insulin to achieve control of their blood glucose level.
8. Prolonged exposure to raised blood glucose levels damages tissues throughout the body by damaging the small blood vessels. The initial changes are reversible but, over time, prolonged raised blood glucose levels can lead to irreversible damage. These microvascular complications occur only in people with diabetes and include:
 - damage to the eyes, which can lead to visual impairment and blindness (diabetic retinopathy)

² Figures quoted in this document are all for England only unless otherwise stated.

³ Diabetic ketoacidosis is a potentially life-threatening acute complication of diabetes caused by an inadequate concentration of insulin in the blood for the body's requirements. It is described in more detail on page 30.

- damage to the kidney, which can lead to progressive renal failure (diabetic nephropathy)
 - damage to the nerves (diabetic neuropathy). Damage to the nerves supplying the lower limbs can lead to loss of sensation in the feet, thereby predisposing to the development of foot ulcers and lower limb amputation. Damage to other nerves can lead to a variety of symptoms, including postural hypotension (feeling faint on standing up), abnormal sweating, gastrointestinal problems (such as diarrhoea), difficulties with bladder emptying and erectile dysfunction (impotence).
9. People with diabetes, particularly Type 2 diabetes, are also at significantly increased risk of developing cardiovascular disease. This results from damage to the walls of the large blood vessels, which can then become blocked. Cardiovascular disease includes:
- coronary heart disease, which can lead to angina, acute myocardial infarction (heart attack) and heart failure
 - stroke and transient ischaemic attacks (cerebrovascular disease)
 - blockage of the large blood vessels supplying the lower limbs (peripheral vascular disease) resulting in poor circulation to the legs and feet, which can cause pain in the legs on walking and can also predispose to the development of foot ulcers and amputation.
10. A number of other conditions also occur more commonly in people with diabetes, including:
- cataracts, which are twice as common in people with diabetes and occur about 10 years earlier than in people who do not have diabetes
 - infections, particularly of the urinary tract and the skin
 - soft tissue conditions, such as frozen shoulder and trigger finger
 - skin conditions, some of which are specific to people with diabetes
 - mental health problems, including depression and eating disorders.

Who Gets Diabetes?

11. Diabetes is becoming more common:
- around 1.3 million people are currently diagnosed with diabetes and in addition many hundreds of thousands may have Type 2 diabetes without yet knowing it
 - the incidence of diabetes is increasing in all age groups
 - Type 1 diabetes is increasing in children, particularly in under fives
 - Type 2 diabetes is increasing across all groups, including children and young people, and particularly among black and minority ethnic groups
 - a population of 100,000 would be expected to include between 2,000 and 3,000 people with diabetes, approximately 25-30 of whom will be children. These numbers will be significantly higher in those parts of the country with higher proportions of people from black and minority ethnic groups.
12. Diabetes does not affect everyone in our society equally. Significant inequalities exist in the risk of developing diabetes, in access to health services and the quality of those services, and in health outcomes, particularly with regard to Type 2 diabetes. Those who are overweight or obese, physically inactive or have a family history of diabetes are at increased risk of developing diabetes. People of South Asian, African, African-Caribbean and Middle Eastern descent have a higher than average risk of Type 2 diabetes, as do less affluent people. Socially excluded communities, including prisoners, refugees and asylum seekers, and people with learning disabilities or mental health problems, may receive poorer quality care. Risk may accumulate if an individual belongs to more than one of these groups:
- Type 2 diabetes is up to six times more common in people of South Asian descent and up to three times more common in those of African and African-Caribbean descent, compared with the white population. It is also more common in people of Chinese descent and other non-white groups.
 - The prevalence of diabetes rises steeply with age: one in 20 people over the age of 65 in the UK has diabetes and in people over the age of 85 years this rises to one in five. The diagnosis of diabetes may be delayed in older people, with symptoms being wrongly attributed to ageing. Older people may experience discrimination in the degree of active management offered compared with younger people. Standard 1 of the *National Service Framework for Older People* sets out a programme to eliminate any such discrimination.

- Type 2 diabetes is more prevalent among less affluent populations. Those in the most deprived fifth of the population are one-and-a-half times more likely than average to have diabetes at any given age.
- Both mortality and morbidity are increased by socio-economic deprivation. Morbidity resulting from diabetes complications is three-and-a-half times higher in social class V than social class I.
- High-risk, hard-to-reach groups are over-represented in the prison population. Close partnership working between the prison health care team and the local NHS specialist diabetes service is essential.
- The frequency of diabetes in England is higher in men than women. However, women with diabetes are at relatively greater risk of dying than men. This may be because gender compounds other aspects of inequality.

The Impact and Cost of Diabetes

13. As it is a life-long disease diabetes can have a profound impact on lifestyle, relationships, work, income, health, well-being and life expectancy.
14. Diabetes can have a major impact on the physical, psychological and material well-being of individuals and their families:
 - life expectancy is reduced, on average, by more than 20 years in people with Type 1 diabetes and by up to 10 years in people with Type 2 diabetes
 - mortality rates from coronary heart disease are up to five times higher for people with diabetes, while the risk of stroke is up to three times higher
 - diabetes is the leading cause of renal failure, accounting for more than one in six people starting renal replacement therapy; the second commonest cause of lower limb amputation; and the leading cause of blindness in people of working age
 - diabetes leads to additional risks in pregnancy: women with diabetes have an increased chance of losing the baby during pregnancy or at birth, of the baby having a congenital malformation, or of the baby dying in infancy
 - Type 2 diabetes incurs significant direct personal costs, for people with diabetes, including costs associated with managing their diabetes. The average cost in 1999 was estimated to be £802 per year plus lost earnings. The presence of diabetic complications increases personal expenditure three-fold, and doubles the chance of having a carer.

15. Diabetes also has a significant impact on health and social services:
- around 5% of total NHS resources and up to 10% of hospital in-patient resources are used for the care of people with diabetes
 - people with diabetes are twice as likely to be admitted to hospital as the general population and, once admitted, are likely to have a length of stay that is up to twice the average
 - the presence of diabetic complications increases NHS costs more than five-fold, and increases by five the chance of a person needing hospital admission
 - one in 20 people with diabetes incurs social services costs and, for these people, the average annual costs were £2,450 (1999). More than three-quarters of these costs were associated with residential and nursing care, while home help services accounted for a further one-fifth. The presence of complications increased social services costs four-fold.

The National Service Framework for Diabetes

16. The National Service Framework (NSF) programme was established to improve services by setting national standards to drive up service quality and tackle variations in care. Each NSF sets national standards, identifies the interventions and actions that will help meet those standards and the milestones against which NHS performance will be measured.
17. *The National Service Framework for Diabetes* has been informed by the advice of an External Reference Group (membership shown in the Annex). It builds upon the vision of the St Vincent Declaration and is being published in two stages. This document, *National Service Framework for Diabetes: Standards* sets out the aims, standards, rationales and key interventions, together with the implications for planning services.
18. In keeping with the principles of *The NHS Plan*, and *The Expert Patient*, the primary goal is to enable the person with diabetes, or at risk of developing diabetes, to manage their own lifestyle and diabetes, by providing support and structured education as well as drugs and treatments. Diabetes exemplifies the critical importance of this approach – all the evidence suggests that a partnership between the person with diabetes and their clinical and support team can improve outcomes and quality of life.

19. The National Service Framework for Diabetes builds on published NSFs, especially:
 - *National Service Framework for Coronary Heart Disease*: diabetes accounts for nearly one-fifth of hospital expenditure in coronary heart disease (CHD). Preventing or delaying the onset of diabetes and good management of diabetes will contribute to the achievement of the goals in the *National Service Framework for Coronary Heart Disease*
 - *National Service Framework for Older People*: the prevalence of diabetes increases with age. Poorly controlled diabetes increases the risk of hospital admission and prolongs length of stay once admitted, and trebles the risk of stroke. Getting services right for people with diabetes will therefore be an important measure in delivering the standards in the *National Service Framework for Older People*.
20. There are also strong links with forthcoming NSFs:
 - **Renal Services**: diabetes is a major cause of end-stage renal failure, and of need for dialysis and kidney transplant. Improving the care of people with diabetes will reduce the development and progression of renal disease, potentially reducing the number of people who develop end-stage renal failure.
 - **Children**: diabetes can affect children of all ages. Developing services that put children and young people with diabetes at the centre of care, and support them through the transition to adult services, will provide a model for the forthcoming Children's National Service Framework. Diabetes can complicate pregnancies: the Children's NSF will also set standards for maternity services more widely.
21. The second stage of the NSF, the *National Service Framework for Diabetes: Delivery Strategy*, will be published in summer 2002 and will take account of the views received from the consultation on service models and performance indicators. It will set out the actions to be taken by local health and social care systems, milestones, performance management arrangements and the underpinning programmes to support local delivery.
22. A Diabetes NSF Implementation Group will be set up to work with the NHS and others to develop a delivery strategy for the Diabetes National Service Framework that takes account of the implementation of *Shifting the Balance of Power within the NHS*. Views expressed on the service models and performance indicators set out on the website will inform the work of the Implementation Group.

The Evidence Base for Key Interventions

23. The key interventions underpinning the standards in this NSF are based on research evidence and are set out in each section of Chapter 2. The views and experiences of people with diabetes, the work of the Audit Commission⁴ and the report of the Health Services Ombudsman⁵ have informed the development of this NSF. More details are provided on the Diabetes NSF web page www.doh.gov.uk/nsf/diabetes The typology below has been developed to distinguish between the different levels of supporting evidence.

Levels of Evidence

Level 1: Meta-analyses, systematic reviews of randomised controlled trials, or randomised controlled trials

Level 2: Systematic reviews of case-control or cohort studies, or case-control or cohort studies

Level 3: Non-analytic studies, eg case reports, case series

Level 4: Expert opinion (in the absence of any of the above)

Conclusion

24. Between them, this *National Service Framework for Diabetes: Standards* document and the *National Service Framework for Diabetes: Delivery Strategy* will set out a systematic programme to deliver a service built around the needs of people with diabetes. They herald a 10-year programme of change to enable more people to live free of diabetes, more people to live free from the complications of diabetes and their consequences; and more women to deliver healthy babies with less risk to themselves.
25. To achieve these goals, diabetes services will be:
- *Person-centred:* empowering the individual to adopt a healthy lifestyle and to manage their own diabetes, through education and support which recognises the importance of lifestyle, culture and religion, and which, where necessary, tackles the adverse impact of material disadvantage and social exclusion.

⁴ <http://www.audit-commission.gov.uk/publications/pdf/nrdiabet.pdf>

⁵ <http://www.ombudsman.org.uk/hsc/document/hc13/hc13.htm>

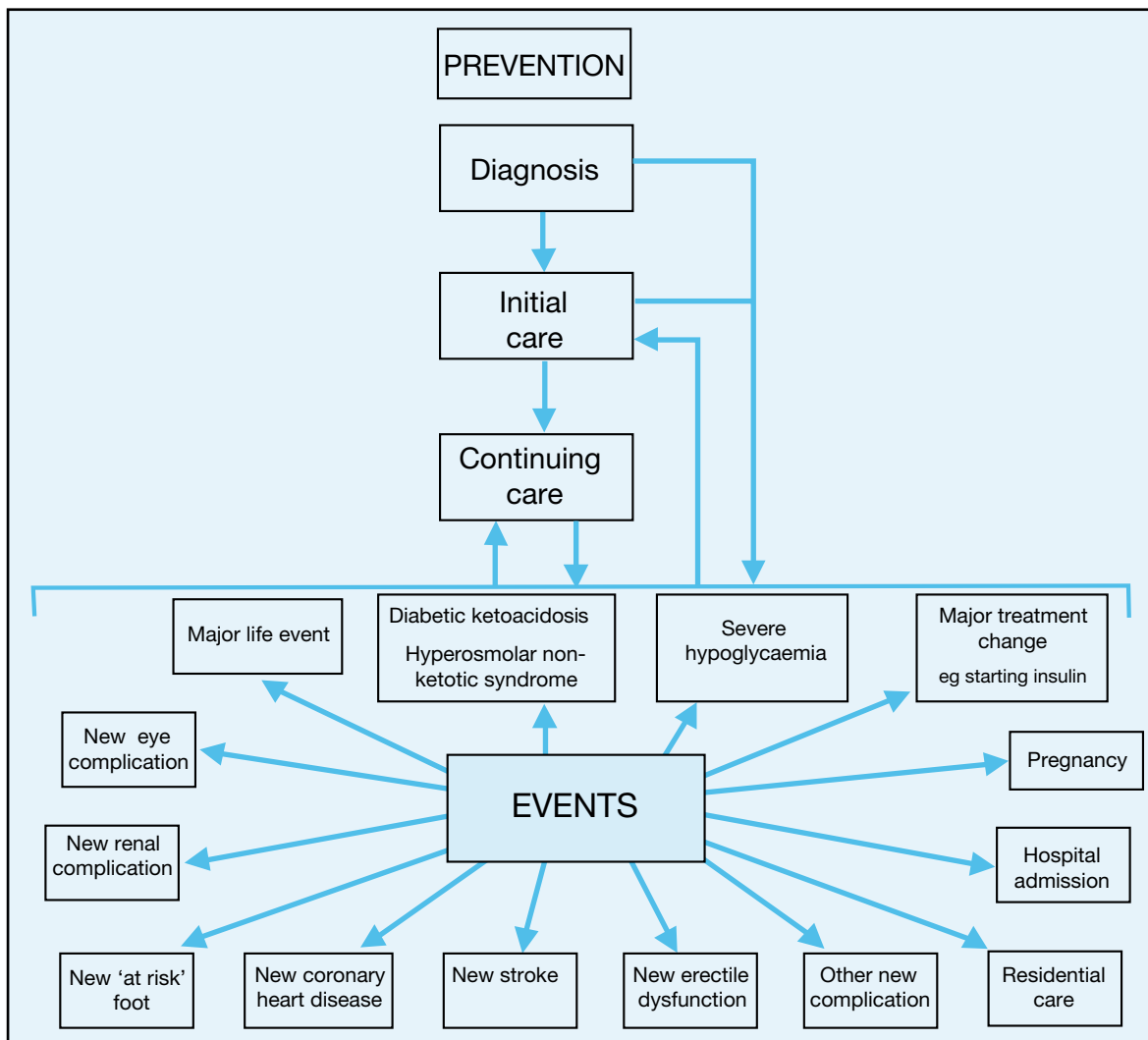
- *Developed in partnership:* ensuring goals and the respective responsibilities of the individual and the diabetes team are agreed and clearly set out in a regularly reviewed care plan.
 - *Equitable:* ensuring that services are planned to meet the needs of the population, including specific groups within the population, and are appropriate to individuals' needs.
 - *Integrated:* drawing on the knowledge and skills of health and social care professionals across a multidisciplinary diabetes health care team, including primary care and social care as well as specialist services.
 - *Outcomes oriented:* narrowing the inequalities gap between those groups whose outcomes are poorest and the rest; minimising the risk of developing diabetes and its complications and maximising the quality of life for individuals by empowering staff to deliver, evaluate and measure care.
26. Delivering this vision and embedding these principles in practice requires staff throughout the NHS to understand the experience of diabetes and diabetes care, and to recognise the expertise of people who live with diabetes. The aims will be to empower people with diabetes through skills, knowledge and access to services to manage their own diabetes and fulfil their potential to live long lives free of the complications that can accompany diabetes.

CHAPTER 2: STANDARDS

Introduction

1. This chapter sets out the standards for the prevention and management of diabetes and for the participation of people with diabetes in decisions about their care. For each group of standards the overall aim is identified, together with the rationale for the standards and a summary of key interventions. Full details of the interventions are at www.doh.gov.uk/nsf/diabetes
2. The diagram below summarises the prevention and management of diabetes. Further details of each stage of this pathway are provided in the supporting documents published on the website.

Diagram summarising the prevention and management of diabetes



Prevention of Type 2 diabetes

Aim

To reduce the number of people who develop 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.

Rationale

1. The number of people with Type 2 diabetes is rising, with an increasing number of young people being diagnosed. Some risk factors for developing diabetes (such as family history, increasing age and ethnic origin) are non-modifiable. However, other risk factors (such as being overweight or obese, having an adverse distribution of body fat and being physically inactive) are modifiable and need to be the focus of prevention strategies.
2. The increase in Type 2 diabetes mirrors the increase in the proportion of people, including children and young people, who are either overweight or obese. Excessive body weight reduces the body's ability to respond to insulin and is therefore a risk factor for Type 2 diabetes. Approximately one in five adults in England is now obese (defined as a body mass index⁶ >30 kg/m²) and two in five are overweight (defined as a body mass index 25–30 kg/m²). The body's distribution of fat is also important. Excess fat stored around the waist, referred to as central obesity, is also a risk factor for diabetes, whatever the body mass index.
3. Regular physical activity lowers the risk of developing Type 2 diabetes by increasing insulin sensitivity. This reduction in risk of diabetes is independent of body weight. Physical activity rates are low across the entire adult population – around six in ten men and seven in ten women are not sufficiently physically active. Rates of inactivity are higher among older people and in some black and minority ethnic communities.
4. Multi-agency action is required to reduce the numbers of people who are physically inactive, overweight and obese, by promoting a balanced diet and physical activity across the population. In order to have the greatest impact, action must start in childhood. These interventions will also contribute to a reduction in the number of people who develop coronary heart disease (CHD). Both Type 2 diabetes and CHD are more common in people of South Asian, African and African-Caribbean descent, and initiatives must include elements developed with, and appropriate for, these communities.

⁶ Body mass index is calculated by dividing a person's weight (in kilograms) by the square of their height (in metres)

5. Action is also needed to help those who are already overweight or obese to lose weight, and people who are physically inactive to increase their levels of physical activity. There is clear evidence that individuals who have impaired glucose tolerance⁷ can reduce their risk of developing Type 2 diabetes if they are helped to eat a balanced diet, lose weight and increase their physical activity levels.

Key Interventions

- The overall prevalence of Type 2 diabetes in the population can be reduced by preventing and reducing the prevalence of overweight and obesity and the prevalence of central obesity in the general population, particularly in sub-groups of the population at increased risk of developing diabetes, such as people from minority ethnic communities, by promoting a balanced diet and physical activity. **(Level 4)**
- Individuals at increased risk of developing Type 2 diabetes can reduce their risk if they are supported to change their lifestyle by eating a balanced diet, losing weight and increasing their physical activity levels. **(Level 1)**

Implications for Service Planning

6. The NHS and partner organisations will need to review their local strategies for improving diet and nutrition, increasing physical activity, reducing overweight and obesity, and helping people to maintain weight loss, to ensure that they are targeting sub-groups of the population at increased risk of developing diabetes, particularly people from minority ethnic groups. Strategies will need to consider people of all ages, particularly children, and to link with existing work based in schools and the wider community.
7. The NHS will need to develop appropriate protocols and programmes to provide advice and support to people known to be at increased risk of developing Type 2 diabetes in order to help them reduce this risk. These protocols and programmes should be complementary to those for cardiovascular disease.
8. Health professionals, particularly those working in primary care, should receive continuing education about:
- the risk factors for diabetes
 - the potential for preventing diabetes through the modification of these risk factors
 - interventions that are effective in preventing, treating and managing overweight and obesity, and increasing physical activity.

⁷ People with impaired glucose tolerance have difficulty maintaining their blood glucose levels within the normal range but are able to maintain their blood glucose levels below the diabetic range. They have a greatly increased risk of developing diabetes and cardiovascular disease.

Identification of people with diabetes

Aim

To ensure that people with diabetes are identified as early as possible.

Standard 2

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

Rationale

1. Many people are unaware that they have diabetes, either because they have no symptoms, or because they ascribe symptoms, such as tiredness and lethargy, to the stresses and strains of everyday life. Health care professionals may also misinterpret the symptoms of diabetes when people first describe them to them.
2. The rapid onset of Type 1 diabetes means that only a small proportion of people remain undiagnosed for any length of time. Children and young people with Type 1 diabetes can become ill very quickly and some develop such high blood glucose levels before they are diagnosed that they present with diabetic ketoacidosis (DKA). The earlier diagnosis of Type 1 diabetes could prevent some of the deaths resulting from DKA. Type 2 diabetes may be present for several years before diagnosis and nearly half of those identified as having Type 2 diabetes already have complications, such as diabetic retinopathy, diabetic neuropathy or cardiovascular disease.
3. Raising awareness of the symptoms and signs of diabetes among the public, particularly among sub-groups of the population at increased risk of developing diabetes, and among health professionals, can help to ensure that people with symptoms and/or signs of diabetes are identified as early as possible.
4. Some individuals are known to be at increased risk of developing Type 2 diabetes, including people who have been found previously to have impaired glucose regulation (impaired glucose tolerance and/or impaired fasting glycaemia)⁸ and women who have a history of gestational diabetes⁹. For these people, follow up and

⁸ People with impaired glucose regulation have difficulty maintaining their blood glucose levels within the normal range but are able to maintain their blood glucose levels below the diabetic range. They have a greatly increased risk of developing diabetes and cardiovascular disease. The World Health Organisation has now defined two categories of impaired glucose regulation: impaired glucose tolerance (IGT) and impaired fasting glycaemia (IFG).

⁹ Gestational diabetes is defined as any degree of impaired glucose regulation, resulting in raised blood glucose levels of variable severity, which is first recognised during pregnancy. (See page 36).

regular testing can lead to the earlier diagnosis of diabetes in those who go on to develop the condition. This should be complemented by advice and support to reduce their risk of developing diabetes, and information to help them recognise the symptoms and signs of diabetes.

5. People who have multiple risk factors for diabetes – such as family history, ethnic background, obesity, increasing age – also need advice and support to reduce their risk of developing diabetes and information about the symptoms and signs of diabetes. In addition, opportunistic screening (testing for diabetes when people are in contact with health services for another reason) will identify some people who do not know that they have the condition.
6. Opportunistic screening can help, but there is also a logical case for a more systematic approach to offering screening. People may have undiagnosed Type 2 diabetes for many years before they are diagnosed, by which time some may already have developed complications of diabetes. There is emerging evidence to suggest that it may be clinically and cost effective to offer screening to those sub-groups of the population at increased risk of developing diabetes.
7. The *National Service Framework for Diabetes* provides the opportunity to clarify policy in this area, and the UK National Screening Committee (NSC) has been asked to advise the Department of Health. The NSC has decided that further research, which may require some complex studies, is needed to inform their advice. It will report to the Department of Health in 2005.

Key Interventions

- Increased awareness of the symptoms and signs of diabetes among both health professionals and the general public can result in the earlier identification of people with diabetes. **(Level 3)**
- Follow up and regular testing of individuals known to be at increased risk of developing diabetes (people who have previously been found to have impaired glucose regulation and women with a history of gestational diabetes) can lead to the earlier diagnosis of diabetes. **(Level 2)**
- Opportunistic screening of people with multiple risk factors for diabetes can lead to the identification of some individuals with previously undiagnosed diabetes. **(Level 2)**

Implications for Service Planning

8. The NHS and partner agencies will need to develop local plans to ensure that health and other professionals most likely to come into contact with people with undiagnosed diabetes are aware of the symptoms and signs of diabetes. These include:
 - primary care and community health care staff, particularly those working with older people or black and minority ethnic groups
 - NHS Direct staff
 - staff working in hospitals
 - residential and nursing home staff
 - staff working in specialist cardiology and renal teams
 - pharmacists, optometrists, dentists and podiatrists.

9. The NHS will need to:
 - be able to identify people who have previously been found to have impaired glucose regulation and women who have had a previous diagnosis of gestational diabetes, so that they can be followed up and offered regular testing
 - use its information systems to benchmark the prevalence of diabetes in populations with similar socio-demographic characteristics so that any likely under-diagnosis can be identified.

Empowering people with diabetes

Aim

To ensure that people with diabetes are empowered to enhance their personal control over the day-to-day management of their diabetes in a way that enables them to experience the best possible quality of life.

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.

Rationale

1. Users of the NHS should have choice, voice and control over what happens to them at each step of their care. Empowering people with long-term conditions in their relationships with health and other professionals enables them to assert control over their lives, build confidence and be active partners in their care.
2. The Expert Patient Taskforce¹⁰ noted that, although people have needs specific to their individual disease, they also have a core of common requirements, for example:
 - knowing how to recognise and act upon symptoms
 - dealing with acute attacks or exacerbations of the disease
 - making the most effective use of medicines and treatment
 - understanding the implications of professional advice
 - establishing a stable pattern of sleep and rest and dealing with fatigue
 - accessing social and other services
 - managing work and the resources of employment services

¹⁰ Department of Health. *The Expert Patient: A New Approach to Chronic Disease Management in the 21st Century*. London: Department of Health, 2001.

- accessing chosen leisure activities
 - developing strategies to deal with the psychological consequences of illness
 - learning to cope with other people's response to their chronic illness.
3. Diabetes is a chronic life-long condition that impacts upon almost every aspect of life. Living with diabetes is not easy. Medication is usually self-administered, whilst lifestyle changes involving diet and physical activity require commitment and active involvement. Those with Type 1 diabetes have to balance the risks of hypoglycaemia against the longer-term risks of hyperglycaemia. Those with Type 2 diabetes usually need to make changes in their lifestyle, but this can be difficult to do if the individual does not feel ill or the impact of not doing so does not have immediate repercussions.
 4. People who take on greater responsibility for the management of their diabetes have been shown to have reduced blood glucose levels, with no increase in severe hypoglycaemic attacks, a marked improvement in quality of life and a significant increase in satisfaction with treatment. However, for a range of reasons, a significant proportion of people with diabetes do not understand key elements of their diabetes care.
 5. Additionally a diagnosis of diabetes can lead to poor psychological adjustment, including self-blame and denial, which can create barriers to effective self-management. The diagnosis can also create or reinforce a sense of low self-esteem and induce resistance and depression. While the health benefits of self-management and care are clear, a commitment to the person with diabetes having choice, voice and control over what happens to them means that this must be balanced with their autonomy in choosing how they live their life with diabetes. The health professional's role is to ensure that choices are informed by an understanding of, and information about, the risks and consequences of the choices being made.
 6. The provision of information, education and psychological support that facilitates self-management is therefore the cornerstone of diabetes care. People with diabetes need the knowledge, skills and motivation to assess their risks, to understand what they will gain from changing their behaviour or lifestyle and to act on that understanding by engaging in appropriate behaviours. Other beneficial factors include:
 - a family and social environment that supports behaviour change: families and communities provide both practical support and a framework for the individual's beliefs
 - the tools to support behaviour, for example, affordable healthier food options both at home and in the workplace
 - active involvement in negotiating, agreeing and owning goals

- knowledge to understand the consequences of different choices and to enable action.

Key Interventions

- Structured education can improve knowledge, blood glucose control, weight and dietary management, physical activity and psychological well-being, particularly when this is tailored to the needs of the individual and includes skills-based approaches to education **(Level 1)**
- Personal care plans can help empower people with diabetes **(Level 4)**
- Patient held/accessed records can facilitate self-care **(Level 4)**

Implications for Service Planning

7. The NHS and partner agencies will need to develop, review and audit programmes for empowering people with diabetes, which include:
 - behavioural change programmes
 - structured education programmes
 - the provision of information about diabetes and its management
 - effective care plans
 - patient-held accessible records
 - the use of new technologies, including the Internet.
8. The NHS will need to ensure that service providers have the attitudes, skills and knowledge to provide person-centred care, including communication, counselling and behaviour change support skills. The Long Term Conditions Care Group Workforce Team, set up by the Department of Health, will review and make recommendations in this area.

Clinical care of adults with diabetes

Aim

To maximise the quality of life of all people with diabetes and to reduce their risk of developing the long-term complications of 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.

Rationale

1. For most people with diabetes, coming to terms with their lifelong condition will be challenging. They may grieve for the loss of earlier identities as a 'healthy person' and will need to adjust to the fact that they have a long-term condition, the treatment of which may involve fundamental changes in their lifestyle if they are to reduce their risk of developing long-term complications. Key to this will be their ability to control their blood glucose and, where necessary, to reduce their blood pressure. The treatment and care required will vary as people's length of time living with diabetes increases and as they negotiate major life events.
2. There is robust evidence that meticulous blood glucose control can prevent or delay the onset of microvascular complications. It may also reduce the risk of developing cardiovascular disease. However, this requires effort and dedication on the part of the person with diabetes and the health professionals working with them. For people with Type 1 diabetes, insulin is the mainstay of blood glucose management and is essential for survival. For people with newly diagnosed Type 2 diabetes, the majority of whom are overweight, weight loss and increased physical activity are the first intervention, followed by the addition of medication, as appropriate.
3. Up to 70% of adults with Type 2 diabetes have raised blood pressure and more than 70% have raised cholesterol levels. Both increase the risk of developing cardiovascular disease as well as microvascular complications. Pre-menopausal women with diabetes do not have the same protection against coronary heart disease as other pre-menopausal women. Tight blood pressure control improves health outcomes in people with Type 2 diabetes. Results for people with Type 2 diabetes who participated in trials to assess the effectiveness of lipid-lowering therapy suggest that a reduction in cholesterol levels may also reduce their risk of cardiovascular

events. Stopping smoking is one of the most effective ways of reducing the risk of developing cardiovascular disease and also reduces the risk of developing microvascular complications.

4. Structured diabetes care programmes, which include the provision of regular recall and review of people with diabetes, can improve the quality of diabetes care and result in better glycaemic control and quality of life, reductions in cardiovascular risk factors, lower rates of long-term complications and lower mortality rates. This is particularly so when combined with interventions targeted at the health professionals providing diabetes care, such as reminders to undertake annual reviews, the provision of guidelines and the opportunity to participate in continuing education.

Key Interventions

- Improving blood glucose control reduces the risk of developing the microvascular complications of diabetes in people with both Type 1 and Type 2 diabetes. **(Level 1)**
- Improving blood glucose control may reduce the risk of people with diabetes developing cardiovascular disease. **(Level 1)**
- Controlling raised blood pressure in people with diabetes who have co-existing hypertension reduces their risk of developing both microvascular complications and cardiovascular disease. **(Level 1)**
- Reducing cholesterol levels in people with diabetes who have raised cholesterol levels may reduce their risk of cardiovascular disease. **(Level 2)**
- Smoking cessation in people with diabetes who smoke reduces their risk of both cardiovascular disease and microvascular complications. **(Level 2)**
- Regular recall and review of people with diabetes can improve the quality of diabetes care and subsequent outcomes for people with diabetes. **(Level 1)**

Implications for Service Planning

5. The NHS, with partner agencies, will need to review the local provision of diabetes services so that they can identify any deficiencies.
6. The NHS will need to agree, implement and audit protocols for:
 - the initial assessment and care of people presenting with diabetes – these should be implemented in all health care settings where people with newly diagnosed diabetes may present (eg general practice, NHS Direct, accident and emergency departments, other hospital settings, community pharmacies)

- the continuing care of people with diabetes
 - the identification and follow-up of non-attenders
 - the provision of appropriate support for people who are housebound or who are living in residential or custodial settings, to ensure they are receiving structured diabetes care
 - ensuring all laboratories undertaking HbA_{1c}¹¹ estimations are participating in approved external quality assessment schemes and using analytical methods which meet the recommended minimum criteria for consistency and quality
 - ensuring that analysers used for point-of-care testing of HbA_{1c} are included in approved external quality assessment schemes.
7. The NHS will need to ensure that all health professionals involved in the diagnosis and care of people with diabetes receive continuing training to ensure that they are appropriately skilled in the diagnosis and management of diabetes.

11 An HbA_{1c} test provides a way of assessing the average blood glucose level over the previous 6-8 weeks

Clinical care of children and young people with diabetes

Aim

To ensure that the special needs of children and young people with diabetes are recognised and met, thereby ensuring that, when they enter adulthood, they are in the best of health and able to manage their own day-to-day diabetes care effectively.

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.

Rationale

1. Children and young people with diabetes are subject to all the normal pressures and pleasures of physical, emotional and social development. Their needs as an individual within a family or family system, and the role of their parents or carers and siblings in sustaining them from initial diagnosis through childhood to independence, are key. Those who develop Type 1 diabetes require lifelong insulin replacement therapy, which will need to be regularly adjusted as they grow. Good blood glucose control is essential for normal growth and development and to avoid the acute long-term complications of diabetes. The optimisation of diabetes control is also important for their intellectual and educational attainment. While physical maturity will be largely complete by the late teens, young people continue forming their identities into early adulthood. During this period, they face unique pressures to conform to social, cultural and sexual norms, which may challenge their ability to manage their diabetes.

2. There has been a steady rise in the incidence of diabetes in children and young people in recent decades. The majority of children and young people with diabetes have Type 1 diabetes and the risk of developing Type 1 diabetes is similar for all ethnic groups. However, Type 2 diabetes is also increasingly being diagnosed in young people, particularly in those from minority ethnic groups. Maturity onset diabetes of the young (MODY)¹² and other rare genetic disorders of insulin metabolism may also be diagnosed in children and young people. People who develop diabetes in childhood can have a reduced life expectancy – their lifespan may be reduced by as much as 20 years – and many develop the long-term complications of diabetes, such as nephropathy and retinopathy, before they reach middle age.
3. Parents of young children with diabetes need to be actively involved in the day-to-day diabetes management of their children. Others, such as staff in nurseries and schools, will also be involved in the day-to-day care of children and young people with diabetes.
4. Children and young people with diabetes need the support of a health service not only expert in child health and diabetes, but also able to support them through the transitions from childhood through adolescence to adulthood. Diabetes is often more difficult to control during the teenage years and in early adult life due both to the hormonal changes of puberty and to the emotional roller-coaster that often characterises adolescence. Young people have higher rates of diabetic emergencies and death rates are significantly higher than in young people without diabetes. Greater effort is required to ensure effective diabetes control at this time than at any other stage of life both by health professionals and by young people themselves.
5. The transfer of young people from paediatric diabetes services to services for adults with diabetes often occurs at a sensitive time for the individual concerned, both personally and from the point of view of their diabetes. Many find the culture change unacceptable and non-attendance rates at adult diabetes clinics are often higher in young people and young adults. Care can also become disjointed and young people can feel unsupported. This may be exacerbated when young people leave home and adopt more mobile lifestyles.
6. The forthcoming Children's National Service Framework will identify issues relevant to the delivery of all children's services. The Children's National Service Framework will complement the National Service Framework for Diabetes.

¹² MODY includes several forms of diabetes that are associated with monogenic defects of β -cell function. They are frequently characterised by the onset of mild hyperglycaemia at an early age (usually before the age of 25 years) and are usually inherited in an autosomal dominant pattern. People with these forms of diabetes have impaired insulin secretion with minimal or no defect of insulin action.

Key Interventions

- The provision of education for school staff and health professionals can lead to the earlier recognition of new-onset diabetes in children and young people before it progresses to diabetic ketoacidosis. **(Level 3)**
- Small group interventions (either children with their parents, or young people without their parents) that address practical diabetes management issues and provide a forum for support and guidance can lead to improvements in knowledge of diabetes management, self-care and blood glucose control. **(Level 3)**
- Good blood glucose control leads to optimal physical growth and development and reduces the risk of acute and long-term complications. **(Level 3)**
- The planned transfer of the care of young people with diabetes from paediatric diabetes services to adult diabetes services promotes diabetes self-care and improves outcomes. **(Level 4)**

Implications for Service Planning

7. The NHS and partner organisations will need to agree, implement and audit protocols for:
 - the initial assessment and care of children and young people presenting with diabetes – these should be implemented in all health care settings where people with newly diagnosed diabetes may present (eg general practice, NHS Direct, accident and emergency departments, other hospital settings, community pharmacies)
 - the continuing care of children and young people with diabetes
 - the transfer of young people from paediatric diabetes services to adult diabetes services
 - the identification and follow-up of non-attenders
 - the provision of appropriate support for children and young people living in residential settings, including boarding schools and care homes, and for looked after children.

Management of diabetic emergencies

Aim

To minimise the impact on people with diabetes of the acute complications of diabetes.

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.

Rationale

1. The acute complications of diabetes include diabetic ketoacidosis (DKA) and hyperosmolar non-ketotic syndrome (HONK), both of which are characterised by very high blood glucose levels resulting from a severe lack of insulin; and hypoglycaemia, when the blood glucose level falls too low. Children and young people with diabetes are particularly susceptible to diabetic emergencies. People with diabetes and their carers need to be alert to the dangers of these potentially life-threatening situations. They need to know how these emergencies can be prevented and how to detect and respond rapidly to the early signs of an emergency. Health professionals also need to know how to respond.
2. The prevalence of the acute complications of diabetes can be reduced through education of people with diabetes and all 'front line' health professionals about how to avert hypoglycaemic episodes and how to prevent DKA and HONK.
3. DKA is an avoidable, potentially life-threatening, complication of diabetes and is caused by an inadequate concentration of insulin in the blood. As a result, the cells in the body are unable to use glucose as an energy source and have to rely on the body's fat reserves. Blood glucose levels rise, as do the by-products of fat metabolism (ketone bodies). The latter causes the blood to become more acidic than usual. About a quarter of cases of DKA occur in people with newly presenting Type 1 diabetes. In those with previously diagnosed diabetes, insulin omission, infection and other severe acute illness, such as myocardial infarction or pneumonia, are the main precipitating causes.
4. DKA may lead to drowsiness and coma. People who develop DKA require urgent hospital treatment. DKA continues to be a prominent cause of death in people with diabetes, particularly in children and young people. Cerebral oedema (swelling of the

- brain) is a serious complication of DKA. This is more common in children and young people and carries a high risk of permanent neurological damage and death.
5. HONK is a life-threatening condition, which mainly occurs in older people with Type 2 diabetes. In about a third of cases of HONK, it is the first manifestation of Type 2 diabetes. The blood glucose level rises to very high levels but acidosis does not develop. Severe dehydration can result. Mortality from HONK is high, with reported death rates as high as 58%.
 6. Hypoglycaemia is a common side effect of treatment with insulin and can also occur in people with Type 2 diabetes treated with some types of oral hypoglycaemic drugs (eg long-acting sulphonylureas). Irregular or missed meals, exercise and alcohol consumption can predispose to hypoglycaemia. The brain is dependent on a continuous supply of glucose as its main energy source and, when blood glucose levels fall below a critical level, brain function is affected. This can lead to confusion, fits and coma and can, on occasion, be fatal.
 7. The risk of severe hypoglycaemia, defined as hypoglycaemia requiring the help of others to reverse it, may be higher in people receiving intensive insulin therapy. Fear of hypoglycaemia can be a major obstacle to the achievement of the blood glucose levels required to prevent the long-term complications of diabetes. Repeated episodes of hypoglycaemia may seriously impair quality of life. For example, it may restrict educational and employment opportunities and ability to drive, as well as participation in sports and social activities. Although severe hypoglycaemia does not appear to cause long-term impairment of brain function in adults, it may result in neuropsychological impairment in children, particularly in younger children. All steps should therefore be taken to prevent severe recurrent hypoglycaemia in young children with diabetes, particularly those under five years of age.

Key Interventions

- The risk and severity of diabetic ketoacidosis can be reduced by the provision of guidance and advice to people with diabetes on how to manage changes in blood glucose control that occur during other illnesses ('sick day' rules). **(Level 4)**
- Most episodes of hypoglycaemia can be managed in the community, either by the person with diabetes, a relative or carer, their GP or by ambulance personnel. **(Level 4)**

Implications for Service Planning

8. NHS, and partner agencies where appropriate, will need to agree, implement and audit protocols for the:
 - provision of education for people with diabetes and their families and people who work with people at risk of the acute complications of diabetes, particularly those who work with children, about the signs and symptoms of diabetic emergencies, their avoidance and their management
 - recognition and initial management of diabetic emergencies by frontline emergency staff (eg ambulance personnel, GPs, accident and emergency department staff) in all settings where people with acute complications of diabetes may present, including the home, general medical and dental practices and other primary care settings, accident and emergency departments and other hospital settings
 - management of DKA and HONK in hospital.
9. Training will also need to be provided for local health and other relevant workers to ensure that they are aware of the local services available for the management of diabetic emergencies.

Care of people with diabetes during admission to hospital

Aim

To ensure good quality consistent care is provided for people with diabetes whenever they are admitted 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.

Rationale

1. People with diabetes are admitted to hospital twice as often and stay twice as long than those without diabetes. They occupy one in ten acute hospital beds.
2. They also frequently describe poor experiences of inpatient care, particularly in relation to:
 - inadequate knowledge of diabetes among hospital staff
 - inappropriate amounts and timings of food and inappropriate timings of medication
 - the lack of information provided
 - delays in discharge resulting from their diabetes, especially when diabetes was not the original reason for their admission.
3. Timely liaison with the diabetes team can both prevent the need for diabetes-related admissions and, where hospital admission is unavoidable, prevent complications during admission and delayed discharge.
4. The employment of a specialist nurse to oversee the diabetes management of people with diabetes during their admission to hospital can reduce their length of stay and release bed space. Patients are also more knowledgeable about, and satisfied with, care provided in this way.

5. Surgery in people with diabetes is associated with increased clinical risk. This can be reduced by adherence to locally agreed evidence-based guidelines for the management of people with diabetes during surgical procedures.

Key Interventions

- Outcomes for people with diabetes following admission to hospital can be improved by better liaison between the diabetes team and ward staff. **(Level 3)**
- Perioperative outcomes for people with diabetes can be improved by the adherence to locally agreed evidence-based guidelines for the management of people with diabetes during surgical procedures. **(Level 3)**

Implications for Service Planning

6. The NHS will need to review the systems in place for ensuring that, when people with pre-existing diabetes are admitted to hospital, they continue to receive effective diabetes care and are enabled to continue to manage their own diabetes wherever possible.
7. Hospitals will be expected to have in place, and regularly to update and audit the implementation of, hospital-wide protocols for the management of people with diabetes in all clinical situations, including during investigative and operative procedures (including day surgery, booked and emergency surgery) and during admissions for other illnesses. These protocols will need to encompass:
 - the involvement people with diabetes in decisions concerning their diabetes care
 - the provision of healthier food and snack choices
 - the monitoring and maintenance of blood glucose control, including the provision of intravenous infusions of insulin and fluids
 - diabetic wound management
 - the appropriate timing of investigations or operative procedures
 - the particular needs of people from different minority ethnic and religious groups, including access to appropriate food choices
 - the provision of clear information to people with diabetes about the management of their diabetes during their hospital stay and after discharge
 - liaison with and referral to the diabetes team.

Diabetes and Pregnancy

Aim

To achieve a good outcome and experience of pregnancy and childbirth for women with pre-existing diabetes and for those who develop diabetes in 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.

Rationale

1. The aim of maternity care is to ensure that all pregnant women have a positive experience of pregnancy and childbirth and receive care that promotes their physical health and psychological well-being and optimises the health of their baby. Although some women's experience of a 'medicalised' and high-intervention labour and delivery can be a negative or frightening one, this need not be the case if they and their partner are involved in decision-making and kept fully informed.
2. Diabetes is the most common pre-existing medical disorder complicating pregnancy in the UK. Approximately one pregnant women in 250 has pre-existing diabetes. This is associated with increased risks for both mother and baby.
3. Women with pre-existing diabetes are much more likely to lose their baby than women who do not have diabetes, either during pregnancy as a result of a miscarriage or an intrauterine death, or after birth. In the UK, perinatal mortality rates¹³ amongst the babies of diabetic mothers are up to five times higher than in the general population. Congenital malformations are the main cause of this high perinatal mortality. These result from abnormal fetal development during the six weeks following conception. Later in pregnancy, the main risks to the baby are excessive fetal growth (macrosomia), which can result in damage to both the baby and the mother during delivery. The main risk to the baby after delivery is hypoglycaemia. These risks can be reduced if near-normal blood glucose levels are achieved before and around the time of conception, throughout pregnancy and during labour.

¹³ Perinatal mortality rate is defined as the number of stillbirths plus the number of deaths during the first week of life per 1000 live births.

4. Pregnancy results in increasing insulin resistance and, if this is not matched by more insulin, hyperglycaemia ensues. However, intensified glucose control can also increase the risk of hypoglycaemia. Pregnancy can also result in the progression, if present, of diabetic retinopathy and diabetic nephropathy. Women with pre-existing diabetic nephropathy also have an increased risk of pre-eclampsia, hypertensive disease of pregnancy and placental insufficiency. Maternal deaths in women with diabetes are now thankfully rare, but do still occur occasionally.
5. Outcomes can be improved if women with pre-existing diabetes are supported to plan their pregnancies and to optimise their blood glucose control before and throughout their pregnancies. They should receive close monitoring and specialist care throughout pregnancy and childbirth.
6. Between 2 and 12 percent of women develop gestational diabetes¹⁴, which is more common in women from minority ethnic groups. These women are more likely to have large-for-dates babies, a risk that can be reduced by reducing maternal hyperglycaemia. Women whose blood glucose levels revert to normal after delivery have an increased risk of developing Type 2 diabetes later in life. They can reduce this risk by increasing their physical activity levels, eating a balanced diet and avoiding excessive weight gain.
7. The Children's National Service Framework will set standards for maternity services and will complement the National Service Framework for Diabetes.

Key interventions

- Tight blood glucose control before and during pregnancy in women with pre-existing diabetes leads to a reduction in congenital malformation rates and perinatal mortality rates. **(Level 1)**
- Tight blood glucose control during the third trimester can reduce the risk of fetal macrosomia and its associated consequences. **(Level 3)**
- Tight blood glucose control during labour reduces the risk of neonatal hypoglycaemia. **(Level 3)**

¹⁴ Gestational diabetes is defined as any degree of impaired glucose regulation, resulting in raised blood glucose levels of variable severity, which is first recognised during pregnancy. This includes Type 1 diabetes presenting for the first time during pregnancy; Type 2 diabetes identified during pregnancy, which in many cases was probably present, but undiagnosed, before the pregnancy; and lesser degrees of impaired glucose regulation, which in most cases reverts to normal after the pregnancy.

Implications for Service Planning

8. The NHS will need to agree, implement and audit local protocols for the management of pregnant women with diabetes. These should cover:
 - the provision of advice to all women of child-bearing age with diabetes about the importance of good blood glucose control before and during pregnancy
 - the provision of pre-conception care
 - the provision of antenatal care, including the detection and management of microvascular complications of diabetes and the detection and management of obstetric complications
 - the provision of intrapartum and postpartum care
 - the detection and management of neonatal hypoglycaemia and other neonatal complications in babies born to women with diabetes.

9. The NHS will also need to review local policies for the detection and management of gestational diabetes to ensure that they are in line with the latest guidance from the National Screening Committee.

Detection and management of long-term complications

Aim

To minimise the impact of the long-term complications of diabetes by early detection and effective treatment and by maximising the quality of life of those who develop 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.

Rationale

1. People with diabetes are at risk of developing the microvascular complications of diabetes: diabetic retinopathy (damage to the eyes), diabetic nephropathy (damage to the kidneys) and diabetic neuropathy (damage to the nerves). They are also at increased risk of developing cardiovascular disease, including coronary heart disease, stroke and peripheral vascular disease.
2. The impact of the microvascular complications can be reduced if they are detected and treated at an early stage.
3. Early detection of sight-threatening **diabetic retinopathy** and treatment with laser therapy can prevent visual impairment. The quality of life of those who develop visual impairment can be improved by access to low vision aids, information, psychological support and appropriate welfare benefits.

4. Angiotensin converting enzyme (ACE) inhibitors can delay the onset of **diabetic nephropathy**¹⁵ in people with diabetes who are found to have microalbuminuria¹⁶. Tight control of raised blood pressure, as well as tight blood glucose control, can significantly reduce the rate of progression of diabetic nephropathy.
5. Diabetic foot problems are the most frequent manifestation of **diabetic neuropathy**. Foot ulceration and lower limb amputation can be reduced if people who have sensory neuropathy affecting their feet are identified and offered foot care education, podiatry and, where required, protective footwear. Prompt treatment of foot ulcers can reduce the risk of amputation. For those who require amputation, their rehabilitation can be optimised through the provision of care by integrated, multidisciplinary, rehabilitation, prosthetic and social support teams.
6. People with diabetes who develop cardiovascular disease can benefit from secondary prevention measures already recommended for the general population in the *National Service Framework for Coronary Heart Disease*, including treatment with low dose aspirin, β -blockers and lipid-lowering agents. In addition, outcomes for people with Type 2 diabetes who have a heart attack are improved if they are treated with intensive insulin therapy.
7. Regular surveillance for, and effective management of, other conditions that occur more commonly in people with diabetes, such as depression and erectile dysfunction, can reduce the impact of these conditions on the quality of life of people with diabetes.

15 Diabetic nephropathy is diagnosed clinically and is defined as the presence of clinical proteinuria (urine dipstick persistently positive for protein or albumin excretion >300mg/day) in a person with diabetes who does not have any other renal disease.

16 Microalbuminuria is defined as an increased excretion of albumin to between 30–300mg/24 hours or 20–200 μ g/min (ie less than the level of albuminuria detectable by dipstick urine tests).

Key Interventions

- Regular surveillance for diabetic retinopathy in adults with diabetes and early laser treatment of those identified as having sight-threatening retinopathy can reduce the incidence of new visual impairment and blindness in people with diabetes **(Level 1)**
- Treatment of people who have microalbuminuria with ACE inhibitors can reduce their rate of progression to diabetic nephropathy **(Level 1)**
- Tight blood pressure and blood glucose control in people with diabetic nephropathy can reduce the rate of deterioration in their renal function, as well as their risk of cardiovascular disease **(Level 1)**
- People with diabetes identified as being at increased risk of developing lower limb complications can reduce this risk by participating in a foot care programme that provides foot care education, podiatry and, where required, protective footwear **(Level 1)**
- In people with diabetes who develop foot ulceration, prompt intervention can minimise their risk of subsequent disability and amputation **(Level 1)**
- People with diabetes who have established cardiovascular disease can benefit from the secondary prevention measures already recommended for the general population in the *National Service Framework for Coronary Heart Disease* **(Level 1)**
- Administration of intensive insulin therapy to people with diabetes who sustain a heart attack can reduce their risk of death by 30% **(Level 1)**

Implications for Service Planning

8. The NHS, with partner agencies, will need to:
 - review the local provision of services for the detection and management of people with long-term complications of diabetes
 - put systems in place for ensuring that all young people and adults with diabetes receive regular surveillance for the long-term complications of diabetes and for those conditions which occur more commonly in people with diabetes
 - agree, implement and audit local guidelines for the management of people with long-term complications, which are consistent with national guidance.

CHAPTER 3: NEXT STEPS

Introduction

1. This document, the *National Service Framework for Diabetes: Standards*, sets a direction of travel for diabetes prevention and care with clear standards for the NHS and partner agencies.
2. The second stage of the *National Service Framework for Diabetes: Delivery Strategy*, will be published in summer 2002. It will take account of comments received from the consultation on the detailed interventions, service models and performance indicators described on the website. It will set out the action to be taken by local health and social care systems, milestones, performance management arrangements and the underpinning national programmes to support local delivery.

The Context for Implementation

3. The discussion document *Shifting the Balance of Power within the NHS*¹⁷ proposed the organisational changes required to deliver the reforms set out in *The NHS Plan*:
 - Primary Care Trusts will become the lead NHS organisation in assessing need, planning and securing all health services, and improving health. They will forge new partnerships with local communities and lead the NHS contribution to work jointly with local government and other partners.
 - NHS Trusts will continue to provide services, working within delivery agreements made with Primary Care Trusts. They will be expected to devolve greater responsibility to clinical teams and to foster and encourage the growth of clinical networks across NHS organisations.
 - Strategic Health Authorities, to be established, subject to legislation, in 2002, will lead the strategic development of local health services and performance manage Primary Care Trusts and NHS Trusts on the basis of local accountability agreements.
 - The Department of Health will focus on supporting the delivery of the NHS Plan and social care goals. The four Directors of Health and Social Care will oversee the development of the NHS and provide the link between NHS organisations and the Department. The NHS Modernisation Agency (including the Leadership Centre) and the NHS University will support the development of frontline staff and services.

¹⁷ Department of Health. *Shifting the Balance of Power within the NHS: Securing Delivery*. London: Department of Health, 2001.

4. The Delivery Strategy will set out actions and milestones required of each level of the service and partner agencies.

National Action to Support Implementation

5. In developing this NSF we have identified a number of synergies with other priorities. The NSF therefore builds on the programme of published NSFs, especially those for Coronary Heart Disease and Older People. It will also link with the forthcoming NSFs for Renal Services and Children.
6. At the same time, we need to take account of the wider priorities for modernisation. In particular, we have noted the concerns about the cumulative impact of the NSF programme, together with *The NHS Cancer Plan*¹⁸, especially on primary care. The National Director for Primary Care, David Colin-Thome, is leading a project to look at the implementation of National Service Frameworks so as to manage the pressures on primary care. This will include specific programmes and trained staff to support primary care.
7. Work will also continue at national level on underpinning programmes to support delivery, including research and development, clinical decision support systems, information, workforce development, and performance management:
 - a Research Advisory Committee has been established jointly with the Medical Research Council with the involvement of Diabetes UK and will produce a topic review of research on diabetes in May 2002
 - the National Institute for Clinical Excellence will be publishing guidelines on Type 1 and Type 2 diabetes as well as a series of appraisals. Details can be found at www.nice.org.uk
 - a Diabetes Information Strategy will be published early next year
 - a Care Group Workforce Team for Long-Term Conditions will take a national view of the workforce implications of the standards and interventions and produce an interim report for the NSF Implementation Group by May 2002.
8. A proposed set of performance indicators to monitor progress towards the achievement of each standard and proposals for setting up virtual practice-based diabetes registers are on the web www.doh.gov.uk.nsf.diabetes. Views on these are welcomed.

18 Department of Health. *The NHS Cancer Plan: A plan for investment. A plan for reform*. London: Department of Health, 2000.

The Diabetes NSF Implementation Group

9. A Diabetes NSF Implementation Group will now be set up to steer the development of the *National Service Framework for Diabetes: Delivery Strategy*. This will be co-chaired by Professor Mike Pringle (Co-chair of the Diabetes External Reference Group) and Dr Sheila Adam (Director of Policy in the Department of Health). The NSF Implementation Group will involve a wide range of stakeholders, including people with diabetes. It will use workshops and conferences as appropriate and will work with the range of external stakeholders to:
- identify the most effective ways to support the NHS and partner agencies in implementation
 - review the service models and performance indicators proposed in the light of comments received
 - ensure effective links with the underpinning programmes on clinical governance, workforce, information, and research & development
 - develop specifications for tools to support local delivery, including templates for protocols, technology appraisals, clinical guidelines and clinical audit tools
 - clarify the roles and responsibilities of NHS organisations for delivery
 - build constructive links with the delivery mechanisms for the other NSFs and *The NHS Cancer Plan*, including within primary care
 - explore the possibilities of partnership between the NHS, Patient Advocacy Groups such as Diabetes UK, the Royal Colleges, the pharmaceutical and health care industries and others, to support effective implementation of the NSF
 - prioritise its recommendations, taking account of the likely resources and capacity of the NHS to deliver, and ensuring that the delivery strategy addresses health inequalities.

Local Action to Support Planning

10. *The NHS Plan*¹⁹ sets out clearly how all parts of the NHS will work together to develop partnerships at all levels of care: between patients, their carers and families, and NHS staff; between the health and social care sectors; across different government departments; between the public sector, voluntary organisations and private providers. The goal is to ensure a patient-centred service.

¹⁹ Department of Health. *The NHS Plan: A plan for investment. A plan for reform*. London: Department of Health, July 2000.

11. Where Local Diabetes Services Advisory Groups (LDSAGs) have worked well they have championed a patient-centred approach, the involvement of people with diabetes in planning and have been a force for change. With the abolition of Health Authorities and the forthcoming programme on diabetes, we need to consider how such mechanisms can evolve to continue to play such roles within the new structures of the NHS.
12. In the meantime, some local services will already have put in place some of the interventions and service models proposed on the web. We intend that, by setting out the standards we wish to achieve in this NSF, service providers can feel confident to continue to make progress in line with the standards set out here.
13. From 2002, NHS Trusts will begin to carry out annual surveys of patients' and carers' experience of the services they have received. In addition, there will be a rolling programme to assess specific areas of care, and this will include diabetes. The survey will provide a baseline from which we can trace improvements over time, providing a foundation for local action, based on the views of people with diabetes. This work will be taken forward through the programme on public and patient involvement and *The Expert Patient*.
14. Over the coming year the NHS will wish to establish the current position by undertaking a baseline assessment of services and consider the implications of the standards and interventions for planning and organising services.

Conclusion

15. We are publishing this document now to give local health and social care systems the opportunity to develop thinking on implementing the *National Service Framework for Diabetes: Standards* in the lead up to April 2003. Where Local Diabetes Services Advisory Groups exist, their work may provide the basis for this.
16. The next steps in the Diabetes NSF will be signalled by the publication of the *National Service Framework for Diabetes: Delivery Strategy* next year. Implementation will take place from April 2003, and Primary Care Trusts, working with local partners in their new alliances, will need to ensure that planning, resource allocation and service agreements reflect the NSF.
17. The Diabetes NSF Implementation Group will welcome comments at diabetes.nsf@doh.gsi.gov.uk or via:

Diabetes NSF
Department of Health
Wellington House
133–155 Waterloo Road
London SE1 8UG

ANNEX

External Reference Group Membership

Chairs:

Mike Pringle	Chair of Council*, Royal College of General Practitioners (*until November 2001)
Peter Houghton	Regional Director, Eastern Regional Office, Department of Health

Members:

George Alberti	Professor of Medicine, University of Newcastle President, Royal College of Physicians
Zac Arif	Director, London Primary and Community Services Access Project, London Regional Office, Department of Health
Debbie Bamford	Chief Executive of Woking Primary Care Group
Peter Betts	Consultant Paediatrician and Paediatric Endocrinologist, Southampton General Hospital
Ian Donnachie	Chief Executive, Bradford Health Authority
Azhar Farooqi	Principal in General Practice, East Leicester Medical Practice Clinical Governance Lead, Leicester City Central Primary Care Group
Owain Gibby	Consultant Physician, Royal Gwent Hospital, Newport
Trisha Greenhalgh	Principal in General Practice, Temple Fortune Health Centre Professor of Primary Health Care, University College, London.
Geeta Patel	Person with Type 1 diabetes
Veena Raleigh	Assistant Director, Research and Information, Commission for Health Improvement
John Rostill	Chief Executive, Walsall Hospitals NHS Trust
Paul Streets	Chief Executive, Diabetes UK
Sheridan Waldron	Dietetic Manager & Senior Dietitian for Children's Diabetes Leicestershire Nutrition & Dietetic Service
Rosemary Walker	Independent Diabetes Specialist Nurse, formerly of Havering Hospitals NHS Trust, Romford
John Weinman	Professor of Psychology, Guy's & St Thomas' Hospital, London (co-opted, September 2000)
Joan Wheeler	Person with Type 2 diabetes
Rhys Williams	Professor of Epidemiology & Public Health, Nuffield Institute for Health, University of Leeds
Bob Young	Consultant Physician, Salford Royal Hospitals

A list of people who have contributed to the work of the External Reference Group and the production of this document is on the web.

