

IMPROVING HEALTH IN WALES



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# National Service Framework for Diabetes in Wales

Delivery Strategy



Llywodraeth Cynulliad Cymru  
Welsh Assembly Government



# **Improving Health in Wales**

## **National Service Framework for Diabetes in Wales: Delivery Strategy**

*A national framework within which health professionals, people living with diabetes and communities can work together to improve diabetes services in Wales.*

Further copies of this document are available from

Health Services Policy and Development  
Welsh Assembly Government  
Cathays Park  
Cardiff  
CF10 3NQ

Tel: 029 2082 5519

The National Assembly for Wales Internet site at [www.wales.gov.uk](http://www.wales.gov.uk)





## Foreword



The recent Audit Commission '*Service Review of Diabetes in Wales*' - Primary Care Survey, indicates that the total number of people with diagnosed diabetes in Wales is about 3.5% of the population, with the possibility of as many as 50,000 people undiagnosed. The number of those affected by diabetes is predicted to double worldwide, rising to at least 5% of the world population by the year 2010<sup>1</sup>, largely as a result of lifestyle factors, poor diet and lack of physical activity. This figure may already have been reached in Wales.

Diabetes can have a significant impact on the quality of life of individuals, their families, friends, carers and the wider society. The emotional and social effects are often underestimated. If diabetes is poorly controlled or undetected, complications ensue, possibly resulting in heart attacks, strokes, foot ulcers, amputation of lower limbs, renal failure, nerve damage and blindness. In Wales, the prevalence of diabetes, and its complications, is higher amongst people from some minority ethnic groups and those who are socially disadvantaged.

Research has shown that better management of diabetes significantly reduces the risk of developing complications. For example eye screening to detect diabetic retinopathy can reduce the incidence of blindness by half. The All Wales Diabetic Retinopathy Screening Programme will be a significant advance in diabetes management in Wales.


There are many areas of good practice and good quality services across Wales. We want to see good practice developed in all areas, thereby reducing the inequalities in health care. Everyone with diabetes deserves access to high quality care and support.

The Diabetes National Service Framework standards were launched in Wales in April 2002. The Delivery Strategy is the foundation for the planning and implementation of the standards and developing partnerships with people with diabetes. Helping and supporting people to manage their care in this way can reduce disability and life expectancy can be increased.

The NSF is a ten-year plan, and sets out national objectives against which NHS performance can be judged. It offers local health services the opportunity to produce and disseminate implementation plans, and sets

targets, which will result in improved services and high quality care and support for all those with diabetes, their families, friends and carers throughout Wales.

I would like to thank all those who have been involved in developing the Diabetes NSF Delivery Strategy, which offers the vision of the future of diabetes care in Wales.

A handwritten signature in black ink that reads "Jane Hutt". The signature is written in a cursive, flowing style.

**Jane Hutt**

Minister for Health and Social Services

## Executive Summary

The Diabetes National Service Framework for Wales: Standards document was published in April 2002 and provides a vision of diabetes services which:

- leads to fewer people developing diabetes and improved care for people known to have diabetes
- is developed in partnership with health care staff, centred around the needs of people with diabetes, equitable, integrated and focused on delivering the best outcomes for the person with diabetes
- offers care that is structured and pro-active providing people and their carers with the support they need to manage their own condition
- is encapsulated in standards, key interventions and implications for service planning

### The key elements proposed in the Delivery Strategy are:

- setting up local diabetes networks or similarly robust mechanism, strengthening joint partnerships between Local Health Boards and Local Diabetes Service Advisory Groups
- reviewing the Audit Commission Baseline Service Review reports, establishing and promulgating local implementation arrangements to achieve the standards
- putting in place registers and clinical management systems published with the Delivery Strategy (Annex 2)
- All Wales Diabetes Retinopathy Screening Service
- participating in comparative local and national audit
- dedicated education and advice for people with diabetes
- ensuring that staff working with people with diabetes engage in continuous professional development and updating in diabetes education

The Delivery Strategy offers a framework for the NHS to build capacity to:

- put in place building blocks for the NHS to reach the National Service Framework targets over the next ten years.
- deliver the national targets.

# Chapter 1

## Setting the Scene

### What is diabetes?

Diabetes\* is a chronic and progressive condition 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. Whilst diabetes can result in ill health, disability and even in premature death, these can often be prevented or delayed by effective self-management, education and high-quality care. About 9%<sup>2</sup> of acute sector NHS costs are spent on diabetes and the management of its complications. Diabetes can also have a significant impact on the families or carers of people with diabetes and consideration of their needs is also paramount. 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 the body's inability to utilise it.

*There are two main types of diabetes: Type 1 diabetes and Type 2 diabetes.*

### Type 1 diabetes:

In people with Type 1 diabetes, the pancreas is no longer able to produce insulin because the insulin-producing  $\beta$ -cells have been destroyed by the body's immune system. Without insulin to move glucose from the bloodstream to the body's cells, glucose builds up in the blood and is excreted in the urine. Type 1 diabetes develops most frequently in children, young people and young adults. About 15% of people with diabetes have Type 1 diabetes. Symptoms can include increased or excessive thirst, passing urine frequently – particularly during the night, often resulting in enuresis - (bed-wetting, especially in children), 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 an elevated blood glucose level. People with Type 1 diabetes need daily injections of insulin to survive. Failure to take insulin can result in hyperglycaemia, and eventually diabetic ketoacidosis\*\*. If too much insulin is injected relative to diet and physical

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\* In this document the term diabetes refers to diabetes mellitus

\*\* Diabetic ketoacidosis is potentially a life threatening complication of diabetes caused by an inadequate concentration of insulin in the blood for the body's requirements

activity levels, this can lead to hypoglycaemia (very low blood glucose). Both hyperglycaemia and hypoglycaemia can lead to coma and, if untreated, death.

To prevent short and long term complications, people with diabetes need to maintain their blood glucose within certain limits, which will require adjustments in their diet, activity and lifestyle.

### **Type 2 diabetes:**

About 85% of people with diabetes have Type 2 diabetes, which in many cases could either have been prevented or its onset delayed. In Type 2 diabetes, the pancreas  $\beta$ -cells are not able to produce sufficient insulin for the body's needs, or the body is unable to properly utilise insulin produced (insulin resistance). Type 2 diabetes is most commonly diagnosed in adults over the age of 40, and many may have a close relative who has diabetes, although increasingly it is appearing in children and young adults. Symptoms usually appear more gradually than in the case of Type 1 diabetes, and diabetes may not be diagnosed for some years. The majority of people with Type 2 diabetes are overweight or obese and do not take enough exercise. The most significant modifiable risk factor for Type 2 diabetes is to tackle overweight and obesity. These issues will therefore need to be central to local health prevention and promotion strategies. Establishing control of diabetes, including weight and activity management as well as control of blood glucose, blood pressure and lipids will contribute to better outcomes. Of particular concern, Type 2 diabetes, previously considered an adult condition, is now increasingly being seen in overweight children, who could face very serious health consequences in the long term.

The National Institute for Clinical Excellence will be publishing guidelines on Type 1 and Type 2 diabetes as well as a series of appraisals which will also be applicable in Wales. Details can be found at [www.nice.org.uk](http://www.nice.org.uk)

### **Complications of Diabetes**

People with diabetes are more at risk of complications if they experience any of the following: prolonged hyperglycaemia, hypertension or dyslipidaemia. These manifestations of the condition can result in small (microvascular) or large (macrovascular) blood vessel damage. This small or large vessel damage manifests itself by reducing the blood supply to essential organs.

## **The microvascular complications are:**

### **Diabetic retinopathy:**

Damage to the eyes, which can lead to visual impairment and blindness. Diabetes is the leading cause of blindness in people of working age.<sup>3</sup>

### **Diabetic nephropathy:**

Damage to the kidney, which can lead to progressive renal failure. Diabetes is the leading cause of renal failure, accounting for more than one in six people starting renal replacement therapy.<sup>4</sup>

### **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, sometimes requiring lower limb amputation<sup>5</sup>. Diabetes is the second commonest cause of lower limb amputation.<sup>6</sup> Damage to other nerves can lead to a variety of symptoms, including postural hypotension, gustatory (abnormal) sweating, gastrointestinal problems (such as diarrhoea), difficulties with bladder emptying and erectile dysfunction (impotence).

## **The macrovascular complications are:**

### **Coronary heart disease:**

Which can include angina, acute myocardial infarction (heart attack) and heart failure. Mortality rates from coronary heart disease are up to five times higher for people with diabetes.<sup>7</sup>

### **Cerebrovascular disease:**

Strokes and transient ischaemic attacks can occur when the vessels supplying the brain/brainstem become damaged. Stroke is three times more frequent in people with diabetes.<sup>8</sup>

### **Peripheral vascular disease:**

Damage to the blood vessels supplying the legs resulting in poor circulation. Affected people may experience pain in the calves and are sixteen times more likely, than a person without diabetes, to require amputation of lower limbs.<sup>9</sup>

## Other Complications of Diabetes

**Complications during pregnancy and birth:** Diabetes, if not well controlled during pre-conception or in pregnancy, can result in an increased risk of congenital malformation of the foetus, intrauterine death or macrosomia (heavy birth weight) babies. Babies born to mothers with diabetes are also more likely to require neo-natal care.<sup>10 11 12</sup>

**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 affecting the urinary tract and the skin.

**Dental**, periodontal gum disease (which can significantly affect glycaemic control) is commoner in people with diabetes.

**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.

## THE IMPACT AND COST OF DIABETES

As a life-long condition, diabetes can have a profound impact on lifestyle, relationships, work, income, health, well being and life expectancy. It has a major impact on the physical, psychological and material well being of individuals, their families and carers, as well as on health and social services:

- 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.<sup>13</sup>
- 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 the person with diabetes requiring a carer.<sup>14</sup>

Diabetes also has a significant impact on health and social services:

- Around 9% of acute sector NHS costs spent on diabetes and management of its complications.<sup>15</sup>
- 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.<sup>16</sup>
- The presence of diabetic complications increases NHS costs more than five-fold. People with diabetes are five times more likely to need hospital admission.
- One in 20 people with diabetes incurs social services costs and, for these people, the average annual costs were £2,450 in 1999, and are likely to have increased since then. 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.<sup>17</sup>

## Diabetes does not affect everyone equally

Significant inequalities exist in the risk of developing diabetes, in access to health services, the quality of those services, and in health outcomes, particularly with regard to Type 2 diabetes.

Type 2 diabetes is up to six times more common in people of South Asian (Indian, Pakistani and Bangladeshi) 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.<sup>18</sup>

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, this is clearly unacceptable.<sup>19</sup>

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.<sup>20</sup> 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 5 than social class I.<sup>21</sup>

Socially excluded groups – including those in custodial settings, refugees and asylum seekers, people with learning disabilities or mental health problems and people who reside in Nursing or Residential Care Homes – may be more prone to the complications of diabetes and receive poorer quality care. Also, the number of people at high risk of diabetes and those with diabetes in the 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.<sup>22</sup>

The frequency of diabetes is higher in men than women. However, women with diabetes are at relatively greater risk of dying than men.

***Risk may accumulate if an individual belongs to more than one of these groups***

## **Our developing understanding of diabetes**

The last hundred years have seen significant advances in our understanding of diabetes, and our capacity to treat it and 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. The St. Vincent Declaration, ratified by the World Health Organisation's Regional Committee for Europe in 1991, set aspirations and goals for reducing the impact of diabetes. Since then, there have been significant developments, including:

- 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, by reducing the risks of the development of the complications of diabetes.

- Evidence that supported self-care improves outcomes, with the diabetes specialist nurse playing a key role.
- New and improved therapies.
- Effective organisation, involving a register, recall system and review for people with diabetes.

## Chapter 2

### Introduction to the Diabetes National Service Framework (NSF) for Wales

The Assembly is looking to develop a coherent programme of National Service Frameworks (NSFs) that must take account of the wider priorities for improving health in Wales working in partnership with the Department of Health and other key partners on underpinning programmes to support delivery.

The NSF programme was established to define standards and service models, together with milestones and performance management arrangements for implementation, to improve service quality and tackle variations in care. It sets out a ten-year programme of change to deliver first class care and support for children and adults with diabetes.

The NSF has been developed as two documents:

1. The 12 NSF Standards, published in April 2002, showing the level of diabetes care that we need to reach. The Standards were informed by the advice of an External Reference Group, and set out the aims, standards, rationales and key interventions, together with the implications for planning services.
2. The Delivery Strategy will assist in identifying how the Standards can be best implemented. It offers a systematic programme of reform providing a clear direction and scope for local priorities across Wales, enabling local staff to build upon existing good practice as well as closing any gaps in service provision.

In keeping with the principles of *Improving Health in Wales*<sup>23</sup> and *Better Health, Better Wales*, the primary goal is to enable the person with diabetes, or those at risk of developing diabetes, to manage their own lifestyle and diabetes, through support and structured education as well as drugs and treatments. Evidence suggests that a partnership between the person with diabetes and their clinical and support team can improve outcomes and quality of life. Delivering this vision and embedding these principles in practice requires staff throughout the NHS to understand the experience of people with diabetes and diabetes care, and to recognise the expertise of people who live with diabetes.

A Diabetes NSF Implementation Group (External Reference Group) was set up in Wales in 2001 to steer the development of the National Service Framework. It was a multi-agency, multi-professional group, including patients and carers. The Group worked with a wide range of stakeholders and advised on the production of the Standards Document, Baseline Review and Delivery Strategy. Workshops, focus groups and conferences were held to inform this process. The Project Board substituted the Implementation Group in January 2003, bringing together the External and Internal Reference Groups.

In 2001, the Welsh Assembly Government identified the importance of taking forward initiatives in preparation for the Diabetes NSF. One million-pound was allocated to LHGs and Trusts for a period of three years. £250,000 a year funded national projects on an All Wales basis to assist with the development of the Delivery Strategy.

A NSF Officer was funded by the Welsh Assembly to work in partnership with Diabetes UK Cymru to help engage the views of people living with diabetes in supporting the delivery of the NSF.

The Delivery Strategy identifies the key actions needed, based on research evidence commissioned to help inform the process, and the views and experiences of people with diabetes. The Baseline Review undertaken by the Audit Commission<sup>24</sup>, Market Research Wales Focus Group work and the report of the Health Services Ombudsman<sup>25</sup> have all informed the development of this NSF. More details are provided on the Diabetes NSF web page, [www.wales.nhs.uk](http://www.wales.nhs.uk) (click on *Subject Index, Health and National Service Framework*).

This NSF aims to **"empower people with diabetes through skills, knowledge and access to services to manage their own diabetes, with support, and fulfil their potential to live long lives free of the complications that can accompany diabetes"**.

To achieve this, NSF implementation needs to 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 where necessary, tackles the adverse impact of material disadvantage and social exclusion.

- **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, social care, the voluntary sector and specialist services, and maximising the quality of life for individuals by empowering staff to deliver, evaluate and measure care.
- **Targeted:** narrowing the inequalities gap by targeting groups with the greatest health needs; minimising the risk of developing diabetes and its complications.

## Links with other strategies

The NSF for Diabetes builds on other healthcare priorities:

The Welsh NSF for coronary heart disease (CHD) ***Tackling Coronary Heart Disease in Wales: Implementing Through Evidence***: There is considerable overlap between CHD and diabetes. Preventing or delaying the onset of diabetes and good management of diabetes will contribute to the achievement of the goals of the *Implementing Through Evidence* document.

**Renal Services:** Diabetes is a major cause of end-stage renal failure, and of the 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, and therefore helping to realise the aims of the proposed Renal NSF for Wales.

**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.

**Older People:** The prevalence of diabetes increases with age. Poorly controlled diabetes increases the risk of hospital admission and prolongs length of stay. This NSF will help contribute to further work being undertaken on older people through the Older People's NSF.

## Welsh Language Act 1993

In the context of Wales, the provision of a quality service involves having due regard to the provision of care in Welsh and English (and other languages) according to the wishes of the patient. Organisations are reminded of their responsibilities under their Welsh Language Schemes to treat English and Welsh on the basis of equality in their dealings with the public in this context. Even when not explicitly stated, these requirements need to be applied to all aspects of service planning and delivery outlined in the document.

This discipline offers a vehicle to also give consideration to the needs of those who speak other languages. This is particularly relevant given the high prevalence of diabetes in certain minority ethnic communities in Wales and the UK as a whole.

## Chapter 3

### Actions and structures to support Implementation

#### The context for Implementation

In November 2001 the Minister for Health and Social Services announced the structural changes to deliver the renewal of the NHS in Wales set out in *Improving Health in Wales - A Plan for the NHS with its partners*.<sup>23</sup>

The five Health Authorities in Wales were abolished in April 2003 and a statutory Local Health Board (LHB) established in each local authority area. LHBs provide the building blocks of the new NHS in Wales, becoming the lead organisations in assessing need, planning and securing health services and improving health. They work in partnership with communities and lead the NHS contribution to work jointly with local government and other partners. There is a duty placed on each Local Health Board and Local Authority to work together to develop and implement a strategy for health, social care and well being for people in the area. This will include agreeing joint investment priorities and the joint planning of interface services, based on a joint assessment of need.

LHBs, Local Authorities, NHS Trusts and the voluntary sector will work together to ensure joined-up, and where appropriate, integrated commissioning arrangements for hospital and community services within local authority areas. There will be some 14 local partnerships throughout Wales linking LHBs, local authorities and NHS Trusts, to secure the best possible range and quality of services through effective value for money commissioning.

In addition to securing tertiary services, the Specialist Services Commission for Wales will be strengthened to provide dedicated guidance, support and facilitation more generally in relation to acute services commissioning. It will also provide advice to the NHS in Wales in relation to more specialised secondary and regional services commissioning. NHS Trusts will continue to provide services, working within delivery agreements.

There will be a strengthening of the NHS Directorate within the National Assembly, both in the area of strategic planning and in the operational arm

of the organisation. This includes the establishment of three Regional Assembly Offices in North, Mid and West and South Wales, ensuring that concerted effort at national and local levels will deliver local services to provide national standards of care.

The NHS Directorate will focus on supporting the delivery of the health and well-being agenda set out in the NHS Plan for Wales. An Implementation Programme sets out actions and milestones required to ensure that the undertakings in the NHS Plan for Wales be delivered.

## Workforce Planning

Workforce planning data is collected annually from NHS Trusts and LHBs in Wales and used to inform the commissioning of centrally funded education and training for healthcare professional staff. The numbers of training places commissioned each year directly relate to the number of newly qualified staff the NHS forecasts it will require. The workforce planning process is based on identified need rather than on affordability.

An all staff, all Wales approach is taken when dealing with workforce issues in Wales. The All Wales Workforce Development Steering Group, chaired by the Director of NHS Wales, has been established to support the service in filling its current vacancies and increasing staffing levels in line with the staffing targets set in October 2002. Sub Groups have also been set up to support the Steering Group. A NSF and Clinical Networks sub group is one of these and is to be established in the near future. Workforce issues relating to the Diabetes NSF will be dealt with through this mechanism.

The workforce planning process collects data on Endocrinology and Diabetes Mellitus (Consultants, Associate Specialists and Staff Grades). Data is collected on all staff groups who have an input into diabetes care, including nurses, Allied Health Professionals (including dieticians), Clinical Scientists and also staff in Primary Care. This information, however, is not broken down into care specific categories.

## Research and Development

A review of the current and future research on Diabetes in the United Kingdom "*Current and Future Research on Diabetes, A Review for the Department of Health and the Medical Research Council*" has been published with the English delivery Strategy for Diabetes and is available on

the Department of Health's web-site. The review was conducted by an Advisory Committee and informed by an open public consultation organised in conjunction with Diabetes UK.

A key theme from the review highlights opportunities for translating the biomedical science research into clinical and public health practice. The Welsh Assembly Government will be considering how best to take this forward in the context of the research and development strategy for health and social care.

## Local action to support planning

***Improving Health in Wales*** sets out clearly, how all parts of the NHS will work together to develop partnerships that lead to improved patient-centred services. Building upon the experience of CHD, cancer and other areas, this section describes the organisational steps the LHBs should take to assist Diabetes NSF implementation. They should ensure that mechanisms are in place that:

- engage all stakeholders, including clinical and other staff, managers, people living with diabetes, local authorities, the voluntary sector and the independent/private sector.
- work across traditional service boundaries.
- have clear lines of accountability.

Realising these three principles and building on the Audit Commission reports, the LHBs will produce local implementation plans.

Many parts of Wales already have Local Diabetes Advisory Groups (LDSAGs) that have membership from key stakeholders, including healthcare professionals, managers, voluntary sector, people with diabetes and their carers. They have always championed a patient-centred approach encouraging the involvement of people with diabetes in planning local services. Where LDSAGs already exist and operate successfully, LHBs may choose to develop them as a mechanism for local Diabetes NSF implementation. Where they do not currently exist or operate successfully, LHBs will need to establish groups with multi-stakeholder input as part of the implementation process. The role of these local implementation groups (or LDSAGs) should include;

- development of a local plan for diabetes care and prevention, with specific locally agreed objectives and targets.
- advising on the development of a service specification and protocols to meet identified needs.
- developing systems to facilitate the achievement of the targets and of user satisfaction.
- monitoring and auditing the quality of the service against the targets and standards set.
- developing a local information system to assist in this process and identify shortfalls.
- links between the deliverers and receivers of care.

The involvement of people living with diabetes in LDSAGs (or equivalent) will need to be facilitated by adequate training and support.

Each LDSAG will require a user reference group of people living with diabetes, supported by the NHS locally. This will require modest investment to facilitate meetings, including provision of a suitable venue, light refreshments and secretarial/administrative support. It is envisaged that in many cases, but not exclusively, a NHS Trust and the LHB(s) area(s) it serves will form the basis of the Group.

## Evaluating Performance

As with all strategies and frameworks it will be important to ensure that the recommendations contained in the Diabetes NSF bring about the changes/outcomes needed and envisaged. An essential part of the NSF development process will therefore be the agreement and implementation of:

- **outcome measures** – to ensure that the results expected from the implementation of the NSF are achieved by the procedures and processes put in place.
- **performance indicators** – to ensure that on-going improvement and progress is achieved in line with agreed annual targets.

## Minimum Standards and Continuous Improvement

As referred to above there is a need to set measures and targets with due regard to the Performance Improvement Frameworks under which health and social care organisations and professionals operate.

The priorities and requirements of the Welsh Assembly Government for the NHS in Wales for 2003-2004, issued in January 2003 (WHC (2003) 01), set a precedent for the establishment of minimum standards – targets that must be achieved by all health organisations and are hence absolute standards; and continuous improvement targets that contain an expectation that substantial and demonstrable progress will be made towards them i.e. quantifiable and substantial improvement over the financial year in these areas. Attention should be paid to this approach in the setting of NSF related measures and targets.

The emphasis in the SaFF (Service and Financial Framework) round will be on re-engineering and innovation, incorporating changes in clinical practice, which will streamline pathways of care and create more efficient, high quality and cost effective services. There will also be a focus on the management of demand and capacity across the health system. The allocation of funds to LHGs made available, by the Minister in 2001, for projects relating to the NSF, continues until March 2004.

The Audit Commission identified that funding for diabetes services throughout Wales was difficult to identify, as historically, it has emanated from the 'general medical purse'. The financial requirements for implementation of the Diabetes NSF will be identified by each LHB/LDSAG during planning of the service developments required to attain the objectives of the Standards. The Audit Commission reports issued to each LHB will assist in the planning process and will then be reflected in the SaFF process. The pace of development over the ten-year period will need to be considered alongside available funding and will have to be phased accordingly.

## Clinical Audit

A clinical information report has been produced to support this Delivery Strategy. This will assist the production of information, including appropriate READ coding, audit framework, and guidelines on how to use them, replicating the requirements of the quality indicators within the new GMS contract (See Annex 2).

In the future, national clinical audit developments will be steered by the Office for Information on Health Care Performance being established within the Commission for Health Audit and Improvement (CHAI). The Office will be responsible for assessing performance (including clinical and performance indicators), national clinical audits and national surveys of patients and staff.

As part of this work, the Office will set out criteria against which national clinical audits will be assessed. It will endorse national clinical audits that conform to the criteria and may provide support to enable existing audits not meeting these criteria to do so.

## Professional education and training

Ongoing continuing professional development and training should underpin the NSF Delivery Strategy. This will take a variety of forms to suit the training needs identified. Currently opportunities exist to undertake courses in diabetes management for continuing professional development that is at the heart of continuous quality improvement. (See Education and Training – Annex 5.)

Regular and ongoing training of healthcare professionals involved in diabetes care – particularly those in primary care, where most people’s diabetes is managed should include: -

- **Risk factors for diabetes:-** the potential for preventing diabetes through the modification of risk factors and interventions that are effective in managing weight, treating blood pressure and cholesterol and encouraging physical activity.
- **Knowledge of screening issues:-** identifying those at high risk of diabetes and knowledge of signs and symptoms of diabetes.
- **Diagnosis and examination:-** including the identification of the complications of diabetes.
- **Clinical management:-** including the management of diabetes and its complications associated conditions and cardiovascular risk factors.

- **The provision of education and support for people with diabetes (to include their family and carers):-** including the ability to impart the necessary knowledge, motivation, and behaviour change and self-care skills. These skills will enable people with diabetes to take responsibility for their own healthcare, and equip them with an understanding of the emotional and social problems likely to be faced by people with diabetes.
- **Management of diabetes emergencies:-** awareness of the local services available and what to do in the event of an emergency.
- **Record keeping:-** i.e. the maintenance of adequate diabetes records, a diabetes register, a call/recall system via patient lists and the use of hand held records.
- **Cultural awareness training and management of vulnerable groups:-** this is particularly relevant given the high prevalence of diabetes in certain minority ethnic communities in Wales and the particular challenges in delivering diabetes services to these groups.

Sufficient time and funding should be allocated by LHBs and Trusts to enable all relevant professionals to undertake training, including validated and accredited courses. Regular updating is also important to ensure that staff are aware of improvements and changes in diabetes management, treatment regimes, and techniques. This may include study days organised by in-house training facilitators, clinicians, specialist nurses or by the local NHS or education provider, single profession study days/courses to enhance development within the profession, Practice and Personal Development Planning and non accredited courses.

There is also a role for people with diabetes in educating healthcare professionals about the condition, to help develop a better understanding of the patients' perspective and appreciate patients' expertise.

Education and training for professionals should include the wide range of staff likely to come into contact with people with diabetes, including local authority staff such as teachers, leisure centre staff, social care staff and NHS Direct. This could be facilitated via local authority involvement in LHBs.

## Education and support of people living with diabetes

It is also beneficial for family members or carers to be encouraged and welcomed to attend the educational sessions, as their understanding of the condition and support of the person with diabetes is of great importance.

The Diabetes NSF aims to empower people living with diabetes, therefore initial and ongoing education and information are all-important. The aim of such education and information is to facilitate and support self-management, and it needs to be available at the time of diagnosis and also later on. Ad-hoc information is an important element of this, as are structured education programmes. See Diabetes UK website for examples of good practice at [www.diabetes.org.uk](http://www.diabetes.org.uk) and the Welsh Assembly Government Diabetes NSF website at [www.wales.gov.uk](http://www.wales.gov.uk).

Support, as distinct from education, of people living with diabetes is also important. Such support could include counselling and/or psychological support, and access to self-help groups and other forms of peer support. Healthcare professionals' training needs to include training in supporting people living with diabetes, communication and listening skills. Voluntary organisations should also be recognised for the vital role that they play across Wales.

## Patient and Public Involvement

A key requirement of *'Improving Health in Wales'* (Chapter 3) is to ensure that patients and the public are fully involved in the design, delivery and monitoring of health services. The overall benefits include better outcomes of health care, increased patient satisfaction, more responsive and cost effective health care services, and a general strengthening of public confidence in the NHS. This commitment ensures that every NHS Trust and LHG, produced for the first time, from 2002, annual action plans setting out proposals for patient involvement and patient focus. This was supported by the Assembly through the production of *'Signposts – A practical guide to public and patient involvement in Wales'*. The introduction of the 'Expert Patient' Programme and the strengthening of the role of Community Health Councils (CHC) in their support of patients, now includes the provision of patient advocates across the 9 CHC 'federation' areas of Wales.

## Expert Patient Programme – Pilot Programmes (Wales)

Expert Patient Programmes<sup>26</sup> (EPP) also known as self management programmes are about providing training and education to develop the confidence and motivation of people to use their own skills and knowledge to take effective control over living with a chronic illness. Two pilot projects established in Gwynedd and Swansea LHBs, will provide an opportunity to test this in a rural and urban setting. The LHB structure provides a basis for close partnership working with local health, social care, voluntary organisations, community groups and community health councils.

The schemes will establish local arrangements to support development of an EPP so that it is possible to focus on the needs of local people and their communities. The EPP pilots commenced in March 2003 and will run for 12 months. It will be important to learn lessons from these schemes before any consideration is given to the way forward in terms of wider application.

## Primary care contracts

Implementation of the Diabetes NSF in primary care is expected to take place in the context of the proposed new General Medical Services (GMS) contract. This is being negotiated between the NHS Confederation and the BMA General Practitioners' Committee. The new GMS contract framework agreement makes clear that new work would be recognised and rewarded in a number of ways. The contract currently being negotiated envisages the provision of essential, additional and enhanced services.

In addition, the contract provides for an optional quality and outcomes framework, which would attract additional remuneration. Within the clinical domain of the quality and outcomes framework sits a series of evidence based quality indicators specific to diabetes.

## All Wales Diabetic Retinopathy Screening Programme

**"The aim of the All Wales Diabetes Retinopathy Screening Programme, is that by 2005 a minimum of 80% of people with diabetes to be offered screening, rising to 100% offered by the end of 2006".**

This programme was launched in July 2002 as part of the All Wales Eye Care Initiative Programme, which includes the Low Vision Aids, and Eye Health Examination programmes. These are important developments for Wales and have direct relevance to the implementation of the Diabetes NSF. It is expected that contact details (i.e. patient lists) taken from the practice based diabetes registers will assist with call and recall for appointments for retinal screening. People with diabetes will be offered screening with digital cameras, for the early detection (and treatment if required) of diabetic retinopathy as part of a systematic programme that meets national standards. Specific services will be developed to meet the needs of the hard to reach groups such as the housebound, and develop links with the ethnic groups to encourage uptake.

Optometrists who are accredited within the Wales Eye Care Initiative will continue to provide the diabetic retinopathy co-management of the person with diabetes and link into the DRSS – underpinning and supporting the scheme.

## Clinical Governance

**Quality Care and Clinical Excellence** outlined our ten-year plan for improving the quality of health services in Wales. This was followed by the clinical governance guidance contained in WHC (99) 54. Clinical governance is a framework through which NHS organisations are accountable for continuously improving the quality of their services and safeguarding the standards of care by creating an environment in which clinical care will flourish.

The key components of clinical governance are patient involvement, risk management, clinical audit, staffing and staff management, education and training, clinical effectiveness, use of information and strategic capacity. Trust boards and LHBs support and monitor the development of each of the clinical governance components to continuously improve patient care.

NSFs are based on the best available evidence of clinical effectiveness, and they set explicit standards (targets) to achieve consistency and high quality care for specific medical conditions.

The Diabetes NSF has clear standards, key actions and targets for achieving best practice and improving the patient's experience of care. Progress will be monitored through the clinical governance framework, particularly through clinical audit and through patient involvement in evaluation.

## Accountability for Delivery

Each LHB will need to establish a system of auditing the management of people with diabetes. The audit must include levels of compliance with the locally agreed patient pathways and protocols. The audit should be undertaken jointly by primary and secondary care. The LHB and Trust should publish the results as a joint annual report in partnership with the LDSAG (or equivalent) and submit it to the Assembly. Progress will be monitored as part of the wider monitoring of the NHS under the SaFF. Implementation of the Diabetes NSF will be subject to review by the Commission for Healthcare Audit and Improvement (CHAI), after its establishment in 2004.

# Chapter 4

## Implementation and Action Plans

### Twelve Evidence Based Standards for Improving Services for People Living with Diabetes in Wales

#### Standard 1

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

#### Standard 2

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

#### 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.

#### 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.

#### 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.

### **Standard 7**

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

### **Standard 8**

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

### **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.

### **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.

# Implementation of Standard 1

## 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.

### AIM

To reduce the number of people who develop 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 is now obese (defined as a body mass index  $>30$  kg/m<sup>2</sup>) and two in five are overweight (defined as a body mass index 25-30 kg/m<sup>2</sup>). 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 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.

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 tolerance 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.

## 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.

Objective	Actions	Performance	Responsibility
<p><b>Objective 1.1</b></p> <p>Ensure that action to improve diet, nutrition, increased physical activity, reducing overweight and obesity and monitor healthy weights are integrated into national and local strategies with particular emphasis on ethnic and vulnerable groups and children.</p>	<p>Action to promote healthy lifestyle identified in strategic documents.</p> <p>Monitor local targets.</p> <p>Identify and disseminate examples of good practice across Wales.</p>	<p>Promote healthy lifestyles in, Health, Social Care and Well-Being Strategies (HSCWBS) for publication April 2004 – Action during 2004/2005.</p> <p>On Assembly website by April 2003 and on going.</p>	<p>Welsh Assembly Government</p> <p>LHBs</p> <p>Welsh Assembly Government</p>
<p><b>Objective 1.2</b></p> <p>Reduce the risk of Type 2 diabetes consistent with the CHD NSF, through increased awareness and support.</p>	<p>Identify and monitor local needs.</p> <p>Identify and monitor local targets (ref. Key Action 6-9 CHD NSF).</p> <p>Develop protocols and programmes integrated into local HSCWBS.</p>	<p>Develop a strategy for identification and monitoring of local needs.</p> <p>Action 2003 and on going.</p>	<p>Primary care teams</p> <p>LHBs</p> <p>LHB</p> <p>Primary care teams</p>
<p><b>Objective 1.3</b></p> <p>Ensure continuous professional development (CPD) for health care professionals and others (particularly in primary care) to support and update knowledge and skills in risk factor management of at risk individuals.</p>	<p>Support CPD opportunities for HCPs with the focus on socially excluded groups, care homes for the elderly, custodial settings and minority ethnic groups.</p>	<p>Evidence of ongoing and updated CPD.</p>	<p>LHBs</p> <p>Primary care teams</p> <p>NHS Trusts</p> <p>NHS Direct</p>

## The Implementation of standard 2

### Standard 2

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

### AIM

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

### 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 stresses and strains of everyday life. Health care professionals may also misinterpret the symptoms of diabetes when people first describe their symptoms 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 many 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 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) and women who have a history of gestational diabetes. For these people, follow up and regular testing can lead to the earlier diagnosis of diabetes in those who go on to develop the condition. Advice and support to reduce their risk of developing diabetes, and information to

help them recognise the symptoms and signs of diabetes should complement this.

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.

<b>STANDARD 2</b>			
The NHS will develop, implement and monitor strategies to identify people who do not know they have diabetes.			
<b>Objective</b>	<b>Actions</b>	<b>Performance</b>	<b>Responsibility</b>
<b>Objective 2.1</b> Raise awareness of the signs and symptoms of diabetes amongst health and other professionals most likely to come into contact with people with undiagnosed diabetes.	Develop and implement CPD programmes to address the needs of: <ul style="list-style-type: none"> <li>• Primary and Community Care</li> <li>• Staff working in hospitals</li> <li>• Residential/Nursing Homes</li> <li>• Specialist cardiology and renal team</li> <li>• Pharmacist, optometrists, dentists, podiatrists etc</li> <li>• NHS direct staff</li> </ul>	CPD Programme delivery 2005/6 and reviewed annually.	NHS Trusts LHBs Primary care teams
<b>Objective 2.2</b> Strengthen the identification, monitoring and benchmarking systems in high risk individuals.	Ensure effective identification and follow up systems for people found to have impaired glucose regulation and gestational diabetes.  Ensure that all valid information is provided on practice based registers.	To be evidenced by April 2004.  Action 2003 and on-going clinical audit. Annual reports, first due April 2004.	NHS Trusts LHBs Primary care teams  LHBs Primary care teams

<b>Objective 2.2 (Cont'd)</b>	<b>Actions</b>	<b>Performance</b>	<b>Responsibility</b>
	Use NHS information systems to benchmark the prevalence of diabetes and monitor trends, particularly in low socio economic and ethnic groups.	Action 2003 and on-going Clinical audit. Annual reports, first due April 2004.	NHS Trusts LHBs Primary care teams National Public Health Service
<b>Objective 2.3</b> To improve diet, weight management and physical activity, particularly among children, ethnic minority and other vulnerable groups.	Implement health promotion activities as identified in Annex 3.	Evidence regarding health promotion activities by 2004/5. Monitor progress annually.	LHBs National Public Health Service Primary care teams

## Implementation of Standard 3

### Standard 3

All children, young people and adults with diabetes will receive a service that 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.

### 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.

### 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 Taskforce 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 exacerbation's of the disease
- making the most effective use of medicines and treatment
- understanding the implications of medical 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
- 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 lives with diabetes. The health professional's role is to ensure that people can develop an understanding of and receive information about, the risks and consequences of the choice 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 change: families and communities provide both the 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.

### STANDARD 3

All children, young people and adults with diabetes will receive a service, which encourages partnership in decision-making, support 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.

Objective	Actions	Performance	Responsibility
<p><b>Objective 3.1</b> Develop programmes to strengthen and support self-care management, to help empower all people with diabetes to maintain a healthy lifestyle, involving families and carers.</p>	<p>Implementation of a Self Management Programme</p> <p>Implementation of a structured education plan based on a self help programme for all people with diabetes their families and carers.</p> <p>Ensure access to appropriate professional support as required.</p>	<p>Expert Patient Pilot Project commencing April 2003 for review and dissemination throughout Wales 2004.</p> <p>Education plan in place by 2004</p> <p>Demonstrate availability of access in end of year report April 2004.</p>	<p>Welsh Assembly Government LHBs LDSAGs</p> <p>LHBs LDSAGs NHS Trusts Primary care teams</p> <p>LHBs LDSAGs NHS Trusts</p>

<b>STANDARD 3 (Cont'd)</b>			
<b>Objective 3.2</b>	<b>Actions</b>	<b>Performance</b>	<b>Responsibility</b>
Develop partnership with active involvement of parents, carers and people with diabetes in the development of local service and care plans.	Develop and support mechanisms to ensure active involvement of people with diabetes and carers in the planning and delivery of services e.g. LDSAGs.  Develop targeted information in an appropriate format and language and addressing the needs of vulnerable groups.	Participation of people with diabetes and their carers in the planning and delivery of services in HSCWB plan & LHB annual report – 2004.  Ensure literature available in appropriate format 2004/5.	LDSAGs LHBs NHS Trusts   LHBs LDSAGs Voluntary Organisations

## The Implementation of Standard 4

### 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.

### 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.

### 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. High

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, including those in residential/nursing care homes and custodial settings, 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.

## 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.

Objective	Actions	Performance	Responsibility
<b>Objective 4.1</b> Develop, implement and audit protocols for initial assessment and continuing care and monitoring of people with diabetes.	Initial assessments implemented in all health care settings for newly diagnosed people with diabetes. This includes GP's, NHS Direct, A&E, community pharmacists and other community settings.	Continual monitoring and updating of protocols.	NHS Trusts NHS Direct LDSAGs LHBs
	Develop protocols for identification, assessments and audit implementation.	Annual review to detect complications of diabetes Entries on Diabetes Register for audit purposes. – 2004.	NHS Trusts LDSAGs LHBs
	Ensure protocols are in place for the identification and follow up of non-attendees.	Monitored in annual clinical audit.	NHS Trusts LDSAGs LHBs

<b>STANDARD 4 (Cont'd)</b>			
<b>Objective</b>	<b>Actions</b>	<b>Performance</b>	<b>Responsibility</b>
	<p>Develop services to ensure that vulnerable groups e.g. housebound, receive structured diabetes care.</p> <p>Ensure that all laboratories undertaking HbA1c examinations including analysers used are participating in approved external QA schemes.</p>	<p>Evaluation of service development and improvement (SaFF).</p> <p>To be included in audit.</p>	<p>LHBs</p> <p>NHS Trusts</p>
<p><b>Objective 4.2</b> Review local provision of diabetes services to identify gaps and areas for service development.</p>	<p>Utilise the Audit Commission Baseline Review to identify action and service development areas.</p> <p>Monitor and review through SaFF process and service development and other appropriate mechanisms.</p>	<p>Annual planning – service developments/financial requirements via SaFFs annually.</p>	<p>NHS Trusts LDSAGs LHBs</p> <p>LHBs Welsh Assembly Government</p>

## Implementing standards 5 & 6

### 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.

### 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.

### 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 parent or carer 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 glucose control is essential for normal growth and development and to avoid the acute and 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) and their 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 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.

<b>STANDARD 5</b>			
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.			
<b>Objective</b>	<b>Actions</b>	<b>Performance</b>	<b>Responsibility</b>
<b>Objective 5.1</b> To ensure that diabetes services for children and young people are of a high standard and appropriately adapted to meet their needs.	Diabetes protocols for children developed and implemented in partnership with key stakeholders.	In place and audited by 2004.	LDSAGs LHBs NHS Trusts Local Authorities - Education Departments
<b>Objective 5.2</b> Support the needs of children and families with diabetes.	Establish family and peer support systems and appropriate information. Access to psychological/counselling if/when required.	Systems in place by 2004.  In place and audited by 2005.	NHS Trusts Voluntary organisations  LHBs NHS Trusts
<b>STANDARD 6</b>			
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.			
<b>Objective</b>	<b>Actions</b>	<b>Performance</b>	<b>Responsibility</b>
<b>Objective 6.1</b> To ensure the smooth transition from paediatric to adult services.	To establish young adult clinics or develop and establish a transitional clinic process from community based care with appropriate information and support and with the informed consent of the individual.	In place and audited by 2005.	NHS Trusts Primary care teams LDSAGs LHBs

## Implementing Standard 7

### Standard 7

The NHS will develop, implement and monitor agreed protocols for rapid and effective treatment of diabetic emergencies by appropriately trained healthcare professionals.

### AIM

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

### 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 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 or 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. And carries a high risk of 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 HONK is the first manifestation of Type 2 diabetes.

The blood glucose rises to a very high level 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, (e.g. 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.

## 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.

<b>Objective</b>	<b>Actions</b>	<b>Performance</b>	<b>Responsibility</b>
<b>Objective 7.1</b> Strengthen the recognition and management of diabetic emergencies.	Provide appropriate information to people living with diabetes, identifying signs and symptoms of diabetes emergencies and its avoidance and management. Implement protocols to increase awareness and effective management of diabetes emergencies in all settings, especially the home, medical and dental practices, residential and nursing homes and custodial settings.	Appropriate information provided by 2004/5 – reviewed annually.  Protocols developed and implemented by 2004/5.	LHBs NHS Trusts  LHBs Primary care teams
	Ensure all health professionals are trained in the identification and management of diabetes, including ambulance personnel, A + E staff and primary care.	See Standard 2 Objective 2.1.	See Standard 2 Objective 2.1
	Develop and implement protocols to manage all diabetes emergencies across hospital settings.	Protocols in place by 2004 and outcomes audited 2005.	Ambulance Trusts IDSAGs NHS Trusts

## Implementing Standard 8

### 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.

### AIM

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

### RATIONALE

1. People with diabetes are admitted to hospital twice as often and stay twice as long as 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
- Inadequate opportunity to discuss issues with specialist nursing team.

3. Timely liaison with the diabetes team can both prevent the need for diabetes-related admission 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, arrangements then being made for specialist nurses to continue care in the community in relation to discharge planning, thereby releasing 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.

## 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.

<b>Objective</b>	<b>Actions</b>	<b>Performance</b>	<b>Responsibility</b>
<b>Objective 8.1</b> Effective care and continuing self management of diabetes in the hospital setting.	In partnership with key stakeholders develop and implement protocols to enable people with diabetes to; <ul style="list-style-type: none"><li>• be involved with decision-making regarding their diabetes care.</li><li>• access provision of healthy food and snack choices.</li><li>• monitor and maintain blood glucose control,( including provision of intravenous infusions of insulin and fluids).</li><li>• receive access to diabetes wound management.</li><li>• access podiatrist/foot clinic if required.</li></ul>	In place and audited by 2005.	NHS Trusts

Objective 8.1 (Cont'd)	Actions	Performance	Responsibility
	<ul style="list-style-type: none"> <li>• have their investigations managed or operative procedures appropriately timed.</li> <li>• have their different cultural and religious needs met, including access to appropriate food choices.</li> <li>• receive oral hypoglycaemic medication / insulin appropriately timed in relation to meals.</li> <li>• access clear information about the management of their diabetes during hospital stay and after discharge.</li> <li>• liaison with the Diabetes Team.</li> <li>• access dietetic advice.</li> <li>• receive follow-up on discharge from hospital.</li> </ul> <p>Education and updating of ward based nursing staff and junior medical staff</p>	<p>Programme in place by 2004</p>	<p>NHS Trusts</p>

## Implementation of standard 9

### 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.

#### 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.

#### 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 woman 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 rates amongst the babies of mothers with diabetes 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 foetal development during the six weeks following conception. Later in pregnancy, the main risks to the baby are excessive foetal 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.

4. Pregnancy results in increasing insulin resistance and if more insulin does not match this 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.

5. 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.

6. 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 pre-pregnancy and throughout pregnancy and childbirth.

7. Between 2 and 12 percent of women develop gestational diabetes, which is more common in women from minority ethnic groups. These women are more likely to have large-for-date 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. As they are significantly at risk of developing Type 2 diabetes they should receive routine follow up and attend for annual review.

**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.

<b>Objective</b>	<b>Actions</b>	<b>Performance</b>	<b>Responsibility</b>
<b>Objective 9.1</b> Ensure effective management of pregnant women with diabetes.	Develop and pilot protocols for effective diabetes management pre conception, intra partum, post partum and during pregnancy. Review local policies for the detection and management of gestational diabetes in pregnant women and post partum follow up. Attend for annual review.	In place and audited by 2005.  Audit by 2005.	LHBs NHS Trusts Primary care teams  LHB NHS Trusts

## Implementing standards 10, 11 and 12

### Standard 10

All young people and adults with diabetes will receive regular surveillance and screening 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.

## 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.

## 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 diabetes is 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, and psychological support and appropriate welfare benefits. People with diabetes are also entitled to free eye examination through the General Ophthalmic Services.

4. Angiotensin converting enzyme (ACE) inhibitors can delay the onset of **diabetic nephropathy** in people with diabetes who are found to have microalbumuria. Tight control of raised blood pressure, as well as tight control of blood glucose levels, 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. Examination of the feet should be included in annual review. 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 *"Tackling Coronary Heart Disease in Wales: implementing through evidence"* including treatment with low dose aspirin,  $\beta$  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.

<b>STANDARD 10</b> All young people and adults with diabetes will receive regular surveillance for the long-term complications of diabetes.			
<b>STANDARD 11</b> 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 the risk of disability and premature death.			
<b>STANDARD 12</b> All people with diabetes requiring multi-agency support will receive integrated health and social care.			
<b>Objective</b>	<b>Actions</b>	<b>Performance</b>	<b>Responsibility</b>
<b>Objective 10.1</b> To ensure all people with diabetes are receiving regular surveillance for long term complications of diabetes.	Ensure all people with diabetes are reviewed according to NICE guidelines and local protocols.	Annual review and data collected using READ codes (See Annex 1) Audited annually.	LHBs LDSAGs NHS Trusts Primary care teams
<b>Objective 11.1</b> Detection, management and timely referral /diabetic complications.	Protocols developed to influence timely referral to appropriate speciality/ investigation / treatment as required.	Record (as above) +audit Annually – Introduce from 2004.	NHS Trusts LHBs Primary care teams
<b>Objective 12.1</b> Ensure effective multi-agency support between health and social care.	Develop joint protocols to strengthen partnership working.	Diabetes management as part of integrated care and unified assessment process.	NHS Trusts LHBs Social Services Voluntary Organisations

## Summary of Report – Information Management and Technology Sub-Group

### The NSF on Diabetes

*"National Service Frameworks (NSFs) are being developed to address variations in standards of care and to achieve greater consistency in the availability and quality of services, by putting in place mechanisms which will enable best care to be provided to all."*

As outlined in the NHS Wales White Paper "Quality Care and Clinical Excellence", National Service Frameworks provide a systematic approach to driving up standards to improve quality across health care sectors, in partnership with social care and other organisations. They:

- set national standards and define service models for a service or care group;
- put in place programmes to support implementation.

The English NSF on Diabetes aims to *"establish performance measures against which progress within agreed timescales would be measured.....and to have a systematic approach to the detection of the long-term complications of diabetes with regular, planned review and delivery initially prioritised to the highest risk groups."*

**In order to be able to develop the service to our people with diabetes and be able to monitor progress, (and in due course, outcomes), the establishment of a meaningful information system is essential.**

Most clinical data in the NHS is gathered inefficiently and in an unstandardised, unstructured manner. Consequently it is difficult to access and not useable as worthwhile information. Diabetes is no exception. What is more, in the light of current evidence, caring for the person with diabetes has become multifaceted and mutiprofessional. There is also the culture of more information for patients and empowerment for them to take a more active role in their care plans.

In order for such a complex system of care to work effectively and efficiently, there should be a method of information flow where each individual care provider can be able to contribute and have access to 'fit for purpose' information at the point of care.

The King's Fund suggests that diabetes management should be a primary care led service, with seamless integration with secondary and tertiary care provider. Thus, a shared record, in which the interventions of Consultant Physicians, GPs, hospital, community and practice nurses and Allied Health Professionals, are recorded would not only support shared care and facilitate teamwork, but also: -

- Enable the creation of a patient profile.
- Eliminate inappropriate, duplication of procedures.
- Identify any change in the patient's condition to provide more appropriate and quicker change in management.
- Use the skills of a clinical team to provide an optimum service at minimum cost and inconvenience to patient and care provider.
- Enable comparable information on clinical quality to be derived to support clinical audit, clinical governance and performance management purposes.

Whilst recognising that clinical data has special problems, and not least that of confidentiality, it is imperative that in order to maximise the usefulness of these data, common standards in inputting should be defined and any such standard should try and anticipate future augmentation. We would then have the ability to access large amounts of information of individual patients and aggregates and have reliable comparative data. Research activities and more appropriate use of resources could develop almost as by-products of service, which could have considerable benefits to the process of quality GP commissioning. Thus, we could:

- develop accurate population based information systems for people with diabetes
- develop structured programmes for the systematic reviews of patients and keep up to date records

- develop systematic programmes to monitor and audit processes and outcomes and recall patients for regular review
- ensure access to podiatrists and dieticians, when carrying out annual reviews with patients
- ensure provision of support and education to hospital and community staff, and work with them to develop guidelines for referral and management of people with diabetes
- ensure that staff, particularly GPs and practice nurses, are well-trained and kept up to date with new developments
- support clinical audit, clinical governance and performance management purposes.

The patient with diabetes should be offered:-

1. An annual review.
2. A regular follow-up programme.
3. Regular specialist investigation when appropriate.
4. An open and quick referral to a "problem clinic" run by a consultant.

Along the lines suggested by the English NSF, a core underpinning dataset to support a person with diabetes in managing their care should be established. The dataset will cover key risk factors, processes, intermediate outcomes and final outcomes, and support information that the person with diabetes or the carer, can hold, understand and act upon.

A suggested pro-forma for an annual review dataset is included in Figure 1. Supporting information, held in the generic patient record, would include patient identifiers, ethnicity, family history and lifestyle profile.

**Figure 1**

Identified <input type="text"/>	Visual acuity R <input type="text"/>	Treatment <input type="text"/>	Complications <input type="text"/>
Date <input type="text"/>	Visual acuity L <input type="text"/>		
Type of Diabetes <input type="text"/>	Retinal Grade R <input type="text"/>		
Date of Diagnosis <input type="text"/>	Retinal Grade L <input type="text"/>	Date of Photo <input type="text"/>	Concurrent Illness <input type="text"/>
Peripheral Pulse R <input type="checkbox"/>	Peripheral Neuropathy L <input type="checkbox"/>		
Peripheral Pulse L <input type="checkbox"/>	Peripheral Neuropathy R <input type="checkbox"/>		
Height <input type="text"/>	Urine Microalbumin <input type="checkbox"/>	Dietitian <input type="checkbox"/>	Plan <input type="text"/>
Weight <input type="text"/>	Microalbumin Level <input type="text"/>	Podiatry <input type="checkbox"/>	<input type="text"/>
BMI <input type="text"/>	Urea <input type="text"/>	Optometrist <input type="checkbox"/>	
BP Sys <input type="text"/>	Creatinine <input type="text"/>	Other Health Professional 1 <input type="text"/>	
BP Dias <input type="text"/>	Lipids <input type="text"/>	Carer <input type="text"/>	
HbA1c <input type="text"/>	Education <input type="text"/>	Care Plan <input type="checkbox"/>	
Smoking <input type="checkbox"/>	Understanding Checked <input type="checkbox"/>	DNA <input type="checkbox"/>	Next Appointment <input type="text"/>
Smoke Num <input type="text"/>			Patient Dissent <input type="checkbox"/>

**Complications** could include;

Ischaemic heart disease, hyperlipidaemia, hypertension, vascular disease, retinal disease, renal disease and foot disorders.

**Education** could include;

Diet, exercise, smoking and alcohol.

Each item is linked to a Read code, in order to facilitate audit, using the Welsh audit software package.

Again in line with the English approach, it is recognised that there will be a need for other extended datasets established over a longer period to meet the needs of information sharing at each point in the Care Pathway and specialist areas, such as the management of pregnant women and children with diabetes, have been excluded. Indeed, even developing this data set has not been without its problems and will not please all. However, it is felt that there is an urgent need by the service for a template for care, while these refinements are being developed.

The linking of data between primary and secondary care remains difficult, particularly as the Read codes are used solely in primary care. It is however, hoped that secondary care provider will co-operate by using this template and perceive this development as an opportunity to move a step closer towards a common record and indeed, a patient held record. In due course,

double entry and other investigations will become less common, reducing expense and inconvenience to patients.

We have also worked with the ICT Foundation Programme for General Medical Practices, which has developed:

- (1) an Education, Training and Development (ETD) Framework
- (2) a Data Quality Initiative (DQI)

These support its aim of improving data quality and the use of clinical information systems to support the delivery of patient care. Both the ETD framework and DQI are intrinsically linked to supporting clinical priorities, in particular the delivery of the Diabetes NSF.

To conclude, this template is seen as the foundation stone for appropriate data management and the development of useful information for the care of the patient with diabetes. It will also serve as an audit tool and assist practices to achieve quality payment if the new GP contract is accepted. The data set will be linked to that of heart disease, which it is anticipated, will also have an all Wales template in the near future. It is recognised that this information package is only the beginning of an evolving process and it is suggested that the process be reviewed at intervals.

### Clinical Terminology Support for the Diabetes National Service Framework

In order to support high quality care for those at risk and those with confirmed diabetes, it is essential to create and maintain consistent and comprehensive patient centred clinical records. This process is facilitated within general practice by the widespread use of sophisticated electronic clinical systems.

The Diabetes National Service Framework outlines twelve evidence based Standards for implementation in Wales. Associated with these twelve Standards are a number of Key Actions that are to be monitored locally and where appropriate reported on nationally.

In order to be able to show that these key actions have been completed and/or monitored it is necessary to collect some basic, patient centred, data on the clinical system in a structured and consistent way. It is clearly important to ensure that these data items support and are a by-product of the day-to-day clinical management of the patient and not an additional 'information burden' on the clinician.

As all of the GP clinical systems incorporate the Read Codes these data items are based on Read Code terms and their associated codes for each of the versions, GP 4 Byte, Version 2 and Clinical Terms Version 3.

Work is currently ongoing to develop a number of Read Code lists to support the clinical management of people with diabetes. The creation of 'virtual registers' within the Clinical Management System will enable consistent call and recall of those at risk, and those with confirmed diabetes and a number of lists to support high quality clinical audit. This work is being supported by and receiving feedback from the appropriate clinical professional bodies.

Clinical system suppliers are being consulted to ensure that these lists can be implemented in a way that makes data capture simple and consistent and to support the implementation of the clinical audit queries.

Two lists of Read Code terms are recommended as being appropriate to use as the target group of lifestyles, conditions and disorders that fall within the remit of the twelve Standards.

- The first short list (List A) forms the basis of the list or register of patients within the Clinical Management system. They would be used to support call and recall of patients and constitute the base population for clinical audit.
- The second more comprehensive list (List B) enables more detailed clinical audit and would serve to provide sufficient information to support clinical governance requirements.

A guiding principle employed in deriving these lists is that the clinical terms should be used prospectively and forms a natural part of the information collected to support the day-to-day clinical management of the patient. It is, therefore, proposed that clinicians should use these lifestyle and clinical diagnostic groups in the following circumstances:

- At the time of new patient registration to record lifestyle, and previous and current medical problems relating to diabetes.
- For existing practice patients when they present with features suggestive of diabetes.
- To review the diagnostic coding of those patients with known risk or actual diabetes who present for review or repeat prescriptions.
- To review lifestyle and clinical diagnostic coding of patients identified from a practice audit.
- This list of Read Codes has been provided for Read Code 4Byte and Version 2. Clinical Terms Version 3 (CTV3) Read Code lists are available and may be obtained from the ICT Foundation Programme for General Medical Practices. Telephone number 01792 607434, e-mail: [enquiries@foundation.wales.nhs.uk](mailto:enquiries@foundation.wales.nhs.uk)
- At the time of publication a small number of required clinical terms and codes were found to be absent from the March 2003 release of Read Codes. Application has been made to the NHS Information Authority to have these added in the next release and an update list will be circulated in due course.

It is intended that the lists developed should be dynamic and keep pace with the services requirements, evolving clinical guidelines and the ability of suppliers to support good quality user interfaces.

## List A Proposed Read Codes to Support Registers for the Diabetes NSF

NSF Data Item	Read Code Preferred Term	GP 4Byte	Version 2	Comments
<b>Health information (family history)</b>				
Family History	FH:Diabetes mellitus FH Fam hyperchoesterolaemia	1252 1269	1252 1269	
<b>Personal and social circumstances</b>				
Ethnicity	Ethnic groups (census)	9S...	9S...	Choose appropriate child term
Exercise grading	Exercise grading Exercise physically impossible Avoids even trivial exercise Enjoys light exercise Enjoys intermediate exercise	138. 1381 1382 1383 138H	138.. 1381. 1382. 1383. 138H.	Choose appropriate child term Due to physical illness or disability Interpreted as sedentary Walks to shops or walks locally once a week Regularly walks dog or takes brisk walks 1-2 times a week
Smoking status	Enjoys moderate exercise Enjoys heavy exercise Competitive athlete  Never Smoked tobacco Ex smoker Data ceased smoking  Cigarette Consumption Cigar consumption Pipe tobacco consumption	1384 1385 1386  1371 137S 137T  137X 137Y 137a	1384. 1385. 1386.  1371. 137S. 137T.  137X. 137Y. 137a.	Brisk walk or gym/swimming 3 times a week Vigorous exercise more than 3 times per week Competitive athlete  Stopped smoking for more than 1 year Enter date ceased smoking, nearest month and year Enter value in number per day Enter value in number per day Enter value in ounces per week

NSF Data Item	Read Code Preferred Term	GP 4Byte	Version 2	Comments
Alcohol consumption	Alcohol consumption	136.	136..	Enter value in units per week
	Teetotaller	1361	1361.	
	Stopped drinking alcohol	1367	1367.	Enter date stopped drinking alcohol
<b>Examination findings:</b>				
Height	O/E - height	229.	229..	Enter value in metres
Weight	O/E - weight	22A.	22A..	Enter value in Kilograms
Body Mass Index	Body mass index	22K.	22K..	Enter calculated value
<b>Diagnoses:</b>				
<b>Diabetes:</b>	Insulin depend diabetes mellitus	C22	C108	This term has now been replaced by Type I diabetes mellitus C10E.
	Non-insulin depend diabetes mell	C21	C109	This term has now been replaced by Type II diabetes mellitus C10F.
	Type I diabetes mellitus	N/A	C10E	The preferred code for Type I
	Type II diabetes mellitus	N/A	C10F	The preferred code for Type II
	Diabetes mellitus autosomal dominant	N/A	C10C	This may be used for Maturity onset diabetes in the young (MODY)
	Gestational diabetes mellitus	C2B	L1809	
	<b>Impaired glucose tolerance</b>	C350	N/A	<b>New term requested from NHS Information Authority</b>
	<b>Impaired fasting glycaemia</b>	C351	N/A	<b>New term requested from NHS Information Authority</b>
	Diabetes mellitus with ketoacidosis	C24	C101	
	Hyperosmolar non-ketotic state in type 2 diabetes mellitus	N/A	C109K	
	<b>Hypoglycaemic state in diabetes</b>	N/A	N/A	<b>New term requested from NHS Information Authority</b>

NSF Data Item	Read Code Preferred Term	GP 4Byte	Version 2	Comments
<b>Complications of diabetes:</b> Ischaemic heart disease	Acute myocardial infarction	G41.	G30..	Use child term if more detail known Use child term if more detail known
	Angina pectoris	G44.	G33..	
Hyperlipidaemia	Hyperlipidaemia NOS	C524	C324	
	Familial hypercholesterolaemia	C525	C3200	
Hypertensive disease	Hypertensive disease	G3..	G2..	Use this if cause of hypertension is not to be essential
	Essential hypertension	G31.	G20..	
Precerebral vascular disease	Precerebral arterial occlusion	G72.	G63..	
Cerebral vascular disease	Cerebral arterial occlusion	G73.	G64..	Use child term if more detail known
	Transient cerebral ischaemia	G74.	G65..	
	Stroke/CVA unspecified	G75.	G66..	
Arterial aneurysms	Aortic aneurysm	G82.	G71..	
Peripheral vascular disease	Peripheral vascular dis. NOS	G86.	G73z.	
	Intermittent claudication	G85.	G73z0	
Retinal disease	Diabetic retinopathy	F521	F420.	Use child term if more detail known GP 4 Byte has synonym of 'Cataract - diabetic' code 'C27.'
	Diabetic cataract	N/A	F4640	
	Registered blind	6689	6689.	
	Registered partially sighted	6688	6688.	

NSF Data Item	Read Code Preferred Term	GP 4Byte	Version 2	Comments
Renal disease	Diabetic nephropathy <b>Persistent microalbuminuria</b>	C26. N/A	C104. N/A	<b>New term requested from NHS Information Authority</b> <b>New term requested from NHS Information Authority</b>
Diabetic neuropathy	<b>Persistent proteinuria</b>	N/A	N/A	
Diabetic neuropathy	Polyneuropathy in diabetes Autonomic neuropathy due to diabetes	C28. N/A	F372. F1711	Use child term if more detail known
Diabetic foot disorders	Ischaemic ulcer diabetic foot	N/A	M2710	Alternative for GP 4 Byte O/E codes as follows:
	Neuropathic diabetic ulcer - foot Mixed diabetic ulcer - foot	N/A N/A	M2711 M2712	2G5G O/E - R diab foot - ulcerated 2G5L O/E - L diab foot - ulcerated
Obesity diagnoses	<b>Central obesity</b>	N/A	N/A	<b>New term requested from NHS Information Authority</b>
	<b>Generalised obesity</b>	N/A	N/A	<b>New term requested from NHS Information Authority</b>
<b>Treatment:</b>	Diabetic on diet only Diabetic on oral treatment Diabetic on insulin Diabetic on insulin and oral treatment	66A3 66A4 66A5 66AV	66A3. 66A4. 66A5. 66AV.	

## List B Proposed Read Codes to Support the Clinical Audit Requirements of the Diabetes NSF

NSF Data Item	Read Code Preferred Term	GP 4Byte	Version 2	Comments
<b>Patient registration details</b>				
Patient age	Patient date of birth	9155	9155	Clinical system to calculate age
<b>Health information (Family history)</b>				
Family History	FH: Diabetes mellitus FH Fam hypercholesterolaemia	1252 1269	1252 1269	
<b>Personal and social Circumstances:</b>				
Ethnicity	Ethnic groups (census)	9S..	9S...	Choose appropriate child term
Exercise grading	Exercise grading Exercise physically impossible Avoids even trivial exercise Enjoys light exercise Enjoys intermediate exercise	138 1381 1382 1383 138H	138.. 1381. 1382. 1383. 138H.	Choose appropriate child term Due to physical illness or disability Interpreted as sedentary Walks to shops or walks locally once a week Regularly walks dog/takes brisk walks 1-2 time a week
Smoking status	Enjoys moderate exercise Enjoys heavy exercise Competative athlete Never smoked tobacco Ex smoker Date ceased smoking Cigarette consumption Cigar consumption Pipe tobacco consumption	1384 1385 1386 1371 137S 137T 137X 137Y 137a	1384. 1385. 1386. 1371 137S 137T 137X. 137Y. 137a.	Brisk walk or gym/swimming 3 times per week Vigorous exercise more than 3 times per week Competative athlete Stopped smoking for more than 1 year Enter date ceased smoking, nearest month and year Enter value in number per day Enter value in number per day Enter value in ounces per week

NSF Data Item	Read Code Preferred Term	GP 4Byte	Version 2	Comments
Alcohol consumption	Alcohol consumption Teetotaller Stopped drinking alcohol	136. 1361 1367	136.. 1361. 1367.	Enter value in units per week  Enter date stopped drinking alcohol
<b>Examination findings:</b> Height Weight Body Mass Index	O/E - height O/E - weight Body mass index	229.. 22A.. 22K..	229.. 22A.. 22K..	Enter value in metres Enter value in kilograms Enter calculated value
Blood pressure	O/E - Systolic BP reading O/E - Diastolic BP reading	2469. 246A.	2469. 246A.	Record value on clinical system Record value on clinical system
Presence of amputation	O/E-Amputated right above knee O/E-Amputated left above knee O/E-Amputated right below knee O/E-Amputated left below knee	2G44 2G45 2G46 2G47	2G44. 2G45. 2G46. 2G47.	There may be a record of amputation as a procedure
Peripheral pulses	O/E - peripheral pulses R. leg O/E - R.post.tib.pulse present O/E - R.post.tib pulse absent O/E - R.dorsalis pedis present O/E - R.dorsalis pedis absent O/E - peripheral pulses L. leg O/E - L.post.tib.pulse present O/E - L.post.tib. pulse absent O/E - L.dorsalis pedis present O/E - L.dorsalis pedis absent	24E.. 24E6 24E7 24E8 24E9 24F 24F6 24F7 24F8 24F9	24E.. 24E6. 24E7. 24E8. 24E9 24F 24F6. 24F7. 24F8. 24F9.	Choose child term for detail      Choose child term for detail

NSF Data Item	Read Code Preferred Term	GP 4Byte	Version 2	Comments
Tactile sensation	O/E - tactile sensation	29B.	29B..	Choose child term for detail Monofilament testing is the preferred method of assessing sensation and is considered to be normal if 7 sites or more out of 10 can be felt. If this is not available then vibration sense, below is a suitable alternative Choose child term for detail
	10g monofil sens R foot abnorm	29B9	29B9.	
	10g monofil sens L foot abnorm	29BA	29BA	
	10g monofil sens R foot normal	29BB	29BB.	
	10g monofil sens L foot normal	29BC	29BC.	
	O/E - vibration sense	29H.	29H..	
	O/E-Vibr sens Rt foot abnorm	29H4	29H4.	
	O/E-Vibr sens Rt foot normal	29H5	29H5.	
	O/E-Vibr sens Lt foot abnorm	29H6	29H6.	
	O/E-Vibr sens Lt foot normal	29H7	29H7.	
Visual inspection & testing	O/E - retinal inspection	2BB.	2BB..	Choose child term to give detail of examination findings
	O/E - visual acuity R eye	2B6.	2B6..	Choose child term to give measured acuity
	O/E - visual acuity L eye	2B7.	2B7..	Choose child term to give measured acuity
<b>Test results:</b>	Haemoglobin A1c level	44TB	44TB.	Record level
	Urine dipstick for protein	4679	4679.	Choose child term for +/-ve and further investigate if +ve
	Urine microalbumin	46W.	46W..	Record level
	Microalbumin excretion rate	46W2	46W2.	Record rate
	Albumin excretion rate	44J6	44J6.	Record rate
	Albumin / creatinine ratio	44J7	44J7.	Record ratio
	24 hour urine albumin output	46N6	46N6.	Record output
	Urine protein	46N.	46N..	Record level
	24 hour urine protein output	467A	467A.	Record output
	Serum creatinine	44J3	44J3.	Record level
	Plasma total cholesterol level	44OE	44OE.	Record level

NSF Data Item	Read Code Preferred Term	GP 4Byte	Version 2	Comments
<b>Diagnoses: Diabetes:</b>	Insulin depend diabetes mellitus	C22.	C108.	This term has now been replaced by Type I diabetes mellitus C10E.
	Non-insulin depend diabetes mell	C21.	C109.	This term has now been replaced by Type II diabetes mellitus C10F.
	Type I diabetes mellitus	N/A	C10E.	The preferred code for Type I
	Type II diabetes mellitus	N/A	C10F.	The preferred code for Type II
	Diabetes mellitus autosomal dominant	N/A	C10C.	This may be used for Maturity onset diabetes in the young (MODY)
	Gestational diabetes mellitus	C2B.	L1809	
	<b>Impaired glucose tolerance</b>	C350	N/A	<b>New term requested from NHS Information Authority</b>
	<b>Impaired fasting glycaemia</b>	C351	N/A	<b>New term requested from NHS Information Authority</b>
	Diabetes mellitus with ketoacidosis	C24.	C101.	
	Hyperosmolar non-ketotic state in type 2 diabetes mellitus <b>Hypoglycaemic state in diabetes</b>	N/A N/A	C109K <b>N/A</b>	<b>New term requested from NHS Information Authority</b>
<b>Complications of diabetes:</b>	Ischaemic heart disease	G41. G44.	G30.. G33..	Use child term if more detail known
	Hyperlipidaemia	C524 C525	C324. C3200	
	Acute myocardial infarction			
	Angina pectoris			

NSF Data Item	Read Code Preferred Term	GP 4Byte	Version 2	Comments
Hypertensive disease	Hypertensive disease	G3..	G2...	Use this if cause of hypertension is not to be essential
Precerebral vascular disease	Essential hypertension Precerebral arterial occlusion	G31 G72.	G20.. G63..	
Cerebral vascular disease	Cerebral arterial occlusion Transient cerebral ischaemia Stroke/CVA unspecified	G73. G74. G75.	G64.. G65.. G66..	Choose child term for more detail  Choose child term for more detail
Arterial aneurysms	Aortic aneurysm	G82.	G71..	
Peripheral vascular disease	Peripheral vascular dis. NOS  Intermittent claudication	G86.  G85.	G73z.  G73z0	
Retinal disease	Diabetic retinopathy Diabetic cataract  Registered blind Registered partially sighted	F521 N/A  6689 6688	F420. F4640  6689. 6688.	Choose child term for more detail GP 4 Byte has synonym of 'Cataract - diabetic' code 'C27.'
Renal disease	Diabetic nephropathy <b>Persistant microalbuminuria</b>  <b>Persistant proteinuria</b>	C26. N/A N/A	C104. N/A N/A	<b>New term requested from NHS Information Authority</b> <b>New term requested from NHS Information Authority</b>

NSF Data Item	Read Code Preferred Term	GP 4Byte	Version 2	Comments
Diabetic neuropathy	Polyneuropathy in diabetes Autonomic neuropathy-diabetes	C28. N/A	F372. F1711	Choose child term for more detail
Diabetic foot disorders	Ischaemic ulcer diabetic foot	N/A	M2710	Alternative for GP 4 Byte O/E codes as follows: 2G5G O/E - R diab foot - ulcerated 2G5L O/E - L diab foot - ulcerated
Obesity diagnoses	Neuropathic diabetic ulcer - foot Mixed diabetic ulcer - foot <b>Central obesity</b> <b>Generalised obesity</b>	N/A N/A N/A N/A	M2711 M2712 N/A N/A	<b>New term requested from NHS Information Authority</b> <b>New term requested from NHS Information Authority</b>
<b>Treatment:</b>	Diabetic on diet only Diabetic on oral treatment Diabetic on insulin Diabetic on insulin+ oral treat SHORT-ACTING INSULIN PREPS MEDIUM/LONG ACTING INSULINS SULPHONYLUREAS BIGUANIDES ACE INHIBITORS CA-CHANNEL BLOCKER+ACE INHIBIT ALPHA-ADRENOCEPTOR BLOCKERS	66A3. 66A4. 66A5. 66AV. f1 .. f2.. f3.. f3.. bi.. bA.. bh..	66A3. 66A4. 66A5. 66AV. f1 ... f2... f3... f3... bi... bA... bh...	Alternative is to use actual prescribed medication, however, some benefits to using both for the purposes of Audit.  Headings terms for drug treatment Read Codes. Choose Appropriate child terms for specific prescribed medication  Read codes for prescribed medication will automatically be assigned in the majority of GP clinical information systems

NSF Data Item	Read Code Preferred Term	GP 4Byte	Version 2	Comments	
<b>Procedure (preventive):</b>	Influenza vaccination	65E..	65E..	Alternatively record prescribed vaccine (see note above)	
	Pneumococcal vaccination	6572.	6572.	Alternatively record prescribed vaccine (see note above)	
	Diabetes mellitus screen	6872.	6872.	For the screening terms add the date that the screen was performed	
	Obesity screen	6878.	6878.		
	Hyperlipidaemia screen	6879.	6879.		
	Diabetic retinopathy screening	68A7.	68A7.		
	Hypertension screen	68B1.	68B1.		
	Diabetic foot examination	66Ab.	66Ab.		
<b>Patient participation</b>	Pt advised re wt reducing diet	N/A	8CA40	GP 4 Byte users only have 'Patient advised re diet' code '8CA4'	
	Pt advised re diabetic diet	N/A	8CA41		
	Pt advised re low cholesterol diet	N/A	8CA47		
	Pt advised re low salt diet	N/A	8CA48		
	Patient advised re exercise	8CA5	8CA5.		
	Patient advised about alcohol	8CAM	8CAM.		
	Smoking cessation advice	8CAL	8CAL.		
	Advice about foot care	6717	6717.		
	<b>Advice about blood glucose control</b>	N/A	N/A		<b>New term requested from NHS Information Authority</b>
	<b>Advice about psychological well being</b>	N/A	N/A		<b>New term requested from NHS Information Authority</b>

NSF Data Item	Read Code Preferred Term	GP 4Byte	Version 2	Comments
Clinical administration	Diabetes management plan given	66AR	66AR.	Add date given
	Diabetic annual review	66AS	66AS.	
	Attends diabetes monitoring	9OL1	9OL1.	
	Diabetes monitoring 1st letter	9OL4	9OL4.	
	DNA - Did not attend diabetic clinic	9N4I	9N4I.	
	Refuses diabetic monitoring	9OL2	9OL2.	
	Refer to podiatry	8H7X	8H7X.	
	Seen by podiatrist	9N2Q	9N2Q.	
	Refer to dietician	8H76	8H76.	
	Seen by dietician	9N27	9N27.	
	Referral to retinal screener	8H7n	8H7n.	
	Seen by retinal screener	9N2f	9N2f.	
	Refer, diabetic liaison nurse	8H7C	8H7C.	
	Seen by diabetic liaison nurse	9N2i	9N2i.	
Referral to smoking cessation advisor	8H7i	8H7i.		
<b>Seen by smoking cessation advisor</b>	N/A	N/A	<b>New term requested from NHS Information Authority</b>	

### Health Promotion Activity To Prevent Diabetes

#### Recommended activity

Obesity and physical inactivity are major risk factors for Type 2 diabetes. There is also clear evidence that individuals who have impaired glucose tolerance can reduce their risk of developing Type 2 diabetes if they eat a balanced diet, lose weight and increase their physical activity levels.

#### Promoting healthy eating and physical activity

A number of Welsh Assembly Government initiatives are currently being implemented to encourage a healthier diet and increase physical activity levels:

- The "Food and Well Being" strategy and action plan, developed in collaboration by the Food Standards Agency Wales and the Welsh Assembly Government, was launched on 13 February 2003. The document outlines the actions required by key players to improve the diet of all people in Wales, but particularly those groups most likely to be affected by inequalities in diet and health. Seminars to support the implementation of the strategy are being held in May 2003.
- The Community Food initiative launched in October 2000 (small grants scheme for projects that actively promote healthy eating among disadvantaged and vulnerable groups).
- Action to improve the nutrition of school-aged children through the Welsh Network of Healthy School Schemes, including fruit tuck shop schemes and breakfast clubs.
- Implementation of the Assembly Government's Healthy Lifestyles Action Plan, which aims to increase levels of physical activity in Wales. The public consultation on the Action Plan ended on 31 January 2003, and the final version will be launched in late spring 2003.

- Development and distribution to all primary schools in Wales of "The Class Moves!", an educational resource which provides a programme to enable children and teachers to discover the pleasures of movement and the benefits of relaxation.
- Inequalities in Health Fund (IHF) projects with a healthy eating and/or physical activity component. (IHF funding is currently targeted at reducing coronary heart disease, but CHD prevention initiatives also address diabetes and cancer prevention aims).

## Smoking prevention and cessation

As well as increasing the risk of heart disease and lung and other cancers, smoking greatly increases the risk of developing complications from diabetes. The Welsh Assembly Government has a comprehensive national smoking prevention and cessation programme in place. Current activity targeted at discouraging young people from smoking includes:

- development and distribution of new education materials on tobacco for primary school children
- support for Smokebugs clubs for primary school children
- participation by Welsh schools in the Smoke-Free Class Competition
- development of Tobacco Action Groups in secondary schools.

Action being taken by the Assembly to help smokers who want to give up includes:

- Continuing support for local smoking cessation services
- Smoking cessation training for primary care professionals
- Piloting adolescent smoking cessation projects
- Provision of a smokers' helpline, and a mass media campaign to promote awareness of the helpline.

### Summary of Market Research Wales Focus Group

When looked at as a set of Standards, they were generally very well received by both users and providers. Many participating in the research, especially users, found them quite hard to grasp as a document, however, and most of the issues arising emerged from the general discussion around their views of the service rather than the Standards themselves (even though these issues were linked to the Standards).

The main priorities for action agreed by both providers and users alike were Standards 1 and 2. Even though the whole set of 12 Standards were all perceived as being vital to the care of people with diabetes, Standards 1 and 2 were viewed as the most important as it is these two that will be most beneficial in terms of identifying and controlling the condition. The two issues of identification and prevention, need to be achieved through:

- raising awareness
- educating health professionals, people with diabetes and the general public
- patient empowerment
- regular checks of high risk groups
- screening of people with diabetes for long-term complications.

The following were perceived as being the next most important priorities:

- the transition of adolescents from paediatric to adult care
- the standardisation of service across Wales
- the integration of primary and secondary care
- the surveillance of long-term complications

In addition to the above, some views on gaps to current service provision were very group specific, particularly the language and culture barriers to

service cited by ethnic minorities. Both providers and ethnic minorities with diabetes thought they were receiving very sub-standard care when compared to the rest of the population.

Other than the ethnic communities, the overall current level of service was perceived to be very good, especially the service given by Diabetic Specialist Nurses. Users, as well as providers, felt the Standards were already being striven for in the service they were receiving, even though they had not been previously formalised, and the reasons they were not being achieved linked to the lack of resources (staff) and funding. In order for the Standards to be achieved successfully both users and providers felt that additional staff resources and funding had to be provided, and that the achievement of the Standards would have to be carefully monitored (therefore requiring the appropriate procedures to be put in place).

### Summary of Report - Training and Education Sub-Group

#### AIM

The aim of the group was to advise the Implementation Group and Welsh Assembly on training and education issues for health care professionals relating to the implementation of the Diabetes National Service Framework in Wales.

The group was multi-professional with representation from primary and secondary care, PAMS, academic establishments, people with diabetes, voluntary sector and representatives from departments within the Welsh Assembly. Three meetings were held and members of the group also arranged an additional meeting at Llangammarch Wells. It was identified that priority must be given to a structured education plan, which involves all health care professionals involved with diabetes care particularly those in primary care.

#### Key Recommendations

1. Establish a Diabetes Education Steering Group.

The Welsh School of Medicine would appear to be the most likely focal point of this group although representation from primary care health professionals will be vital.

2. Wales should be independent in training.

At present, for most educational courses in diabetes, individuals in Wales are required to access courses in England. For the delivery of a Welsh NSF it is vital that a Welsh educational framework is in existence.

3. Further education needs to be patient centred and take into account the experiences of people with diabetes in Wales.

4. If education is to take advantage of potential partnerships with the pharmaceutical industry clear guidelines must be established by the Assembly and made widely available. This would overcome the existing uncertainty and confusion.

5. It is unlikely that any one course or type of delivery will suit all groups of health care professionals. Consideration must be given to both multidisciplinary and more traditional uni-professional courses. Course delivery must examine the potential benefits of residential, satellite and distance learning. The needs of different professional groups and different localities will need to be addressed.

### Summary of Report – Patient and Education and Support Sub-Group

#### Introduction

The Implementation Group identified patient education and support as an important aspect to be considered for the delivery of the Diabetes National Service Framework.

#### Aim

To advise the Implementation Group and Welsh Assembly on patient education and support issues relating to the implementation of the Diabetes National Service Framework in Wales.

#### Objectives

- To develop a menu for patient education, and support and establish methods of clinical, emotional and psychological support professional that will underpin the Delivery Strategy.
- To advise on the use of any available monies for patient training and education in the area of diabetes in 2003/04 as part of the stated phased approach to the delivery of the Diabetes NSF in Wales.
- To comment on patient education and issues arising out of the Standards document.
- To assist the Audit Commission commissioned to carry out the baseline review in Wales.
- To establish guidelines for the working relationship between the NHS and pharmaceutical industry that can be used by those working to develop patient training and education and support strategies as part of the implementation of the NSF.

- To communicate back to the Implementation Group and other relevant groups. The Chair to deliver a final report to the Implementation Group with recommendations for the implementation of the NSF.
- To consider hard to reach groups, and develop strategies for raising awareness with the public, professionals and people with diabetes.

## Membership

Membership was multi-disciplinary and included people with diabetes and carers.

It was also geographically spread to reflect the needs of all parts of Wales. Membership included relevant members of the Implementation Group and Internal Reference Group in the Assembly.

## Issues

- What models of education are available: which are the best ones and how can people be directed to the best ones.
- Working with the pharmaceutical industry.

Diabetes is a life-long condition that will have impact on every part of a person with diabetes' life, therefore it is vitally important that people with diabetes have access to a structured education programme that is culturally appropriate and individualised.

Self-management of diabetes is the cornerstone of diabetes care and this will reduce the risks of the associated complications of diabetes, which are known to reduce life expectancy and quality of life.

## Recommendations:

### 1. Patient Education

All people with diabetes should receive a structured and ongoing programme of education that is language and culturally appropriate and is individualised. This needs to be multi-disciplinary and based on local needs.

## 2. Education for Children

Children to have access to:

- professional education programmes which will include support for teachers and nurses.
- psychology and/or counselling service.
- 24-hour helpline for children and families with diabetes.
- appropriate literature that is standardised and consistent.

## 3. Funding

Education must be resourced, evaluated and monitored. Local Health Boards will need to allocate money for this.

Some initiatives they could spend it on are:

- Raising awareness of the risk factors and those people who are at a higher risk of developing diabetes.
- Support and self-management programmes such as the Peer Support Programme (Merthyr LHG) Chronic Disease Self-Management Programme, 3D Programme (Diabetes UK Scheme for Newly Diagnosed).

## 4. Residential/Nursing Homes

- Training issues will need to be addressed by the Care Standards Inspectorate. Social Services need to be involved in the training. All people with diabetes in residential/nursing homes should have equitable access to services.

## 5. Patient held records

- People with diabetes should be involved in the design of these records and they will need to be piloted in Wales. Patient held records should be integrated with IT.

## **6. Patient/Public Involvement**

- Patient involvement needs to be targeted at as wide an audience of people with diabetes as soon as possible.
- LDSAG needs to be associated with the Local Health Board.
- Patient involvement must be properly resourced.
- Annual review of public/patient involvement to be sent to Welsh Assembly Government.
- People with diabetes should be involved in the planning of diabetes services.

## **7. Working with the Pharmaceutical Industry**

- The Welsh Assembly Government needs to issue guidelines to LHBs.
- Any literature produced should involve people with diabetes in its design and also involve RNIB, Diabetes UK, Wales Council for the Blind and British Heart Foundation.

## **8. Clinical, emotional and psychological support**

- All people with diabetes should have access to psychology and/or counselling service.
- All people with diabetes should have access to intensive education programmes, peer support, chronic disease management programmes and voluntary organisations.

Patient education, support and empowerment programmes should include hard to reach groups. Strategies for raising the awareness of diabetes issues to the public, professionals and people with diabetes should be developed.

## **9. Hard to reach groups**

- Education needs to be provided to minority ethnic communities in an appropriate language and taking into account their religious and cultural needs.

- People who develop sight problems as a result of their diabetes need to have access to information that is provided in appropriate size of font and access to mobility training and social services.
- All people with diabetes who are in prisons need equal access to diabetes services and education.

## 10. Health Promotion

- The sub-group felt that Health Promotion should raise awareness of risk factors and prevention.
- The group felt that a further sub group needed to be set up to take this issue forward.

## Conclusion

Patient education and support services should be a key deliverable of the diabetes NSF and in order for this to be achievable dedicated long term funding will need to be available.

### Summary of the 'Having Your Say' Conference Report

This conference took place in September 2002 in Llandrindod Wells, and gave people living with diabetes from across Wales a chance to voice their views on diabetes services.

The National Service Framework is a 10-year plan, and all at the conference were aware that changes and developments take time and investment. People living with diabetes grasped the opportunity provided by the conference to have their say, and to welcome developments to date and showed they were keen to contribute to future developments in Wales.

Delegates expressed the hope that the Diabetes NSF Project Board set up by the Welsh Assembly Government will support a delivery strategy that puts people with diabetes at the centre of services. It was agreed that the implementation services that support the NSF standards would improve the care of people with diabetes at a time when more people are being diagnosed every week in Wales.

There is a great deal of support and interest amongst people living with diabetes in the NSF and an enthusiasm for the potential development of a patient centred, modern service where people living with diabetes receive evidence based care from knowledgeable, supportive health care professionals and through which they can access the support of voluntary organisations (when they need it).

The conference delegates wanted to see clear action in the areas of:

- Education and training for healthcare professionals and people living with diabetes
- Greater awareness of diabetes and diabetes services amongst healthcare managers/planners and politicians
- User involvement in planning
- Information about local voluntary groups/Diabetes UK and the support they can provide.

The full report and all action points are available on [www.wales.gov.uk](http://www.wales.gov.uk).

## Membership of the Implementation Group

Dr Jane Wilkinson	Chair, consultant in public health
Mrs Helen Nicholls	Dietitian, PAMS representative
Dr Terry Davies	General Practitioner
Dr Owain Gibby	Consultant diabetologist
Dr John Gregory	Consultant paediatrician
Dr Susan Griffiths	Bro Taf health authority
Dr Lyn Harris	Dyfed Powys health authority
Dr Lionel Bloodworth	Consultant nephrologist
Dr John Harvey	North Wales health authority
Dr John Peters	Consultant physician
Mrs Margaret Knight	Diabetes UK Cymru
Mrs Janet Lloyd	Service user,
Mrs Samantha McNamara	Diabetes Specialist Nurse
Professor David Owens	Professor of diabetology,. UWCM
Dr Kamilla Hawthorne	GP with an interest in ethnicity
Dr Terry Thomas	Service user
Mrs Pauline Card	Service user
Mrs Wendy Gane	Service user
Dr Brendon Lloyd	Iechyd Morgannwg health authority
Mrs Joanne Absolom	Local Health Group general manager
Mr Bernard Holton	ABPI (Wales Industry Group)
Dr John Watkins	Gwent health authority
Mr John Sweeney	National Assembly for Wales, PCH
Ms Jackie Dent	Project manager
Mrs Catherine Roberts	NSF officer

We would also like to acknowledge the contributions of Dr Brendan Mason, Mrs Nimisha Joshi, Miss Katie Topliss, Mrs Marjorie Dykins, Mr David Greensmith (deceased), Mrs Vivienne Robins-Grace, and Mrs Maureen Worcester to the work of the Implementation Group.

## Membership of Project Board Replaced Implementation Group January 2003

Mike Ponton	Chair
Jackie Dent	Project Manager
Helen Howson	Welsh Assembly Government
Ms Helen Nicholls	Dietician
Dr. Terry Davies	General Practitioner
Dr Owain Gibby	Consultant Diabetologist
Dr John Gregory	Consultant Paediatrician
Dr. Lionel Bloodworth	Consultant Nephrologist
Dr John Peters	Consultant Physician
Margaret Knight	Diabetes UK Cymru Manager
Sister Samantha McNamara	Specialist Diabetic Nurse
Dr Jane Wilkinson	Consultant in Public Health
Prof. David Owens	Professor of Diabetology, UWCM
Dr Kamila Hawthorne	GP with an interest in ethnicity
Pauline Card	Service User
Wendy Gane	Service User
Nimisha Joshi	Diabetes Facilitator
Catherine Roberts	NSF Officer
Prof. Rhys Williams	Chair of Clinical Epidemiology
Geraint Thomas	ABPI (WIG)
Thea Maunder	Parent
Joanne Absolom	LHB CEOs Representative
Lance Reed	Podiatry
Dick Roberts	Optometry
Dr John Harvey	Consultant Physician
Karen Davies	Research and Development
Maggie Parker	Office of the Chief Nursing Officer
Dr David Phillips	Office of the Chief Medical Officer
Stephen Vaughan	Social Services Inspectorate Wales
Sue Cromack	NHS Human Resources
Carolyn Poulter	Primary care
Christopher Edmunds	Health Information and Faculties
Bethan Jones	NHS Finance

We would also like to acknowledge the contributions of Mr. John Sweeney, Mrs Linda Dyer and Mrs Heulwen Blackmore to their work of the original Project Board.

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<sup>25</sup>[www.ombudsman.org.uk](http://www.ombudsman.org.uk)

<sup>26</sup>[www.doh.gov.uk/cmo/progress/expertpatient/index.htm](http://www.doh.gov.uk/cmo/progress/expertpatient/index.htm)