NHS SCOTLAND

Scottish Diabetes Framework

SCOTTISH EXECUTIVE

Working together for a healthy, caring Scotland

Scottish Diabetes Framework: **Contents**

Scottish Diabetes Framework

Figures and Tables

Scottish Diabetes Framework: **Foreword**

Malcolm Chisholm MSP
Minister for Health and
Community Care

Publication of the full Scottish Diabetes Framework fulfils one of the key commitments in *Our National Health, a plan for action a plan for change*.

Diabetes services are continually developing to take account of new evidence, new challenges and new opportunities. The Scottish Diabetes Framework reflects and accommodates this reality. It is an enabling and supporting mechanism rather than a definitive statement. It is also more than the sum of its parts – both an umbrella for a range of existing and new initiatives and a unifying programme for the improvement of diabetes services.

The Framework has been developed in an open and inclusive way, with the full involvement of people with diabetes and voluntary organisations representing their interests. The process has at all times sought to be a stimulus to innovation and change rather than an excuse for inaction or a cause of 'planning blight'. It is therefore pleasing to be able to report that as this full Framework document is being published, a number of the ideas circulated during the consultation period or announced in November 2001 are already beginning to take root. That is welcome evidence that the commitment to produce a Diabetes Framework is working with the grain of NHS Scotland.

This Framework is quite deliberately not an exhaustive review of diabetes, nor a prescription to solve all of the problems. Change will be evolutionary and progress will be incremental. This Framework marks the start of what is envisaged as a ten year programme to address the increasing problem of diabetes in Scotland. Although the Framework sketches out what the diabetes service of the future should look like, the Working Group has, rightly, not attempted to map out milestones for the whole decade. Instead, the Framework sets out specific targets for the next 2-3 years, which the Working Group believe are key building blocks for the development of integrated, patient-centred diabetes services.

Central to all of this is the development of diabetes Managed Clinical Networks. The Executive welcomes this emphasis, as it believes Managed Clinical Networks are an innovative and appropriate way to provide services for a range of chronic conditions.

The Framework establishes a 'Scottish Diabetes Group' as a national steering group to monitor and support implementation by NHS Boards and makes a commitment to review and reissue the Framework in two years time. This will ensure that Scotland has a strategy for diabetes care that remains relevant and realistic and which can build upon the foundations which this Framework seeks to build. Crucially, the strategy for diabetes in Scotland contains mechanisms to measure and report progress. This is not only nested within the Framework, but builds upon the important complementary work of SIGN, the Clinical Standards Board for Scotland and the Health Technology Board for Scotland's work on a national screening strategy for diabetic retinopathy screening. Thus, the results of the Framework as they are delivered will help to refine the strategy and allow lessons to be learned and good practice to be shared.

If there is one dominant theme throughout this Framework it is the value and importance of collaboration. There must be collaboration between professionals and people with diabetes; between different professionals who make up the diabetes care team; between different organisations involved in the care and treatment of people with diabetes; and between national agencies which need to forge productive links to ensure that intersecting initiatives work together to serve the needs of patients. The basis of good diabetes care is teamwork and it is this that the Scottish Diabetes Framework seeks to promote. I therefore expect that patients with diabetes and health care professionals working together will continue to contribute to shaping high quality diabetes services locally and nationally.

Finally, I should like to record my gratitude to all those who helped to prepare this document. I would also like to pay tribute to the late Professor James Petrie CBE, Chairman of SIGN and the original chairman of the Scottish Diabetes Group. His energetic efforts in the field of clinical guidelines, evidence-based practice and clinical leadership played the key role in preparing the ground for this Framework. The Scottish Executive is committed to building upon this superb platform to develop a world class service for people with diabetes.

Malcolm Chisholm MSP
Minister for Health and Community Care

Scottish Diabetes Framework: **Executive Summary**

Diabetes presents a serious health challenge for Scotland. There are believed to be 150,000 people in Scotland who have been diagnosed with diabetes and there are almost certainly many thousands more who are, as yet, undiagnosed. The number of people developing diabetes is increasing and may double in the next 10-15 years.

Diabetes is a chronic condition with potentially devastating consequences for health. Complications of diabetes include a higher risk of heart disease, stroke, kidney failure, eye disease (diabetic retinopathy) that can lead to blindness, and foot ulceration, which can lead to amputation.

There is robust evidence that good diabetes care (e.g. control of blood pressure, glycaemic control and cholesterol) reduces the risk of complications. The evidence base for diabetes treatment has been collated in a recent SIGN guideline (SIGN 55).

The Scottish Diabetes Framework was developed by a Working Group set up by the Scottish Executive in response to a commitment in *Our National Health: A plan for action, a plan for change*. A consultation paper was widely circulated during Summer 2001 and the responses to that consultation have shaped this document.

The Framework seeks to draw together existing guidance and best practice. It should be read in conjunction with two key documents; the 'Management of Diabetes' guideline produced by SIGN and the clinical standards for diabetes produced by the Clinical Standards Board for Scotland which were both published in November 2001. The standards and the clinical guideline should be viewed as integral parts of the Framework.

As a planning tool, a model of diabetes care was developed by the Working Group. This consists of 22 building blocks, divided amongst six broad headings: Prevention and early detection; Care, monitoring and treatment; Specific groups; Planning and managing services; Implementation; and Community Issues.

The Framework identifies seven of the building blocks as 'first stage' priorities:

- Patient Information, Education and Empowerment
- Heart Disease
- Eye Care
- Strategy, Leadership and Teamworking
- Education and Training for Professionals
- IM&T and Diabetes Registers
- Implementation and Monitoring

In order to support and monitor the implementation of the Framework a Scottish Diabetes Group has been established as a national steering group.

Throughout the Framework a number of 'milestones' and 'actions points' have been included. A **Milestone** represents a significant stage on the way towards creating a high quality patient-centred diabetes service. It marks a point for reflection, assessment of progress and confirmation of direction. An **Action Point** is a specific piece of work that will be undertaken to support this process.

MILESTONES AND ACTION POINTS

Public Education

- Each NHS board should organise in collaboration with other agencies, at least one event to raise public awareness of diabetes during 2002/03. (*paragraph 37*)

Patient Information, Education and Empowerment: Seeking the views of people with diabetes

- Partners in Change will publish a report of its work with people with diabetes by June 2002. (*paragraph 43*)

Patient Information, Education and Empowerment: Patient education

- A report on patient education programmes in diabetes will be produced by December 2002. (*paragraph 46*)

Patient Information, Education and Empowerment: Patient information

- The Scottish Diabetes Group will work with NHS24 to ensure that relevant and up to date information on diabetes care and services is available through NHS24. (*paragraph 47*)
- By September 2002 the Scottish Diabetes Group will agree on and put in place a programme of work to help to ensure that relevant high quality patient information on diabetes is available to patients and carers. (*paragraph 49*)

Patient Information, Education and Empowerment: Patient involvement

- A project to encourage and support patient and carer involvement in the work of Managed Cinical Networks and Local Diabetes Service Advisory Groups (LDSAGs) will be funded in 2002. (*paragraph 52*)
- A guide to encourage the active participation of patients, parents and carers in Local Diabetes Service Advisory Groups (LDSAGs) and other service planning fora will be produced by June 2002. (*paragraph 53*)
- A national meeting for lay members and potential lay members of LDSAGs will be held during 2002. (*paragraph 53*)

Heart Disease

- Good practice models for screening for cardiovascular risk factors in diabetic patients will be defined and disseminated by December 2002. (*paragraph 58*)

Eye Care

- All people with diabetes will have their eye status (retinopathy) recorded on the local diabetes clinical management system by September 2003. (*paragraph 64*)
- The Scottish Diabetes Group will produce plans to take forward the implementation of the report of the Health Technology Board for Scotland on the organisation of services for diabetic retinopathy screening by Summer 2002. (*paragraph 65*)
- A national co-ordinator to support the implementation of the recommendations of the Health Technology Board for Scotland on the organisation of services for diabetic retinopathy screening will be appointed by September 2002. (*paragraph 65*)

Initial and Continuing Care

- Annual measurement of glycated haemoglobin (a measure of the amount of sugar in the blood; HbA1c) will be offered to all people with diabetes by September 2002. The results will be recorded on the local diabetes clinical management system. (*paragraph 69*)

Children and Young People

- An educational video for children with diabetes and their families will be funded, produced and made available by autumn 2002. Every new family will be offered a video or DVD. (*paragraph 84*)

Ethnic Minority Groups

- By September 2003, the Scottish Diabetes Group will publish a report, in conjunction with the Ethnic Minority Resource Centre of the Public Health Institute for Scotland (PHIS), on the epidemiology of diabetes amongst Scotland's ethnic minorities. (*paragraph 85*)

Strategy, Leadership and Teamworking: Leadership

- Clinical leaders should be identified at locality level to champion local integrated diabetes services in all NHS boards by June 2002. (*paragraph 95*)
- A dedicated 'diabetes co-ordinator' to improve communications within the local diabetes community and provide administrative support to enhance integrated care across primary and secondary care should be identified in all NHS boards by December 2002. The co-ordinator should be responsible to the LDSAG for strategy and implementation of policy at locality level. (*paragraph 97*)

Strategy, Leadership and Teamworking: Local Diabetes Service Advisory Groups

- All NHS boards should establish an effective multi-professional Local Diabetes Service Advisory Group (or equivalent) with service user involvement by June 2002. (*paragraph 98*)

Strategy, Leadership and Teamworking: Reporting arrangements

- All NHS boards should publish an Annual Diabetes Report. A report for 2002/03 should be prepared and published by each LDSAG by June 2003. (*paragraph 99*)

Strategy, Leadership and Teamworking: Strategy and Implementation plan

- All NHS boards should publish a local diabetes strategy and implementation plan by April 2003. (*paragraph 100*)

Strategy, Leadership and Teamworking: Workforce planning

- A workforce survey of diabetes services in hospitals and the community (e.g. specialist nurses, podiatrists, dietitians, community nurses, general practitioners and consultants) will be commissioned by January 2003. (*paragraph 101*)

Strategy, Leadership and Teamworking: Diabetes Collaborative Improvement Programme

- A Diabetes Collaborative Improvement Programme will be established by March 2002 to support the sharing of experience and best practice throughout Scotland to improve care and outcomes for people with diabetes. (*paragraph 102*)

Strategy, Leadership and Teamworking: Managed Clinical Networks

- Managed Clinical Networks for diabetes will be established in all NHS Boards by September 2004. (*paragraph 103*)

Education and Training for Professionals

- A short-life group will be established by the Scottish Diabetes Group to assess the availability and quality of existing diabetes education and training, to ascertain the training needs of staff, especially in primary care, and to make recommendations for meeting these needs. A report of this work will be published by December 2002. (*paragraph 110*)

IM&T and Diabetes Registers

- All hospital-based diabetes clinics will be supported by an effective IT system by December 2002. (*paragraph 115*)
- A national IT system to support all aspects of diabetes care will be fully implemented throughout Scotland by December 2005. (*paragraph 115*)

IM&T and Diabetes Registers: Local Diabetes Registers and the Scottish Diabetes Survey

- All NHS boards should submit data for the 2002 Scottish Diabetes Survey in September 2002. (*paragraph 116*)
- A conference for those involved in developing and maintaining local diabetes registers will be held by Summer 2002 to update progress, and foster collaboration between all Scottish regions in the £1.5 million SCI-DC (SCI Diabetes Collaboration) programme. (*paragraph 116*)

Implementation and Monitoring

- The CSBS will publish an assessment of the standards of care provided by diabetes services in 2003. (*paragraph 125*)

Scottish Diabetes Group

- A website to improve collation and dissemination of information about diabetes in Scotland - www.show.scot.nhs.uk/diabetes – will be established by the Scottish Diabetes Group by September 2002. (*paragraph 132*)
- A conference to promote best practice in diabetes care (including service delivery and design, clinical IM&T, research and development, LDSAGs/managed clinical networks, and eye screening) will be hosted in Scotland in November 2002. (*paragraph 132*)
- The Scottish Diabetes Group will review and revise the Scottish Diabetes Framework by Spring 2004. (*paragraph 29*)

Scottish Diabetes Framework: **Introduction**

Diabetes – a priority for Scotland

1. There are believed to be 150,000 people in Scotland who have been diagnosed with diabetes and there are almost certainly many thousands more who are, as yet, undiagnosed. Contrary to popular belief, diabetes is progressive and life-threatening with potentially devastating consequences for health. The complications of diabetes include a higher risk of heart disease, stroke, kidney failure, eye disease (diabetic retinopathy) that can lead to blindness, and foot ulceration, which can lead to amputation. However, there is a great deal that can be done to prevent diabetes and to improve outcomes for people with diabetes.

2. The Scottish Health Plan – *Our National Health: A plan for action, a plan for change* – recognised the potential to make a significant impact on diabetes care and included a commitment to produce a Scottish Diabetes Framework:

> ***'In 2001, we will launch a Scottish Diabetes Framework to draw together existing guidance and best practice in order to raise the standard of diabetes care. The Framework will include plans to establish a national screening strategy for diabetic retinopathy.'***

3. A working group was established to take this forward. The membership of the Group is set out in Annex A. The Group's remit was:

> ***'To produce a Scottish Diabetes Framework which draws together existing guidance and best practice to address the provision of diabetes care throughout the patient journey, and which commands the support of those providing and receiving diabetes services.'***

4. On World Diabetes Day 2001 (14 November) the major milestones of the Diabetes Framework were published alongside two key components of the national work on diabetes – the SIGN clinical guideline on the management of diabetes and the clinical standards for diabetes care. The publication of this document sets out more fully the thinking behind the milestones and also reports on the progress already made towards meeting these objectives.

Diabetes – an international concern

5. The identification in Scotland of the problem of diabetes reflects worldwide concerns about the escalating incidence of diabetes. The 'epidemic' of diabetes, largely as a consequence of changes to lifestyle and diet, is putting increasing strains on all healthcare systems and societies. In Europe, official acknowledgement of the problem came in 1989 with the St Vincent Declaration. This series of recommendations arose from a meeting organised by the World Health Organization (WHO) and the International Diabetes Federation (IDF) in Europe that urged national governments and Health Departments to give formal recognition to the diabetes problem and deploy resources for its solution. Its goal for people

with diabetes was to achieve 'sustained improvement in health experience and a life approaching normal expectation in quality and quantity'. This remains a continuing challenge to governments and health care professionals. Recent national initiatives in Scotland to address the problems of diabetes were initiated as a result of the St Vincent Declaration.

What is diabetes?

6. Diabetes occurs where there is a shortage of, or an inability to respond to, insulin. Insulin is a hormone produced by the pancreas, which is needed to transport glucose (sugar) obtained from food, from the bloodstream into the body's cells where it is converted into energy. This results in a build up of glucose in the blood (hyperglycaemia).

'I don't really understand it – what is diabetes really?'

(Person with recently diagnosed diabetes)

7. The definition of diabetes mellitus (which in this document is simply referred to as 'diabetes') used by the Scottish Intercollegiate Guidelines Network (SIGN), which incorporates the diagnosis criteria set by the World Health Organization (WHO) is set out in the table below. Annex B reproduces, with permission from Diabetes UK, a longer and more straightforward description of the causes, symptoms and treatment of diabetes.

Table 1

Definition and Diagnosis of Diabetes Mellitus

Diabetes mellitus is defined as a metabolic disorder of multiple aetiology characterised by chronic hyperglycaemia with disturbances of carbohydrate, protein and fat metabolism resulting from defects in insulin secretion, insulin action, or both. The clinical diagnosis of diabetes is often indicated by the presence of symptoms such as polyuria, polydipsia, and unexplained weight loss, and is confirmed by measurement of abnormal hyperglycaemia.

The WHO advises that the range of blood glucose indicative of diabetes mellitus are as follows:

- Random venous plasma glucose ≥11.1 mmol/l; or
- Fasting plasma glucose (FPG) ≥7.0 mmol/l; or
- Plasma glucose ≥11.1 mmol/l at two hours after a 75g oral glucose load (the oral glucose tolerance test (OGTT)).

Management of Diabetes, SIGN, 2001 (p.2)

8. Diabetes is a chronic and progressive disease which causes damage to tissues throughout the body by damaging the small blood vessels. Initial changes are reversible, but over the long run, diabetes which is inadequately controlled can lead to a range of serious complications including damage to the eyes (diabetic retinopathy) which can lead to visual impairment and blindness; damage to the kidney (diabetic nephropathy) which can lead to renal failure; and damage to nerves (diabetic neuropathy) which can lead to foot ulcers and lower limb amputation. In addition, people with diabetes are at significantly higher risk of developing cardiovascular disease. This can result in coronary heart disease, stroke and poor circulation to the legs and feet. Diabetes is the fourth-leading cause of death in the UK.

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

- Type 1 is an autoimmune condition in which the body's own immune system destroys the insulin-producing cells in the pancreas. This deficiency needs to be treated with insulin injections. Type 1 usually occurs in people under the age of 30, often in childhood, although it can occur at any age. About 10-15% of people with diabetes have type 1.
- Type 2 diabetes develops when the body is unable to produce enough insulin, or cannot use the insulin the body produces properly (insulin resistance). This type of diabetes usually appears in people over 40 and depending on its stage of development can be treated by a combination of diet and drugs, although insulin may also be required. The development of type 2 is strongly linked to obesity and lack of physical exercise which explains the recent dramatic increase in the incidence of type 2 diabetes, including the worrying trend of type 2 diabetes being identified in ever younger patients.

'I have had diabetes for many years – it is an illness that doesn't show itself – the symptoms are not obvious, like a broken leg – other people don't take it seriously.'

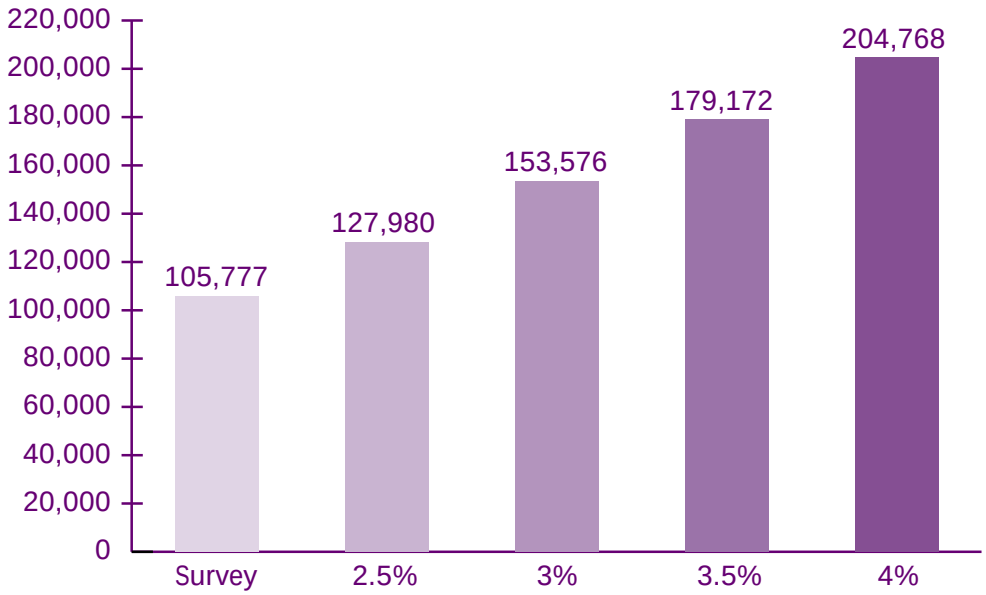
(Person with diabetes)

How many people in Scotland have diabetes?

10. At present, it is not known with any certainty how many people in Scotland have diabetes. Estimates vary and whilst it would be possible to measure the number of people diagnosed as having diabetes, the number of people with diabetes who have not yet been diagnosed can only ever be estimated. Calculations must also take account of the ever-rising number of people developing diabetes.

11. The Scottish Diabetes Survey 2001 is starting to help to answer the question of how many people in Scotland have diabetes. The Survey identified 105,777 people with diabetes, a prevalence of 2.1%. However, even in this provisional survey, eight areas returned figures above 2.1%. The 'true' figure is therefore almost certainly over 2.5% and probably above 3% in some areas.

Figure 1: Number of people with diabetes in Scotland. Scottish Diabetes Survey 2001 and future projections.



The percentages used in the figure above (and taken from the Scottish Diabetes Survey 2001) are based on data provided by the Registrar General for Scotland for a Scottish population of 5,119,200, the mid-year estimate at 30 June 1999.

12. A number of commentators (including the WHO) have suggested that the total number of people with diabetes is set to double over the next 10-15 years. This would mean well in excess of 200,000 people with diabetes in Scotland.

Table 2

Care of people with diabetes in a general practice population

In Scotland, the average GP list size is 1,508. For a practice with 3,000 registered patients, there will be around 90 to 100 individuals with diabetes.

Of these, around 15 to 19 people will have type 1 diabetes. The remainder will have type 2 diabetes. There will probably be two people with diabetes aged under 15 years, while 40 to 48 patients with diabetes will be aged over 65 years.

While a substantial majority of the patients with diabetes will be well and active, there will probably be one patient who is registered blind as a result of diabetes, another who has had a lower limb amputation because of diabetes-related circulatory disease, a further patient who has end-stage renal disease and seven or eight diabetic patients who have had a myocardial infarction (heart attack).

There is increasing evidence that systematic clinical review with good control of glycaemia and blood pressure can delay and even prevent the onset of complications of diabetes. This implies at least one annual review for each person with diabetes. It also implies the existence of a clinical management system to ensure that systematic care is given to all diabetics registered with the practice.

If this systematic care is to be provided in a manner which can be trusted by the person with diabetes, sufficient dedicated time must be made available for each individual to build that relationship, the confidence and the motivation needed. As a minimum, 30 minutes of practice staff time should be allocated towards the annual review for each individual. This would mean approximately six patients could be seen per (three-hour) session. So, in this example, the practice might need to organise about 17 diabetes review clinics per year.

However, a commitment to more systematic diabetes care will also bring with it a need for additional appointments to enable changes in treatment to be implemented and monitored. This reinforces the need to develop the roles of all members of the primary care team.

Derived from Scottish Diabetes Survey 2001

Why are the numbers of people with diabetes increasing?

13. There is an increasing incidence of both type 1 and type 2 diabetes, but particularly the latter. The reasons for the growth in type 1 remain unclear. The more pronounced rise in type 2 diabetes is most often attributed to a combination of better detection and changes to lifestyles (resulting in people taking less exercise) and diet, leading to increasing levels of overweight and obesity. Obese women are at least 27 times more likely to have type 2 diabetes than those of a healthy weight; men who are obese are at least seven times more likely to have type 2 diabetes than men of a healthy weight. In addition, because type 2 diabetes is more common amongst older people, the fact that the population as a whole is ageing means that diabetes will become more common.

What is the economic cost of diabetes?

14. Diabetes is estimated to account for about 5% of NHS costs. In Scotland for 2002/03 this equates to over £320 million. However, as set out in the table below, calculating the true cost of diabetes is not straightforward. The most costly component of diabetes care is the treatment of diabetic complications necessitating hospital in-patient care. Therefore, the prevention of complications has economic benefits as well as obvious benefits for the quality of life of individuals with diabetes.

Table 3

Calculating the cost of diabetes

Calculating the costs of a complex chronic disease such as diabetes is difficult because information and accounting systems in the NHS are not easily subdivided by condition or specialty. Furthermore, apart from the costs directly linked to the diagnosis and management of diabetes itself, there are the costs related to the complications of diabetes (such as heart disease and stroke) which rely on certain assumptions about what proportion of the costs are due to diabetes. In addition, there are the indirect costs of diabetes which are not borne by the NHS, such as ability to work and the quality of life.

Examples of cost studies:

(1) 8.7% of acute sector costs devoted to people with diabetes. Calculated to be an average of £2,201 per person per year, compared to £308 for each non-diabetic person. Currie, Kraus, *et al* (1997).

(2) Type 2 diabetes estimated (on the basis of 2% prevalence) 4.1% of total NHS expenditure. CODE2 UK (2001).

(3) Annual direct cost of care for people with type 2 diabetes calculated at £1,738 (compared to estimate of £1,505 in the CODE 2 UK study). T^{2}ARDIS (2000).

What are the origins of the Scottish Diabetes Framework?

15. The decision to produce a Diabetes Framework was announced in *Our National Health: A plan for action, a plan for change* in December 2000. Dr Mac Armstrong, the Chief Medical Officer, stated from the outset in March 2001 at the conference that launched the start of the Framework process, that it would be developed in an open and inclusive way. At the earliest opportunity, in July 2001, the Framework Working Group issued a consultation paper. The consultation paper was widely circulated and, along with the CSBS diabetes standards, was the subject of two well attended open workshops. This process was intended to:

- Provide an opportunity for all those with an interest in diabetes to contribute towards shaping the direction of diabetes care in Scotland.
- Gather information and evidence to include in the Framework (particularly about local successes which warrant wider dissemination and implementation).
- Publicise information about current and forthcoming developments.
- Alert the NHS in Scotland to the ideas and issues that were likely to be featured in the Framework and in the clinical standards that the CSBS were likely to promulgate.
- Help to build a consensus around the priorities for action.

16. The Scottish Diabetes Framework Working Group received over 100 written responses to the consultation paper, many of which contained detailed and very helpful comment. All the responses were considered by the Working Group and have been used to inform this Framework document. We are grateful to all those who submitted comments.

17. By adopting an open methodology, the Working Group hope that this Framework will be viewed as a natural progression to the ideas set out in the consultation paper and contain few surprises for those now faced with implementing its recommendations.

Table 4

Why diabetes?

The Scottish Executive has increasingly drawn attention to the need to do more in Scotland to tackle the increasing burden of chronic disease, for example, in *Our National Health* and more recently in *Adding Life to Years.* Against this policy background, there are a number of reasons why the Scottish Executive selected diabetes as an early issue for action.

Scottish Diabetes Framework

Diabetes is a serious condition. It increases the risk of ill health and shortens life, particularly through heart disease, stroke and kidney failure. It is a leading cause of blindness in people of working age. It is a leading cause of lower limb amputations. Type 2 diabetes doubles or trebles the risk of dying prematurely.

High impact. Diabetes affects young and old, although it is more common amongst older people. It has particularly poor outcomes for people who are socially/economically excluded. It disproportionately affects people from black and minority ethnic communities.

Increasing numbers. The number of people with diabetes is increasing in Scotland, the UK and worldwide. About 1 in 40 Scots have diabetes and this may rise to as many as 1 in 25 by 2010.

Public awareness of the seriousness of diabetes and its consequences is alarmingly low. For example, Diabetes UK, found that less than half the general public knows that diabetes can cause premature death and around three quarters of those at highest risk of developing the condition do not know that they are at risk.

Robust evidence base. There is evidence that measures can be taken to help to prevent or delay people developing type 2 diabetes and good evidence that diabetes is a condition, which, if diagnosed at the right time, can be controlled, allowing the majority of people to live normally.

Improvements in therapy. There have been some significant changes to the management of diabetes in recent years as a result of new and improved therapies.

Impact on quality of life. There are well-developed standards for the care of people with diabetes. When services are delivered to these standards and are organised in ways that reflect the circumstances of their patients, people are more likely to manage their diabetes, have fewer complications and be able to continue with ordinary activities.

High cost. Managing diabetes and its consequences are costly to the NHS and have a significant financial impact on people with diabetes, their carers and their families.

Track record. Scotland has a good record of service developments in diabetes over recent years. This provides a strong platform on which to build.

One condition, many priorities. Diabetes touches upon a number of other Scottish Executive priorities including social inclusion, inequalities, older people, children, maternity services, ethnic minorities, coronary heart disease, and clinical governance. Diabetes offers a focus to bring together different strands of activity.

Diabetes as a model. The multi-disciplinary and multi-faceted nature of diabetes care makes it a good model for other chronic diseases.

Table 5

Timetable of the development of the Scottish Diabetes Framework

December 2000	Commitment made in *Our National Health* to publish a Scottish Diabetes Framework.
March 2001	'Diabetes in Scotland' conference – formal launch of process of developing the Framework.
April 2001	First meeting of Scottish Diabetes Framework Working Group.
July 2001	Consultation paper issued.
August 2001	First open meeting held jointly with Clinical Standards Board in Polmont (31 August).
September 2001	Second open meeting held jointly with Clinical Standards Board in Glasgow (7 September).
November 2001	The key Framework Milestones, the CSBS Diabetes Standards and the SIGN diabetes guideline published on World Diabetes Day (14 November).
March 2002	Publication of Scottish Diabetes Framework.

How were the evidence base and standards for diabetes developed?

18. The Scottish Diabetes Framework defines the policy framework for diabetes care in Scotland. It should be read in conjunction with two key documents; the 'Management of Diabetes' guideline produced by SIGN and the clinical standards for diabetes produced by the Clinical Standards Board for Scotland which were both published in November 2001. These two documents set out the evidence base for the clinical management of diabetes and the standards to which diabetes services in Scotland should be delivered. The standards and the clinical guideline should be viewed as integral parts of the Framework. All three documents have been developed in a process of inclusive joint working. Thus it is our aim that the Framework document provides a mechanism to support and promote their implementation. The improvements in diabetes care described in this Framework demand the implementation of all three documents.

Table 6

Clinical Standards for Diabetes and the Clinical Standards Board

What is the Clinical Standards Board for Scotland (CSBS)?

The CSBS is a statutory body established as a special Health Board in April 1999. The role of CSBS is to:

- Promote public confidence that the services provided by the NHS are safe and that they meet nationally agreed standards.
- Demonstrate that within the resources available, the NHS is delivering the highest possible standards of care.

CSBS has developed a standard setting and review process in partnership with healthcare professionals and the public. This process complements the legal duty of the board of each NHS body to monitor and improve the quality of healthcare which it provides to individuals (known as clinical governance).

How has the CSBS set standards for Diabetes?

Working in partnership with the Diabetes Framework Working Group, CSBS set up a Subgroup to develop clinical standards for diabetes services. The Board aims to set standards which are *achievable but stretching* and to publish reports identifying areas where standards are being met or exceeded as well as those where they are not being achieved. Health professionals and members of the public are represented and the Subgroup drew on work already undertaken such as SIGN and the St Vincent Declaration. Once the standards had been drafted there was a shared consultation period including both the Framework and the draft standards. Following consultation, both the standards and a summary of the Framework were published. The standards will now be piloted prior to a Scotland-wide review of performance and a national report will then be published.

How will performance against the standards be reviewed?

The review process is being developed with three pathfinder sites across Scotland. A board-wide review of primary and secondary care services will be co-ordinated through the Local Diabetes Service Advisory Group (LDSAG) and the consultant in public health medicine with responsibility for diabetes services.

How will performance against the standards be reported?

The review process will be refined in the light of the experiences of the pathfinder sites. A programme of review visits to all NHS board areas in Scotland will then be scheduled, beginning January 2003.

Generic Standards

In addition to condition-specific standards the Board has developed Generic Standards which apply to clinical services generally. These Generic Standards are grouped under two broad headings; 'patient focus' and 'safe and effective clinical care'.

Patient Focus: designed to ensure that all services respond to patient needs and preferences and that patients are involved in decisions about their own care through effective two-way communication and information sharing. These cover:

Assessment	Initial assessment essential in the development of a plan of care to meet patient needs.
Patient Involvement	Patient care outcomes improve when patients are involved in clinical care decisions.
Patient Information	Information helps patients make informed choices about their care.
Patient/Staff Communication	Good communication between patients and healthcare professionals for effective treatment.
Patient Feedback	Patient comments/complaints contribute to the review and development of services.
Access to Services	Identified healthcare needs and individual preference should determine access to services.
Discharge Arrangements	Effective discharge planning begins on or shortly after admission.

Safe and Effective Clinical Care: designed to ensure that all patients receive safe and effective care and treatment based on available evidence. These cover:

Clinical Guidelines	Care delivered in accordance with clinical guidelines produces better outcomes.
Clinical Audit	Review of clinical practice through audit identifies shortfalls in performance.
Risk Management	Management of risks results in a safer system of work and practices.
Risk Environment	Organisations work to assess, reduce and control environmental hazards.
Staff	Review of competencies and continuing professional development of staff.

The CSBS use the Generic Standards in two complementary ways:

1. As a prompt during its condition-specific reviews, picking up issues that are particularly important in relation to the service under review or on which a dialogue with the Trust under review seems appropriate.
2. To conduct a baseline review of performance against the Generic Standards in each NHS Trust and Island Health Board.

To avoid duplication, the issues covered by the Generic Standards are mentioned in the condition-specific documents only when the relevant project group concludes that there is an additional dimension warranting inclusion.

Clinical Standards Board for Scotland.
CSBS Standard for diabetes (November 2001)

What is the purpose of the Scottish Diabetes Framework?

19. The consultation paper of July 2001 outlined six purposes of the Framework:

- To clarify the direction of travel and to give additional impetus to current positive developments in diabetes care.
- To set out short-term objectives, longer-term milestones and clinical standards in order to create a modern diabetes service.
- To highlight and encourage opportunities to improve services.
- To collate information on all Scottish initiatives relevant to diabetes and create a manageable and accessible resource.
- To highlight and disseminate throughout Scotland and internationally, examples of innovative and high quality services and projects.
- To help foster a climate of collaboration, co-operation and communication amongst the diabetes community in Scotland.

20. Some of these purposes have been achieved by the publication of this document. For some of the others, the Framework puts in place mechanisms for delivery in the longer term. This underlines the fact that the Scottish Diabetes Framework is at least as much about a process of collaboration and on-going service improvement, as it is about the production of a document. This was well recognised by the Working Group which acknowledged that diabetes care requires the co-ordination and co-operation of many people working across a wide range of professions and organisations, and that ensuring that high quality services are available to everyone with diabetes will require a sustained effort over many years. With this in mind, the Working Group set out with the hope of producing a pragmatic document which would:

- Act as a catalyst for change and an enabling document to help the NHS to accomplish more effectively what many people are already attempting to achieve.
- Promote equitable care and help to ensure that SIGN guidelines are put into practice by sharing best practice and addressing the current wide variations in standards.
- Include objectives which are specific, measurable, achievable, relevant, and time-related.
- Provide strategic leadership at locality and national level, without imposing rigid constraints on local implementation.
- Improve the co-ordination and integration of national initiatives on diabetes.
- Focus on implementation, setting clear milestones and putting in place a mechanism to follow-up and monitor progress.

Scottish Diabetes Framework

21. Central to securing implementation and ensuring the drive and continuity necessary to achieve change over many years is the establishment of national leadership that will support local diabetes services. Discussions between the Scottish Executive and the Working Group about the shape of this leadership resulted in the decision to establish a Scottish Diabetes Group. This commitment was highlighted in the publication of the Framework milestones in November 2001. The Scottish Diabetes Group met for the first time in March 2002; its remit to support and monitor the implementation of the recommendations of the Framework.

'Give us the best care whoever we are and however severe our complications. Recognise that without our full co-operation you will be wasting your time. Do everything you can to ensure we stay motivated to look after ourselves, rescue us when we bugger it up, because as sure as hell we will. You can only do this through full integrated diabetes services of the highest quality, treating us as people and not as a medical condition.'

(Person living with diabetes)

Williams R, Airey M, Gilworth G. Integrating Diabetes Services – time to respond. Nuffield Institute for Health, University of Leeds, 2001.

What are the key features of a high quality diabetes service?

22. The Working Group sought to define what a high quality diabetes service should look like in order to guide their thinking about the steps necessary to make sustained improvements to the provision of care for people with diabetes. These features are set out in the table below along with examples of the ways in which these features can be demonstrated.

Table 7

Key features of a high quality diabetes service

Key features	*Demonstrated by (for example)*
Shared vision/ clear strategy	• Existence of a district wide group of all the stakeholders in diabetes care. • Published diabetes strategy (including explicit targets and milestones). • Effective involvement of people with diabetes in developing the strategy. • Explicit link to Local Health Plan and to the Community Plan.

Key features	*Demonstrated by (for example)*
Patient-focused care	• All people with diabetes empowered to manage their own care. • Culturally competent services (see Table 17). • Patients treated as individuals – staff are caring and understanding, respectful and courteous. • Responsive and flexible services. • Easy access to services and information. • Respect for patient confidentiality.
High quality care	• Clinically effective care – use of evidence based clinical guidelines. • Equitable and consistent delivery of services. • Efficient and joined up services – patients seen promptly. • Comprehensive range of services offered to all. • Effective risk management. • Services constantly developing and improving.
Integrated care	• Multi-professional teamworking. • Good communications with patients and between staff. • Efficient services. • Effective planning forum. • Seamless care from the patient perspective. • Managed Clinical Network.
Adequate resources	• Appropriate staffing and facilities. • Acceptable waiting times. • Reliable and consistent service. • Efficient and effective use of available resources.
Well-trained staff	• Staff with appropriate qualifications and engaged in ongoing study.
Good clinical management systems and data	• Clinical care supported by effective IT. • Comprehensive information on all patients in area. • Robust clinical audit. • Results of care reported. • Respect for confidentiality of patient information.

23. Having defined the scope and principles of a high quality service, the Working Group considered how this might be achieved in practice. The approach which was adopted (and which was later endorsed by the consultation process) was based on four simple ideas:

(a) To create a more manageable agenda for improving diabetes services by subdividing the complex whole of diabetes into logical component parts ('building blocks').

(b) To select a limited number of these topics for early action and not seeking to achieve everything at once.

(c) To concentrate initially on strengthening infrastructure and building capacity.

(d) To focus strongly on implementation. To ensure that words become deeds.

Building Blocks of Diabetes Care: An Overview

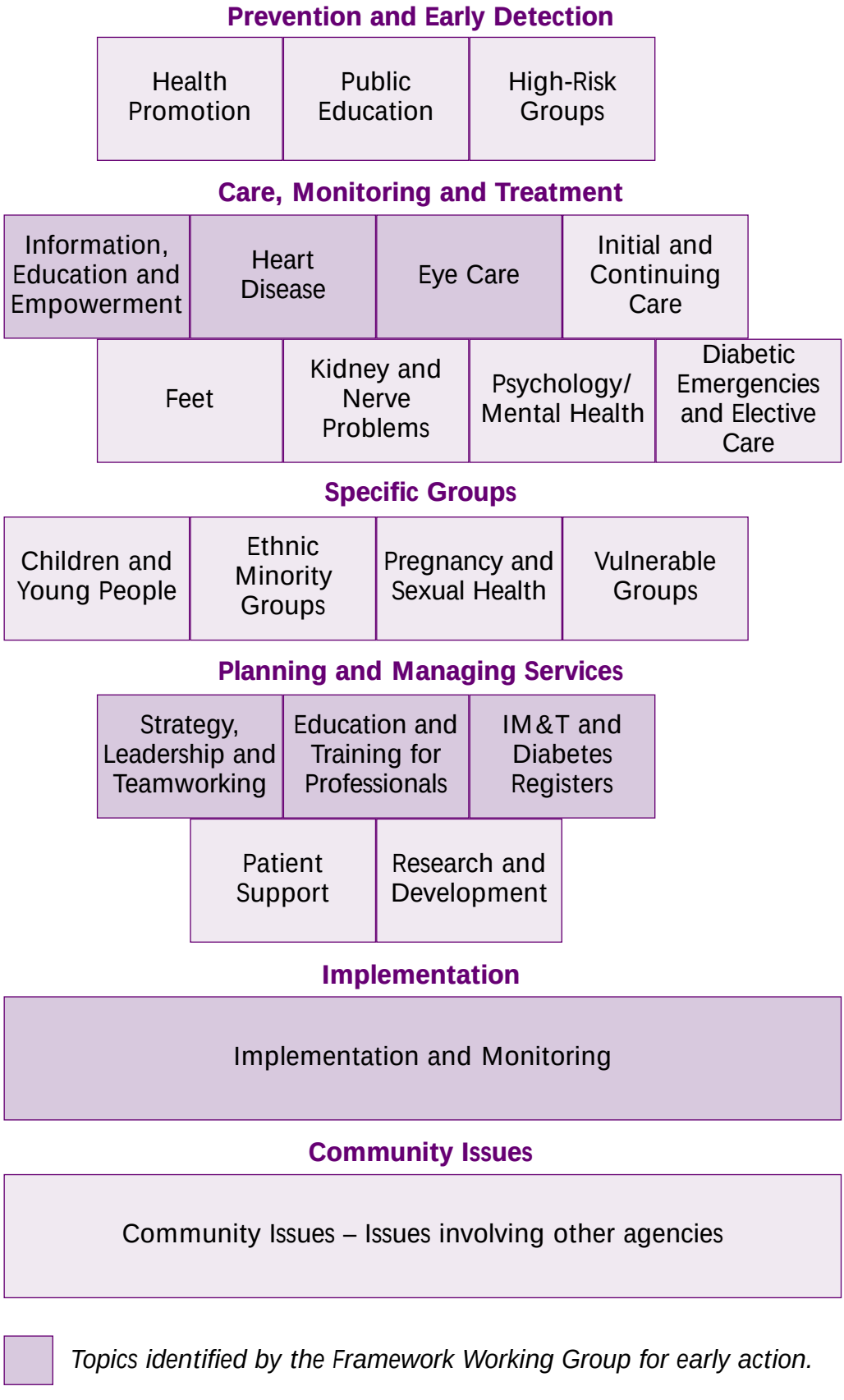
24. The model of diabetes care developed by the Working Group consists of 22 building blocks, divided amongst six broad headings. These are:

- Prevention and early detection
- Care, monitoring and treatment
- Specific groups
- Planning and managing services
- Implementation
- Community Issues.

25. This is a pragmatic model. It is acknowledged that there is some overlap between the 22 building blocks, and that subdividing the care and treatment of diabetes in this way brings with it the risk of losing the concept of holistic care. Nevertheless, the model is an attempt to make the complex and multi-professional nature of diabetes services more manageable. It is a planning tool, not a model for clinical management.

26. All of the 22 building blocks of diabetes are important. However, the Working Group concluded that significant progress towards securing real improvements in services for people with diabetes would only be achieved by focusing on a limited number of issues at a time, rather than by overloading the system with too many objectives. Seven issues for early action were identified by the Working Group and highlighted in the consultation paper. Each of the 22 building blocks is described overleaf.

Figure 2: Building Blocks of Diabetes Care



27. The response to the consultation paper strongly backed the need to limit the number of priorities. However, several written responses and comments at the open meetings proposed that the number of 'first stage priorities' should be extended. Of the topics suggested as additional early priorities, the issue of foot care was the one perhaps most frequently cited. Given the wide range of issues covered by the clinical standards, the commitment to review and revise the Framework within two years and the general level of support for the seven topics proposed during the consultation period, the Working Group concluded that the Framework priority list should not be extended.

The first stage priorities

28. The Working Group confirm the following seven topics as the Framework's 'first stage' priorities:

- Patient Information, Education and Empowerment
- Heart Disease
- Eye Care
- Strategy, Leadership and Teamworking
- Education and Training for Professionals
- IM&T and Diabetes Registers
- Implementation and Monitoring

This is not to ignore the other aspects of diabetes. These seven issues represent a starting point. Action is required across all of the building blocks. Furthermore, a commitment is made to periodically review the Framework in order to take account of progress and to ensure that all aspects of diabetes care are addressed.

MILESTONE

The Scottish Diabetes Group will review and revise the Scottish Diabetes Framework by Spring 2004.

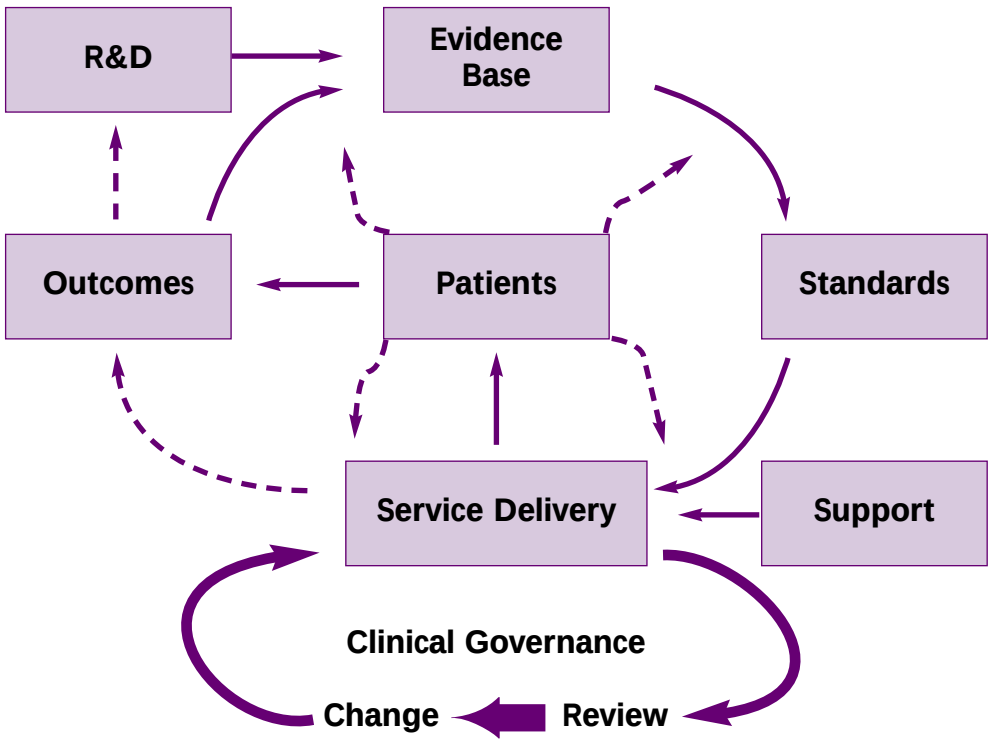
29. Throughout the Framework a number of 'milestones' and 'actions points' have been included. A Milestone represents a significant stage on the way towards creating a high quality patient-centred diabetes service. It marks a point for reflection, assessment of progress and confirmation of direction. An Action Point is a specific piece of work that will be undertaken to support this process.

How it all fits together

30. The Scottish Diabetes Framework is a means to ensure that diabetes services serve the needs of people with diabetes and that the complex interactions of individuals and organisations which together provide and support these services are co-ordinated in the most productive way. This will be achieved by setting clear and realistic priorities and targets, by providing leadership and support and by promoting collaboration amongst all those with an interest in diabetes (most importantly, people with diabetes themselves). This demands relationships based on partnership, mutual respect and trust.

31. Figure 3 below outlines how the different parts of the system fit together. The Framework is the key driver to ensure that this process occurs in practice.

Figure 3: The Healthcare Cycle



Patients. People with diabetes are not only recipients of care, but also the most important determinants of the outcomes of care. They also have a great deal to contribute to research and the definition of standards, as well as to the planning and management of services. Patients have a right to information about the services they receive including about the outcomes of care.

Evidence Base. Services should be provided in line with the best available evidence. There are different sources of evidence, including formal research and development (**R&D**) funded by the Government such as the work of the Chief Scientist Office (CSO), or by the pharmaceutical industry. In Scotland the evidence base of diabetes has been reviewed and synthesised by SIGN and published as a clinical guideline.

Standards. The delivery of services should be guided and evaluated against robust standards, derived from the evidence and based on an understanding of how this evidence can be applied in practice. The Clinical Standards Board is the organisation charged with setting standards for the NHS in Scotland. Standards for diabetes have now been published. These standards are currently being piloted and refined before national review begins.

Service Delivery. All public healthcare providers are subject to clinical governance requirements and have internal mechanisms to monitor their own performance. The service delivered to patients is modified by standards and by audit.

Outcomes. The outcomes of care provided by the NHS are reported in a variety of forms. This includes both general mechanisms such as the Performance Assessment Framework and the publications of the Information and Statistics Division (ISD) and mechanisms specific to diabetes, such as the annual Scottish Diabetes Survey. Reports published by the CSBS are another method of assessing the standard of diabetes care. This Framework also recommends (paragraph 99) that individual NHS boards should publish annual reports of diabetes care in their area as a means of informing local people of the care they can expect to receive. At an aggregate level, the results of care can frequently identify questions which cannot be answered without further research. For individuals, outcomes of care are primarily determined by their own actions.

Table 8

SIGN and Diabetes

The Scottish Intercollegiate Guidelines Network (SIGN) was established in 1993 by the Academy of Royal Colleges and their Faculties in Scotland, to develop evidence-based clinical guidelines for the National Health Service (NHS) in Scotland.

Clinical practice guidelines have been defined as '*systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances*'. They are designed to help practitioners assimilate, evaluate and implement the ever-increasing amount of evidence and opinion on best current practice. Clinical guidelines are intended as neither cookbook nor textbook but, where there is evidence of variation in practice which affects patient outcomes and a strong research base providing evidence of effective practice, guidelines can assist doctors and other health care professionals in making decisions about appropriate and effective care for their patients.

In 1996-97, SIGN published seven documents in the field of diabetes. Five clinical guidelines covered the prevention of visual impairment (SIGN 4), management of diabetes in pregnancy (SIGN 9), management of diabetic renal disease (SIGN 11), management of diabetic foot disease (SIGN 12) and management of diabetic cardiovascular disease (SIGN 19). In addition, reports were published on the good practice in care of children and young people with diabetes (SIGN 10) and a minimum dataset for collection in people with diabetes (SIGN 25).

Late in 1999 work began on the review of these documents and involved the establishment of six new multidisciplinary review groups to consider each of the clinical areas covered by the original topics. A seventh topic, of lifestyle management, was added at this stage to take the number of healthcare professionals and patient representatives who were working on the review to around 100. In September 2000 the Working Group on IT to Support Shared Care in Diabetes which was set up by CRAG, published a document which laid out principles of support and promotion of integrated care for patients with diabetes and also discussed the data collection required in the clinical management of these patients. This group published an extended dataset, based on SIGN 25, which was felt to be more useful for recording information directly relevant to active clinical care than the SIGN document which was felt to be most useful for population-level registers. For this reason, SIGN 25 has not been reviewed at this time. The review guideline was published as a single volume in November 2001 (SIGN 55).

The aim of the guideline has been to provide an updated evidence-based approach to influence current practice in order to reduce the burden of long-term complications, both microvascular and macrovascular, as well as improve pregnancy outcome for the mother with diabetes. The guideline also incorporates the new World Health Organization diagnostic criteria for diabetes mellitus which were implemented in the UK in June 2000.

Support. Healthcare professionals and organisations can be expected to function at a higher level when they are able to access the appropriate support, such as education and training, information and communications technology, guidance on best practice, and opportunities to share innovative ideas. Such support can come from a variety of sources including professional organisations (such as the RCGP and their SPICE-PC programme), academic institutions, the pharmaceutical industry, other NHS bodies and the Scottish Executive. One of the goals of the Framework is to enhance the collaboration and communication between these 'support organisations' to ensure that those who actually deliver the care can obtain the support that they require.

Table 9

SPICE-PC

The Scottish Programme for Improving Clinical Effectiveness in Primary Care (SPICE-PC) is an initiative funded by the Scottish Executive through the Clinical Resource and Audit Group (CRAG). The aim of the programme is to help primary care clinicians to manage common conditions by providing them with the answers to three vital questions:

- What should we be doing?
- What are we doing?
- How does our performance compare with our peers?

The programme enables GP practices to record and review the relevant data. In addition, by means of an electronic analysis system, participating practices are able to receive feed back reports on the performance of their practice, along with comparative data from many other practices in Scotland.

In Diabetes, the programme has produced a set of criteria tailored to primary care which informs clinical teams on the type of input required – for example that people with diabetes should have regular foot and eye checks, appropriate education, and monitoring of their diabetic status. These criteria have been defined to align with the standards set by the CSBS and the goals of the Scottish Diabetes Framework.

Further details can be obtained from the Quality Department, Royal College of General Practitioners (See Annex D for contact details)

Scottish Diabetes Framework:
Building Blocks of Diabetes Care

Prevention and Early Detection

32. Around nine out of 10 people with diabetes have type 2 diabetes, traditionally a condition affecting mainly older people. However, an increasingly sedentary lifestyle and rising levels of obesity are associated with a dramatic increase in the incidence of type 2 diabetes in the younger population. The implications are serious, not least because diabetes is a major underlying cause of heart disease – one of Scotland's major killer diseases and a priority for the public health improvement strategy set out in the White Paper, *Towards a Healthier Scotland.*

33. The onset of type 2 diabetes can, in many cases, be prevented or delayed through avoidance of obesity and with regular physical activity. The high price of diabetes in terms of both morbidity and financial burden upon society make a preventative strategy highly desirable. Type 1 diabetes, on the other hand, is caused by a loss of the body's ability to produce insulin, can only be managed by replacement insulin therapy and is currently not preventable.

Health Promotion

34. Obesity is an increasing problem in Scotland and is strongly linked with the increase in type 2 diabetes. If prevalence continues to rise at the current rate more than one in four adults will be obese by 2010. Promoting healthy eating and physical activity and reducing the burden of obesity in the general population requires the concerted effort of a range of local and national agencies.

35. A key component of the Scottish Executive's strategy to improve public health in Scotland is action to encourage Scots to eat more healthily. A wide range of initiatives are underway within the framework of the Scottish Diet Action Plan, *Eating for Health*. These include the Scottish Community Diet Project (which works with low income communities); the introduction of nutritional standards for school meals in Scotland; and the appointment of a National Diet Action Co-ordinator to promote the implementation of the Plan's recommendations. National agencies supporting this work, through the provision of information on diet and health relevant to prevention, include HEBS and the Food Standards Agency. National agencies supporting this work, through the provision of information on diet and health relevant to prevention, include HEBS, the Food Standards Agency. As well as diet, the Scottish Executive also recognises that daily physical activity is important. The Physical Activity Task Force will set out in June 2002 ideas about where policies and resources need to be directed to encourage greater active living and levels of physical activity for Scotland. Improving diet and physical activity levels are also key objectives of the £100m Health Improvement Fund which, under the auspices of NHS boards and their local partner organisations, is supporting a range of initiatives across Scotland. Generic public health improvement work, such as the establishment of a Health Promoting Schools Unit, will also address diet and physical activity as part of an holistic approach to health.

36. Similar commitment is necessary to combat the incidence of smoking which, in people with diabetes, significantly increases deaths from heart disease. There is a range of prevention and cessation measures in place to reduce smoking levels, including campaigns to raise public awareness, making Nicotine Replacement Therapy (NRT) available on the NHS and the introduction of a charter on smoking in public places. Again, the Health Improvement Fund is enabling important work to proceed in this area.

Public Education

37. Recent work by Diabetes UK has shown that public awareness of diabetes and associated problems is very poor. The consequences of this include a lack of understanding of the potential impact of diabetes, a lack of awareness of how to prevent diabetes and a lack of knowledge about the symptoms of diabetes. The myth of 'mild diabetes' persists. The reality is that a diagnosis of diabetes is a serious matter which should not be ignored. It has been suggested that there are perhaps 90,000 people with diabetes who remain undiagnosed in Scotland and local and national initiatives to raise public awareness and promote early detection should be encouraged. Increasing public understanding of diabetes will require a long-term effort and NHS Boards should take steps to ensure that ongoing health improvement programmes adequately address diabetes issues. A number of areas have found public events to be a valuable means of raising awareness and all areas are encouraged to explore this approach.

ACTION POINT

Each NHS board should organise in collaboration with other agencies, at least one event to raise public awareness of diabetes during 2002/03.

High Risk Groups

38. The UK National Screening Committee (NSC) has reviewed population screening for type 2 diabetes and found that it offers limited benefits. However, the case is stronger for screening sub-groups of the population with specific combinations of population-based risk factors for developing diabetes (e.g. women with a history of gestational diabetes, and people who have coronary heart disease). Other groups with an increased risk of developing type 2 diabetes include those who are overweight; over 40; Asian or African-Caribbean; and/or have a family history of diabetes. Further work is required on the value of screening in particular population sub-groups and a number of pilot projects are being undertaken in England.

'My grandfather and my father and my brother all have diabetes, so at one level I always knew I would be more likely to get it. But it still came as a terrible shock. I suppose you always hope you'll be the one who doesn't get it. I felt so depressed. I just kept thinking about all the things I wouldn't be able to do from now on.'

Care, Monitoring and Treatment

39. People with diabetes live with their diabetes every day of the year, 24 hours a day and so need the knowledge, confidence and support to manage their own condition. People with diabetes should be able to access high quality information, treatment and care, particularly during the period following diagnosis. After diagnosis, people with diabetes should be supported to stay healthy and so minimise the incidence of complications. Information and education about the purpose and importance of medication should be stressed. All people with diabetes should be offered advice about reducing their risk of long-term complications and receive regular surveillance of risk factors. When risk factors are detected, people with diabetes should be supported in controlling these risks and, at an early stage, offered effective treatment to retard the progression of complications. For those people who do develop long-term complications, they should receive effective care including referral to specialist services where appropriate.

40. All of the aspects of care highlighted in this section are essential. However, the ways in which these components of care are organised and co-ordinated to ensure a consistent message are also important and this is considered in more detail in the section below on 'Strategy, Leadership and Teamworking'. From the perspective of a person who has diabetes, a series of specialist clinics may mean frequent, tiring journeys and a significant disruption for the individual and perhaps a friend or relative. There is also the risk of communications between the different service components being poor, resulting in missed referrals or follow-up and inconsistent advice to the patient. Options that were identified by people with diabetes, their relatives and staff through the Partners in Change discussions (see table 11) were: holding specialist clinics used mostly by people with diabetes at a hospital on the same day; or to deliver more care through the patient's primary care team, with good support from specialist services.

41. The annual review is a central part of diabetes care and in highlighting two aspects of diabetes – heart disease and eye care – the Working Group does not wish to imply that the other aspects can be ignored. And indeed, as a result of the consultation process, it was agreed that the Framework needed to include a milestone in relation to HbA1c and this has been included under 'Initial and Continuing Care' below. However, where time and resources need to be prioritised it is recommended that efforts at an organisational level should be concentrated on improving the effectiveness of services to assess and manage the risks of heart disease and to monitor and treat diabetic retinopathy.

Patient Information, Education and Empowerment

CSBS Standard 3 – Patient Focus

All people with diabetes have equitable access to information and multidisciplinary programmes of education, which are tailored to individual needs and specific client groups.

42. Putting patients at the centre of care is one of the central themes of the Framework. This instinct should be an integral part of NHS culture, but as we know, this is not yet always the case. Although patient-centred care is an aspect of all of the Framework's building blocks, it was felt appropriate that it should also be highlighted in its own right. This section incorporates a wide range of issues including the generation and delivery of patient information and education, empowerment and the promotion of self-management and independence and the involvement of people with diabetes in planning, delivery and monitoring services. These themes match the objectives set out in the Scottish Executive's recently published framework responsible for implementing *Patient Focus and Public Involvement*; (see Table 10). Working closely with and learning from the team responsible for implementing *Patient Focus* will be crucial to the delivery of this component of the Diabetes Framework.

Table 10

Patient Focus and Public Involvement

In December 2001 the Scottish Executive published *Patient Focus and Public Involvement* setting out details of NHSScotland's commitment to become a service that does things with patients rather than merely to them. A service that respects each individual patient's personal wishes and preferences as far as possible and involves them in every stage of decision-making.

The paper has four broad complementary and overlapping themes, each with a series of projects and initiatives designed to help staff and patients make patient-focused service a reality. The four themes are:

- ***Building capacity and communications.*** This aims to build the capacity of the NHS to communicate effectively with patients, the public and local communities and will provide training and support to NHS staff and the public to facilitate this work.
- ***Patient Information.*** This will initiate work which will improve the quality, availability and accessibility of information to support patients, the public and local communities.
- ***Involvement***. This will support and encourage the NHS to be able to involve people in decisions about the design and delivery of local health services. This includes support to individuals, local groups, communities and voluntary organisations to make their voices heard.
- ***Responsiveness***. This aims to ensure that NHSScotland becomes a responsive service which listens to the wishes, concerns and complaints of service users, for example by supporting the development of independent advocacy and improving the complaints procedure.

An additional £14 million has been made available over the next three years to take forward this initiative.

Scottish Executive Health Department, Patient Focus and Public Involvement, December 2001

Seeking the views of people with diabetes

43. In order to find out more about the experiences and needs of people with diabetes, Partners in Change were commissioned to undertake a series of meetings with a wide range of patients and carers. Table 11 sets out the scope of this work.

ACTION POINT

Partners in Change will publish a report of its work with people with diabetes by June 2002.

Table 11

Partners in Change: Listening to People with Diabetes

Between October 2001 and March 2002, the Scottish Executive sought out the experiences of people who have diabetes, their families and some of the staff who work in diabetes and related services. This was done through the Partners in Change project, which is funded by the Scottish Executive to ensure that the needs of people with chronic conditions are put at the heart of service planning, delivery and monitoring.

Over 250 people from eight NHS board areas participated in interviews and group discussions. The discussions concentrated on people from sections of the population who tend to have particular needs in relation to their diabetes, or who tend to be included less often in routine feedback about services. They included:

- young people and children
- men and women from the ethnic minority communities
- people with learning difficulties and their key workers and families
- people with sensory disabilities
- people with disabilities
- women who are/recently have been, or plan to become, pregnant, and their partners
- people who have low incomes
- people who have recently been diagnosed as having diabetes
- many of the discussion included older people
- families of people with diabetes.

In each area, people who have experience of diabetes, people from Diabetes UK or staff helped facilitate the discussions, to build on their understanding of the issues raised by people with diabetes and increase their experience of ways to involve people.

Patient empowerment

44. Information and education enable people with diabetes and, where appropriate, those who care for them, to make informed decisions about their diabetes and therefore become key partners of the health care team. People with diabetes must live with their diabetes every day. Set against this, for most people with diabetes, the best possible diabetes service will offer only perhaps a few hours of tests, treatments and advice per year. The involvement of people with diabetes in their own care is therefore essential. People with diabetes need help to acquire the information, skills and confidence to mange their own care, with diabetes services there to provide help and support when needed. The role of health services is important, but the commitment of individuals to their own care is the key determinant of health outcomes. What is needed is mutual understanding of what is possible and a partnership to achieve what is best for the individual. As well as the actions required of health care services, this partnership places demands and responsibilities on people with diabetes. These have been well summarised by Diabetes UK in their 'What care to expect' leaflet.

Table 12

Your responsibilities as a person with diabetes

'Effective diabetes care is normally achieved by team work, between you and your diabetes care team. Looking after your diabetes and changing your lifestyle to fit in with the demands of diabetes is hard work, but you're worth it!

You will not always get your care right; none of us does, but your diabetes care team is there to support you. Ask questions and request more information especially if you are uncertain or worried about your diabetes and/or your treatment. Remember the most important person in the team is you.

The following list of responsibilities is given to help you play your part in your own diabetes care.

It is your responsibility:

- To take as much control of your diabetes on a day-to-day basis as you can. The more you know about your own diabetes, the easier this will become.
- To learn about and practice self-care which should include dietary education, exercise and monitoring of blood glucose levels.
- To examine your feet regularly or have someone check them.
- To know how to manage your diabetes and when to ask for help if you are ill, e.g. chest infection, flu, diarrhoea and vomiting.

- To know when, where and how to contact your diabetes care team.
- To build the diabetes advice discussed with you into your daily life.
- To talk regularly with your diabetes care team and ask questions.
- To make a list of points to raise at appointments, if you find it helpful.
- To attend your scheduled appointments and inform the diabetes care team if you are unable to do so.

What diabetes care to expect, Diabetes UK, 2001 (p.14)

'It's important to get help but it's also important the way they hand back the responsibility.'

(Person with diabetes)

45. Building and maintaining motivation is important to ensure that people with diabetes continue to manage their own diabetes. Points of motivation can change over time and healthcare professionals need to be aware of this and support individuals to make informed choices. Clinical staff also need to be aware of the potential negative effect their words and actions can produce. Feelings of failure or blame are no part of good care. Diabetes self management is difficult and to lapse from optimum care is only human.

'It can be really hard attending clinics … the last thing you need is the people who are supposed to be helping and supporting you, putting you down, telling you you're not doing this right…this sometimes makes you more frightened to reach out for help.'

(Person with diabetes)

Patient education

46. Education and information allow a person with diabetes to deal with blood glucose awareness, cope with stress and adjust their daily insulin dosage as necessary. Encouraging and supporting patients to develop these skills requires training and awareness by healthcare professionals delivering care. Although there are examples of good quality individual and group diabetes education programmes, it is apparent that these are not widespread and information about what is effective is not readily available.

ACTION POINT

A report on patient education programmes in diabetes will be produced by December 2002.

'I get conflicting information. One nurse tells me I can eat a certain thing, another tells me another.'

(Person with diabetes)

Patient information

47. To maintain good health and quality of life, people with diabetes need information about their diabetes as well as about local services and how they are provided. Information is available from a very wide range of sources, with an equally broad range of quality and reliability. Diabetes UK has a long track record of producing good quality information for people with diabetes through its literature, a telephone 'Careline' service that includes multilingual response options and its website. One source of information which is likely to be used increasingly by the public is NHS24 – a Scottish service which aims to provide in a single telephone call, information on health and other healthcare services, advice, an assessment of symptoms by a trained nurse and, where appropriate, direct access to care.

ACTION POINT

The Scottish Diabetes Group will work with NHS24 to ensure that relevant and up-to-date information on diabetes care and services is available through NHS24.

48. The lack of information and practical advice on managing diabetes and living with the condition was frequently raised by the people who met with the Partners in Change team. People with diabetes should have access to educational literature which is relevant, appropriate to their needs, age, language and culture, and non-promotional. The importance of providing material which is culturally appropriate is considered in more detail in the section on ethnic minority groups below (see Table 17). One of the points made most frequently by people with diabetes is the lack of consistency of the information provided, with different professionals often giving conflicting advice. What they want is consistent and reliable information, developed with the involvement of people with diabetes. People with diabetes also value getting information from other patients as well as from staff, and especially from people who have been in the same situation.

'It's good to meet up with other young people.'

(Teenager with diabetes)

49. The Scottish Diabetes Group will need to consider how best to build upon current sources of patient information and how to make best use of the opportunities presented by the Patient Focus initiative.

ACTION POINT

By September 2002 the Scottish Diabetes Group will agree on and put in place a programme of work to help to ensure that relevant high quality patient information on diabetes is available to patients and carers.

'The dietitian had no information for someone who has a vegetarian diet.'

(Man with diabetes from an ethnic minority group)

Patient involvement

50. As well as supporting the development of partnerships at an individual level, the Framework also seeks to promote the involvement of people with diabetes at a strategic level, both in the planning of local services and in shaping policy at national level. The Framework itself has greatly benefited from the contribution of Diabetes UK, the leading charity for people with diabetes, and indeed the Working Group was chaired by the National Manager of Diabetes UK Scotland. The input of people with diabetes responding to the consultation paper and attending the open meetings has also been most helpful.

51. The Framework includes a number of initiatives to increase the influence of the views of people with diabetes on strategic developments. For example, through membership on the new Scottish Diabetes Group (see Table 28) and involvement in Local Diabetes Service Advisory Groups (LDSAGS – see Table 18). Although much of this is concerned with capacity building, the increasing influence of people with diabetes on shaping services is a key theme of the Framework and its implementation.

52. The involvement of people with diabetes on LDSAGs is considered to be particularly important. Although most LDSAGs already include one or more patient representatives, the Working Group believe that lay membership should be strengthened and supported. Patients and carers also have an important role to play in shaping the development of managed clinical networks.

ACTION POINT

A project to encourage and support patient and carer involvement in the work of Managed Clinical Networks and Local Diabetes Service Advisory Groups (LDSAGs) will be funded in 2002.

53. Current members of all LDSAGs or their equivalents were contacted by the Partners in Change team to identify what issues were important to them and to find out what would help them to contribute in these roles. A first network meeting of lay members of LDSAGs in Scotland took place in November 2001 and the intention is to repeat that exercise.

ACTION POINT

A guide to encourage the active participation of patients, parents and carers in Local Diabetes Service Advisory Groups (LDSAGs) and other service planning fora will be produced by June 2002.

ACTION POINT

A national meeting for lay members and potential lay members of LDSAGs will be held during 2002.

Heart Disease

CSBS Standard 4 – Clinical Review

All people with diabetes are offered annual or more frequent examination, where clinically indicated, to monitor the management and progression of their condition. There is intervention as required and support for the modification of lifestyle risk factors.

CSBS Standard 6 – Clinical Management: Cardiovascular Status

All people with diabetes who have identified associated cardiovascular problems are managed according to locally agreed protocols and are considered for referral and additional treatment as clinically indicated.

54. Cardiovascular disease is between two and five times more common in people with diabetes and is the principal cause of death. People with diabetes have an increased incidence of angina, myocardial infarction (heart attack), heart failure, stroke and peripheral vascular disease (disease of arteries to the legs, which potentially leads to gangrene/amputation).

55. The classical cardiovascular risk factors of hypertension (high blood pressure), hyperlipidaemia (high levels of fat in the blood) and smoking are more common in people with diabetes. The greater the number of risk factors, the greater the risk of premature mortality. Modifying these risk factors and improving glycaemic control is likely to reduce the burden of cardiovascular disease. In particular, the traditional management of type 2 diabetes, which focuses on glycaemic control with a little emphasis on risk factor management is now inappropriate. Patients with diabetes should have aggressive risk factor management and attempts to achieve good glycaemic control. Treatment with beta-blockers, ACE-inhibitors, aspirin and statins are more likely to be effective therapies in people with diabetes, and are probably under prescribed.

56. The key issues for clinical management of cardiovascular disease are:

- *Secondary Prevention.* Patients with myocardial infarction, angina, cerebral or peripheral vascular disease are a priority in management. In addition to lifestyle interventions, clinicians should treat these individuals with aspirin, ACE-inhibitors, beta-blockers and statins unless there are clear contra-indications.
- *Controlling hyperlipidaemia.* Each 1 mmol/l reduction of LDL cholesterol represents a 36% reduction in the risk of cardiovascular disease. Using the joint British chart a 10-year risk of 30% should trigger the introduction of a statin.
- *Controlling Hypertension.* Each 10 mmHg reduction in systolic blood pressure is associated with a 15% reduction in the risk of diabetes related death. Patients will often require multiple therapies. The blood pressure target should be 140/80.
- *Anti-Smoking Strategies.* It has been calculated that men with diabetes who stop smoking live on average three years longer than those who continue to smoke. Smoking should be highlighted/discussed at every interview with a health care worker.
- *Good Diabetic Control.* Each 1% reduction in HbA1c is associated with a 21% reduction in the risk of diabetes related death. Metformin is the drug of choice in obese patients with type 2 diabetes. There should be agreed local guidelines for the management of hyperglycaemia.

57. Both coronary heart disease and type 2 diabetes are more commonly associated with deprivation, and as such it is important to target health care resources to such areas.

58. Regular screening for cardiovascular risk factors should be a central part of a diabetes service. Equally, because of the high risk of CHD amongst people with diabetes, people who come into contact with CHD services (e.g. admitted to hospital with a suspected heart attack) should be routinely screened for diabetes.

ACTION POINT

Good practice models for screening for cardiovascular risk factors in diabetic patients will be defined and disseminated by December 2002.

59. Guidelines published by SIGN and standards defined by the Clinical Standards Board for Scotland for aspects of cardiovascular disease will benefit people with diabetes. The CSBS has recently completed its first round of reviews of performance against the clinical standards for Secondary Prevention following Acute Myocardial Infarction. Local and national reports were published in October 2001.

The Coronary Heart Disease and Stroke Reference Group

60. In taking forward work on CHD, the Scottish Diabetes Group will be working closely with the Coronary Heart Disease and Stroke Reference Group which is developing national policy in this area.

Table 13

Coronary Heart Disease and Stroke Reference Group

The Coronary Heart Disease/Stroke Task Force report was published on 11 September 2001. The report formed the basis of a comprehensive, three-month consultation exercise which was completed on 31 December 2001. To take the work of the Task Force forward and consider the response to the consultation, a Coronary Heart Disease and Stroke Reference Group was formed. Membership of the Group is wide ranging and includes patient representatives as well as clinicians.

The Reference Group has been charged with developing a strategy for Coronary Heart Disease and Stroke Services in Scotland over the next decade that will be published in Spring 2002. In developing the strategy, the Reference Group has been asked to promote the development of managed clinical networks for both cardiac and stroke services. The Task Force report highlighted the importance of screening diabetics for cardiovascular risk factors and establishing linkages between care pathways to ensure optimum patient care.

Scottish Executive Health Department, Coronary Heart Disease/ Stroke Task Force Report, September 2001

Eye Care

CSBS Standard 4 – Clinical Review

All people with diabetes are offered annual or more frequent examination, where clinically indicated, to monitor the management and progression of their condition. There is intervention as required and support for the modification of lifestyle risk factors.

CSBS Standard 5 – Clinical Management: Eyes

All people with diabetes who have identified signs of developing diabetes-related, sight-threatening retinopathy, are referred to an ophthalmologist for assessment, and, if necessary, treatment.

61. Damage to the blood vessels in the retina (retinopathy) is a well recognised and common complication of diabetes. It is the largest single cause of blindness amongst working age people in the UK. It has also been reported by people with diabetes that blindness is the most feared complication of their condition.

62. In its early stages, diabetic retinopathy is symptom-free. Consequently, regular eye surveillance is required in order to identify promptly damaging changes to the retina. Early identification of sight threatening retinopathy and treatment by laser therapy has been shown to be effective in preventing the onset of visual impairment. Protection lasts for over 10 years in two-thirds of treated patients. At any time, up to 10% of people with diabetes will have retinopathy requiring specialist ophthalmology follow-up or treatment. Investment in diabetic retinopathy screening has been proven in economic analyses to be good value for money.

63. A recent survey of Health Boards in Scotland found that many people with diabetes are already receiving regular screening for retinopathy but that there is huge variation in methodology, coverage, policy and quality. Excellent practice already exists. The challenge is to establish equitable access to an effective screening programme for all people with diabetes.

64. A first step towards improving eye care for people with diabetes is to improve record keeping to ensure that all patients have had their eyes checked at least once and are in the system to be called back for checks in the future. The Scottish Diabetes Survey 2001 provided some preliminary data about this. It reported that 42% of those on the register had had their eyes screened within the last 15 months and a further 12% had been screened for retinopathy at some point more than 15 months previously. Although these data need to be treated with some caution, the Survey provides an indication of the size of the challenge ahead to improve screening, as well as being a useful mechanism to measure change over time.

MILESTONE

All people with diabetes will have their eye status (retinopathy) recorded on the local diabetes clinical management system by September 2003.

Health Technology Assessment of Diabetic Retinopathy Screening

65. The importance of eye screening as a part of high quality diabetes care was recognised by *Our National Health: A plan for action, a plan for change* that highlighted: 'The Framework will include plans to establish a national screening strategy for diabetic retinopathy.' The Health Technology Board for Scotland (HTBS) selected the organisation of services for diabetic retinopathy screening as one of its first three assessments. That report will be published in April. The key findings of the HTBS report are set out in table 14.

MILESTONE

The Scottish Diabetes Group will produce plans to take forward the implementation of the report of the Health Technology Board for Scotland on the organisation of services for diabetic retinopathy screening by Summer 2002.

ACTION POINT

A national co-ordinator to support the implementation of the recommendations of the Health Technology Board for Scotland on the organisation of services for diabetic retinopathy screening will be appointed by September 2002.

Table 14

Health Technology Board for Scotland

The Health Technology Board for Scotland (HTBS) provides evidence-based advice to NHSScotland on the clinical and cost effectiveness of new and existing health care interventions using a process called Health Technology Assessment (HTA). HTBS has conducted an HTA to determine the most effective and efficient approach to achieving, implementing and sustaining a quality assured, patient-centred comprehensive national screening programme for diabetic retinopathy. It considered all aspects involved in establishing a systematic screening programme including optical devices and patient and organisational issues. The HTA was issued for public consultation in November 2001 and was finalised in Spring 2002. It proposes:

- All patients, aged over 12 or post puberty, with type 1 or type 2 diabetes mellitus should have annual diabetic retinopathy screening (i.e. screening of the retina at the back of the eye).
- Digital retinal photography achieves the highest accuracy of all screening methods and it produces an image that can be stored and transmitted to be added to the clinical record.
- A new grading system for retinopathy is proposed and results will be captured using a link into the main SCI Diabetes database.
- Previous guidance has indicated that pupils should be dilated with eye drops (mydriasis) to ensure adequate image quality and to allow two images of the retina to be taken. However, new research shows that there is little difference in the sensitivity and specificity of the screening test for referable retinopathy when one or two images are taken, and there is evidence that in many patients mydriasis is not required to obtain a high quality single image. As image quality can be immediately assessed with a digital camera the HTBS recommends:
  - Taking a single digital retinal photograph of each eye without mydriasis.
  - If either image is of inadequate quality for grading, a single digital photograph of each eye following mydriasis should be taken.
  - If either image is still inadequate for grading the patient should be referred for examination by biomicroscopy with a slit lamp.

- Patients should be informed that they might need to have eye drops, which may cause blurred vision that will affect their ability to drive. This effect normally only lasts for two hours. In some patients the effects last for up to six hours and in isolated cases effects may last longer.
- Screening may be done by anyone who is accredited, competent, has undergone suitable training and continuing education, and is part of the national quality assurance scheme.
- Screening will be co-ordinated nationally, with NHS Boards designating and empowering individuals responsible for local service delivery.
- Each NHS board will decide how screening will be delivered in its area. Options include mobile delivery in a van, use of an established medical facility, or an optometrist. Costings have been clearly explained in the HTBS report to help NHS boards determine efficient use of their resources to obtain a quality assured screening programme.
- Patients with sight-threatening retinopathy will be referred to special assessment clinics at convenient ophthalmology departments and treated according to Royal College of Ophthalmologists guidelines.
- Patients must be fully informed about the need for diabetic retinopathy screening, the process involved and possible outcomes.
- Patients should be encouraged to attend screening by all health professionals and any barriers to attendance may need to be discussed with a diabetes facilitator.

Health Technology Board for Scotland, Health Technology Assessment of Organisation of Services for Diabetic Retinopathy Screening

Initial and Continuing Care

CSBS Standard 3 – Patient Focus

All people with diabetes have equitable access to information and multidisciplinary programmes of education, which are tailored to individual needs and specific client groups.

CSBS Standard 4 – Clinical Review

All people with diabetes are offered annual or more frequent examination, where clinically indicated, to monitor the management and progression of their condition. There is intervention as required and support for the modification of lifestyle risk factors.

CSBS Standard 8 – Clinical Management: Glycaemia

All people with diabetes have HbA1c measured and recorded as clinically indicated.

66. As soon as possible after diagnosis, people with diabetes should be offered an initial assessment of their condition and of risk factors. The quality and timing of early contacts following diagnosis are recognised as important because it is often during this period that a patient's attitude and response to their diabetes are formed. Early dietetic intervention is a crucial element of initial care, although at present in many areas this is sporadically provided.

67. Beyond initial diagnosis, education and treatment, people with diabetes require long-term and responsive continuing care, typically based around an annual review. An annual review should include provision of advice on lifestyle, assessment of glycaemic control, surveillance for cardiovascular risk, surveillance for long-term complications and surveillance for psychological complications. Table 15 sets out the tests and issues which people with diabetes might expect an annual review to include.

68. Although annual review is the most usual time interval, management and monitoring at more frequent intervals should be undertaken when this is clinically indicated. Difficulties in concordance with treatment and management plans need to be recognised and support developed for patients. Throughout their association with the NHS, support should be available to patients and carers who wish to make lifestyle changes.

69. An important part of the annual review is providing patients with information about their care and their health, including the results of the tests which they undergo. These need to be presented in ways which are understandable and meaningful to patients. Ideally, test results (and in particular HbA1c) should be available and discussed during the annual review. Good practice would include ensuring that the patient has the information he/she needs about his/her diabetes and any changes or complications which are emerging, a review of how the person is living with diabetes and what might help with this. Emotional support for people with diabetes is an integral part of good care. There should also be time for the person to raise any matters of concern and ask questions.

Table 15: Range of tests and issues likely to be covered during a diabetes annual review.

Test	Explanation
HbA1c	HbA1c measures the average level of blood sugar over the previous two-three months. Good glycaemic control is defined by SIGN as a HbA1c of 'around 7%'. However, targets need to be set to suit individual patients and such a challenging target may not be applicable in certain groups of individuals, such as those patients on insulin with hypoglycaemic unawareness, or those who are terminally ill. *Although HbA1c is the gold standard for the assessment of glycaemic control in diabetes, standardisation of results between different laboratories is problematical. Local laboratories should measure HbA1c and correct it to the Diabetes Control and Complication Trial (DCCT) standard.*
Total cholesterol	High cholesterol levels increase the risk of arteriosclerosis in people with diabetes.
HDL cholesterol	High Density Lipoproteins help to reduce the amount of cholesterol in the blood stream. This test would be carried out if total cholesterol is raised.
Triglyceride	High triglyceride levels increase the risk of arteriosclerosis.
Creatinine	High levels indicate deteriorating kidney function.
Blood pressure	High blood pressure is related to the development of heart disease, stroke, kidney and eye damage. SIGN recommend that the target blood pressure for all people with diabetes should be <140/80mm Hg.
Microalbuminuria	Presence of albumin in the urine indicates deterioration of kidney function which could lead to kidney failure.
Visual acuity	Deterioration in the 'VA' – the ability to appreciate visual detail – may indicate worsening diabetes control and/or retinopathy.

Retinal screening	Early detection of changes to the retina (back of the eye) enables treatment to be started in order to preserve sight.
Foot pulses	A reduction in foot pulses suggests reduced circulation to the feet and legs.
Foot nerves	A reduction in the ability to feel heat, pain or touch suggests a reduction on the effectiveness of the nerve supply to the feet.
Body Mass Index (BMI)	BMI is an expression of adult weight in relation to height. The higher the BMI the greater the risk of heart disease/stroke. A BMI of 18-25 is considered a healthy weight.
Lifestyle management	Exercise and physical activity, healthy eating and smoking cessation are key aspects of managing diabetes and its complications.
Review of drug therapy	Patients with diabetes will often require multiple pharmaceutical interventions, especially in patients with type 2 diabetes. Studies from Scotland indicate the greater number of drugs that are prescribed the less chance that patients will actually take these medications. It is extremely important that patients receive the appropriate education as to the indications for the introduction of therapies to lower blood glucose and prevent or treat vascular disease. All healthcare professionals are involved with the education process, but in particular clinicians must be disciplined in titrating to the most effective dose.
Mental well being	Depression is more common in people with diabetes than in the general population.

MILESTONE

Annual measurement of glycated haemoglobin (a measure of the amount of sugar in the blood; HbA1c) will be offered to all people with diabetes by September 2002. The results will be recorded on the local diabetes clinical management system.

Comment. As a measure of average glycaemic control, HbA1c is an essential part of monitoring diabetes. This is a very challenging target – the Scottish Diabetes Survey 2001 reported that of the patients whose data were included in the survey, 73% had had at least one measurement of HbA1c during the previous 15 months. The 2002 Survey will demonstrate if this milestone has been reached.

Feet

CSBS Standard 4 – Clinical Review

All people with diabetes are offered annual or more frequent examination, where clinically indicated, to monitor the management and progression of their condition. There is intervention as required and support for the modification of lifestyle risk factors.

CSBS Standard 7 – Clinical Management: Feet

All people with diabetes who have identified associated foot problems are referred for specialist assessment and, if necessary, treatment.

70. People with diabetes are between 15 and 70 times more likely to undergo lower limb amputations than people without diabetes. Diabetic foot problems are the most expensive of diabetes-related admissions. There is good evidence that people at high risk of developing lower limb complications can be identified and offered effective treatment. The key to the prevention of diabetic foot problems is education in good foot care. Feet checks are an important part of the annual review which all people with diabetes should undergo. An individual baseline (including vascular assessment, neurological assessment, and assessment of function and deformity) should be established for each patient. Personnel trained to assess the presence of risk factors for foot ulceration should undertake annual assessment of the lower limbs. Neuropathy, ischaemia or any deformities of the foot are the key risk factors and a previous history of ulceration infers highest risk. At present, there are wide variations in how thoroughly such checks are carried out and concerns about the quality of health education about foot care available to patients.

Kidney and Nerve Problems

CSBS Standard 4 – Clinical Review

All people with diabetes are offered annual or more frequent examination, where clinically indicated, to monitor the management and progression of their condition. There is intervention as required and support for the modification of lifestyle risk factors.

CSBS Standard 7 – Clinical Management: Feet

All people with diabetes who have identified associated foot problems are referred for specialist assessment and, if necessary, treatment.

CSBS Standard 9 – Clinical Management: Renal

All people with diabetes and identified associated kidney problems are referred for specialist assessment and, if necessary, treatment.

71. Kidney (or renal) disease and nerve problems (neuropathy) are both complications of diabetes caused by damage to the small vessels. It is for this reason that they have been combined together in the same building block. However, the fact that neuropathy plays a part in two other building blocks (feet and sexual health) serves to underline the limitations of the building block model in a clinical setting and acts as a reminder that patient management requires a holistic approach.

Renal Disease

72. End stage renal disease is one of the most serious complications of diabetes and one of the most costly for the NHS. Diabetic renal disease (diabetic nephropathy) usually develops over 15-25 years following the development of diabetes; (although the time may appear shorter in type 2 patients if diabetes had been present but undiagnosed for a number of years). People with diabetes account for 20% of patients undergoing renal replacement therapy in Scotland.

73. In people with diabetes, the presence of microalbuminuria (very small amounts of protein in the urine) and stroke, or an elevated serum creatinine (excess creatinine in the blood) increases the risk of kidney damage and failure. This is especially true in people with problems with kidney function who have high blood pressure. The presence of renal impairment in diabetes is also predictive of a high cardiovascular morbidity and mortality. Diabetic renal disease is also more likely if retinopathy is present. People of South Asian and Afro-Caribbean origin are at higher risk of developing renal disease and renal failure than the white population.

74. There is good evidence that early detection and appropriate treatment can prevent the development and progression of renal impairment. All people with diabetes should therefore be offered an assessment of their renal function as part of the annual review (see Table 15). Those with signs of renal impairment (that is, classified as having microalbuminuria or proteinuria) should be advised about their risk of renal and cardiovascular disease and offered appropriate treatment including tight blood glucose control (HbA1c <7%) and tight blood pressure control (less than 120/70). Those with continuing deteriorating kidney function (serum creatinine over 130 mmol/l) should be referred for specialist joint diabetic/renal opinion.

Neuropathy

75. All people with diabetes should be offered at least annual surveillance for signs of neuropathy (peripheral nerve damage). The most common type of neuropathy is peripheral neuropathy in a ‘glove and stocking’ distribution but especially the lower limbs. This can be insidious from the onset and comprises loss of sensation that may result in ulceration foot deformity. Other symptoms include neuropathic pain. Autonomic neuropathy is also more common in people with diabetes and erectile dysfunction in men should always be considered (see paragraph 89).

Psychology/Mental Health

CSBS Standard 4 – Clinical Review

All people with diabetes are offered annual or more frequent examination, where clinically indicated, to monitor the management and progression of their condition. There is intervention as required and support for the modification of lifestyle risk factors.

76. The emotional and psychological needs and support of people with diabetes are not always a priority in primary and secondary care; physical disease management usually takes precedence. However, the demands of diabetes involving daily decisions about nutrition, physical activity, medication, blood glucose monitoring and stress management as well as additional financial and social burdens can adversely effect patients. Up to 1 in 5 of people with diabetes suffer from depressive disorders and the risk of clinical depression is even higher amongst those with co-morbidity and complications. Depression can have a damaging impact on self-management. At present, the availability of psychological support for people with diabetes is patchy at best with a recent survey reporting that 54% of local services had no psychology input to the care of people with diabetes. There is a need to raise awareness of the 'hidden problem' of depression and other psychiatric illness in diabetes and to introduce more active monitoring of the psychological wellbeing of people with diabetes.

'You get nothing about the emotional side – all the emphasis is on diet.'

(Person with diabetes)

77. Many people who have diabetes have described the value of peer support and of emotional support from other sources that do not involve psychology services. Empathetic support from staff as an integral part of delivering care and good information also have an impact on the mental wellbeing of people with diabetes.

'In addressing the emotional effects of diabetes, it is important to emphasise the quality of the patient/staff relationship, the need to provide emotional support, to listen, help set up support groups for patients and families, and to provide appropriate information.'

(Professional, interviewed by Partners in Change)

Diabetic Emergencies and Elective Care

CSBS Standard 10 – Clinical Management: Acute Management

All people with diabetes who experience an acute diabetic emergency including severe hypoglycaemia, diabetic ketoacidocis (DKA) or hyperosmolar non-ketotic state are rapidly assessed and managed according to local protocols.

Diabetic Emergencies

78. On occasion, people with diabetes will encounter difficulties with their treatment which lead to diabetic emergencies. The acute complications of diabetes can causes distress, disability or even death. The morbidity and mortality rates resulting from these acute complications continue to be high in Scotland. Cerebral oedema and ketoacidosis is the main cause of death, particularly in young people. Recurrent hypoglycaemia is a cause of profound morbidity and occasional mortality. It is also a disincentive for people to achieve tight blood glucose control in the management of their diabetes. Quality of life is affected by recurrent emergencies and recurrent hypoglycaemia may cause restrictions on lifestyle including education and employment, driving, sport and social activities. The prevalence of diabetic emergencies can be reduced through education of both people with diabetes and healthcare professionals on how to avert hypoglycaemic episodes. All hospitals should have a protocol or guideline for the management of diabetic emergencies. People presenting with diabetic ketoacidosis should be managed by a hospital team experienced in the up-to-date management of the diabetes and its acute complications.

Elective Care

79. People with diabetes are admitted to hospital twice as often and stay twice as long as those without diabetes. However, inpatient care for people with diabetes is too often not well managed, especially when diabetes was not the original reason for admission. Often, this is the result of inadequate knowledge amongst hospital staff. There is a need for greater recognition of the particular needs of people with diabetes when they are admitted to hospital. Although some units do provide good diabetes training for non-specialists, there is a need to identify and spread these examples of good practice.

‘I was in a surgical ward so nobody knew anything about diabetes.’

(Woman with diabetes)

Specific Groups

80. Many of the proposals put forward in the Framework are applicable to all patients with diabetes but certain groups are either more likely to be affected by diabetes, or have specific needs which require special consideration of how care can be delivered most effectively.

Children and Young People

CSBS Standard 3 – Patient Focus

All people with diabetes have equitable access to information and multidisciplinary programmes of education, which are tailored to individual needs and specific client groups.

81. As the Scottish Executive pointed out in its response to the Final Report from the Bristol Inquiry, one of the Inquiry's central findings was the lack of priority which had been given to children's services. In Scotland, children's services have already been identified as a national priority, and a Scottish Cabinet Committee, chaired by the First Minister, has been set up to deal with children's issues across the Executive as a whole. In addition, the Child Health Support Group was set up, in 2000, by Susan Deacon, then Minister for Health and Community Care, to drive forward improvements in children's healthcare services across Scotland. It has developed a Template for Children's Services, setting out the key components of a quality, child-centred health service. The development of a combined and integrated child health service must be multi-agency and multi-professional and must take account of the needs of children on a continuum from the healthy child through to those with special and complex health needs and this will include children with diabetes.

82. Over 1,500 children and young people under 15 years in Scotland have diabetes. Scottish children tend to have poor diabetes control (on average) and there is marked variation across the country. Children and young people should be treated in environments appropriate for their age group. To ensure greater uniformity of care and promote best practice where possible, diabetes services should be clearly identified in the Child Health Strategies of every NHS Board.

83. At an appropriate age there should be a planned transfer of care to the adult diabetes service. Adolescence is a high-risk time for development of complications. Unfortunately, many young people do not see the value of staying in regular touch with health professional advice at this critical time. Service provision for adolescents varies across Scotland.

Table 16

Scottish Study Group for the Care of Diabetes in the Young

The Scottish Study Group for the Care of Diabetes in the Young (SSGCDY) is a collaborative group of paediatricians caring for patients with diabetes and adult diabetes specialists with an interest in adolescent care. The group has been responsible for the creation of one of the best diabetes registers of under 15 year old onset in the world and this has resulted in many publications. Hence, we have accurate figures on the incidence and prevalence of type 1 diabetes in Scotland.

In the last few years the SSGCDY has conducted Scotland-wide studies of the quality and outcomes of clinical care in children and young people with type 1 diabetes. These studies have demonstrated poor average glycaemic control (HbA1c 9.1%) and a broad variation in control according to centre (8.1-10.2%). The reasons for the latter are being investigated with the hope of improving results across Scotland.

Factors Influencing Glycaemic Control in Young People With Type 1 Diabetes in Scotland – a population based study (DIABAUD2), Scottish Study Group, Diabetes Care, 2001; 24(2): 239-244

84. The diagnosis of diabetes in childhood can be traumatic for both the child and his or her family. The support and empathy of healthcare professionals is particularly important at this time. It is also a time when families have to make many adjustments to their lives and absorb large amounts of new information. For this reason, good quality accessible information is crucial.

ACTION POINT

An educational video for children with diabetes and their families will be funded, produced and made available by Autumn 2002. Every new family will be offered a video or DVD.

Ethnic Minority Groups

CSBS Standard 3 – Patient Focus

All people with diabetes have equitable access to information and multidisciplinary programmes of education, which are tailored to individual needs and specific client groups.

85. The prevalence of diabetes, type 2 in particular, is between three and four times higher in communities of Asian and African-Caribbean origin than in those of European origin. People from Asian communities with diabetes have a two-three fold increased risk of heart disease and a four-fold increased risk of renal failure. Diabetes education and health promotion need to be culturally sensitive to the targeted communities e.g. religious and cultural practices governing food and its consumption need to be considered. The use of health service provision by people from ethnic minorities varies significantly from the white population, including registration with and visits to a doctor. Language difficulties may have a particular impact. For a variety of reasons, diabetes remains undiagnosed in large proportions of people with diabetes from ethnic minority groups. Consideration may be required to screening ethnic minority communities as an 'at risk' group to facilitate early diagnosis. There is a need to raise awareness of diabetes by, for example, holding events in appropriate community settings such as religious and cultural centres and elderly day care centres.

ACTION POINT

By September 2003, the Scottish Diabetes Group will publish a report, in conjunction with the Ethnic Minority Resource Centre of the Public Health Institute for Scotland (PHIS), on the epidemiology of diabetes amongst Scotland's ethnic minorities.

86. The development of social inclusion policy by the Scottish Executive over the past four years has included a commitment to tackling health inequalities, including those experienced by people from ethnic minority groups. *Our National Health: A plan for action, a plan for change* commits the Executive to require NHS Boards 'to ensure that NHS staff are professionally and culturally equipped to meet the distinctive needs of people and family groups from ethnic minority communities'.

Table 17

Cultural Competence

The needs and wishes of each individual should be recognised and taken into account as far as possible in planning their health and social care. Services should be sensitive and responsive, taking account of the differing age, gender, socio-economic status, beliefs, ethnicity, culture, religion and personal choices of people with diabetes. These principles have underpinned NHSScotland's *Fair for All* agenda and guidance.

NHSScotland is expected to provide culturally competent services. This means:

Respect for others: Understanding, caring, tolerance and responsiveness to the privacy, dignity, values, beliefs, religious concerns and circumstances of others.

Partnership: Constructive relationship with patients, carers, members of the public, community organisations, other statutory and voluntary agencies, administrative staff and professional colleagues with rights and responsibilities on both sides.

Innovation: The generation of exciting ideas and imaginative ways of delivering better services.

Social Justice: A fair approach in developing culturally sensitive services with equitable distribution of opportunities and avoidance of unfair discrimination based on race.

Concerns and issues that need to be addressed in service provision for minority ethnic communities include:

- Flexibility and sensitivity in service provision which will respond to particular needs arising from racial, cultural, linguistic, and religious diversity.
- Appropriate dissemination of information about available services.
- Development of staff understanding of the different naming systems, race awareness, religious and cultural observances.
- Different perceptions of health, mental illness and disability, and appropriate responses to them.
- Flexibility in catering arrangements to meet diverse dietary requirements.
- Monitoring and evaluation arrangements.
- Other concerns revolving around any special factors which need to be taken into consideration in residential, day-care and community settings, and ensuring that families receive appropriate support through advocacy and befriending schemes.

Scottish Executive Health Department, Fair for all: Improving the Health of Ethnic Minority Groups and the Wider Community in Scotland, December 2001

Pregnancy and Sexual Health

CSBS Standard 3 – Patient Focus

All people with diabetes have equitable access to information and multidisciplinary programmes of education, which are tailored to individual needs and specific client groups.

CSBS Standard 4 – Clinical Review

All people with diabetes are offered annual or more frequent examination, where clinically indicated, to monitor the management and progression of their condition. There is intervention as required and support for the modification of lifestyle risk factors.

Pregnancy

87. One in every 250 pregnant women has pre-existing diabetes. Gestational diabetes (GDM) – hyperglycaemia with onset or first recognition during pregnancy – occurs in between 2-12% of pregnancies and is a high-risk state for both the woman and her baby. Diabetes increases the risk of pregnancy complications including obstructed labour, intrauterine death and congenital abnormality. An optimal outcome may be obtained from pregnancy if excellent glycaemic control is achieved before and during pregnancy. Good contraceptive advice tailored to individual needs and pre-pregnancy counselling (PPC) are also essential. Attending PPC clinics increases the likelihood of positive outcomes for mothers and their babies. An experienced, specialist team comprising an obstetrician, physician, specialist midwife/nurse and dietitian, with access to other expertise where necessary should provide comprehensive and intensive maternity care. Labour and delivery of women with diabetes should only be undertaken in hospitals where there is a neonatal unit with intensive care facilities.

'I was scared stiff – I had a sense of overpowering responsibility.'

'It was so important to me, the attitude of staff, that they're really interested in me as a person, not a statistic.'

'I worry for my child, as well as my future health.'

'Mothers are under huge psychological pressure.'

(Women with diabetes interviewed by Partners in Change)

88. A recent audit involving all 22 consultant-led maternity units in Scotland looked at pregnancies to women with type 1 diabetes and at the implementation of the SIGN guideline on the management of diabetes in pregnancy (now incorporated into SIGN 55). This study found that care during and after pregnancy was in line with recommendations, but that pregnancy planning and peri-conceptual care fell short of the guidelines. This points to an area where improvements are required.

Male sexual health

89. For men, diabetes carries with it a high risk of erectile dysfunction, most frequently the result of neuropathy. It is estimated that up to 40% of men with diabetes are effected by erectile dysfunction. This is more common in the elderly, and it is clear that that erectile dysfunction can have profound health effects by causing low esteem and reduce overall quality of life. The possibility of erectile dysfunction should be considered as part of the annual review. Treatment with counselling and sidenafil or other techniques should be offered. In general, current services for erectile dysfunction are reported to be unsatisfactory. Staff should be better trained and supported to raise sensitive issues such as erectile dysfunction as a matter of course in educating patients about their condition.

'I've been asked umpteen other questions but not about impotence.'

'Nurses are mostly young girls, I think they're embarrassed.'

(Men with diabetes discussing impotence interviewed by Partners in Change)

Vulnerable Groups

CSBS Standard 3 – Patient Focus

All people with diabetes have equitable access to information and multidisciplinary programmes of education, which are tailored to individual needs and specific client groups.

90. There are a several groups of people who are at high risk of developing diabetes, and/or who are in a position where diagnosis and management of diabetes is more difficult, or frequently inadequately provided. These groups have been grouped together here in a single building block as groups which will require a targeted and specific approach. By this definition, vulnerable groups include:

- Those living in residential institutions (e.g. nursing homes) where evidence has shown that diabetes care can be less than optimal. This would require specific training of carers and others.
- People living in custodial settings who often have additional psychological and physical problems.
- Ethnic minority groups. There is evidence some ethnic groups have a much higher prevalence of diabetes than others. Targeted advice on prevention and awareness is required.
- Refugees and asylum seekers. It is well recognised that these people often have significant health problems. In addition to increased health care resources there is a need for high quality interpreter facilities. This is particularly important in the areas of education and dietary advice. A targeted approach is required.
- People with learning difficulties. It has already been recognised that people with learning difficulties require increased health care input and several initiatives are under way to improve the situation. In diabetes there is a specific need for health education input both for clients and carers.
- Homeless people. Because of their situation homeless people present particular problems in terms of diagnosis, follow up and access to health care. Work already being undertaken with homeless people should also address the issue of diabetes.
- Adolescents. As discussed elsewhere in this report, many teenagers go through a period of denial and resultant poor diabetic control. The needs of these individuals require to be addressed. Inputs might include ready access to psychological services and specific 'young peoples' clinics with an informal atmosphere and ease of access to health care.

91. Finally and importantly, for many vulnerable groups carers play a vital role. Diabetes services should provide easily accessible advice and support for people caring for those with diabetes.

Planning and Managing Services

92. Diabetes is a complex condition which requires the collaboration and communication of many different clinical staff working in a range of different organisations and agencies. An effective diabetes service demands that these various elements work together with patients and their carers to provide integrated care for people with diabetes, ensuring that the care available is appropriate for the stage, type and status of an individual's diabetes. Such a service needs clear objectives, sound leadership, a well trained workforce, high quality data and effective IT, constructive engagement with the people served and a culture which promotes teamworking. All of this points to the development of 'Managed Clinical Networks' as the most effective way ahead for diabetes services.

93. Managed Clinical Networks are defined as: 'linked groups of health professionals and organisations from primary, secondary and tertiary care, working in a co-ordinated manner, unconstrained by existing professional and Trust/Health Board boundaries to ensure equitable provision of high quality and clinically effective services'. Diabetes was cited in MEL(1999)10 as the exemplar condition that requires effective Managed Clinical Network activity in NHS Scotland, a view endorsed by the Framework Working Group.

Strategy, Leadership and Teamworking

CSBS Standard 2 – Organisation: Pathway of Care, Teamworking and Integration of Services

There is an agreed area-wide structured programme of care which clearly defines: reporting arrangements and accountability; the care that people with diabetes should expect to receive; the processes of care that will be followed after diagnosis (including pre- and peri-operative management); the protocols and guidelines that determine which clinician is responsible for the delivery of specific aspects of care; criteria for referral.

94. There is increasing evidence that early diagnosis and the provision of systematic care to people with diabetes improves health outcomes and delays or prevents complications of diabetes. During a lifetime of care, people with diabetes need access to a wide range of healthcare skills including medical, nursing, dietetic, podiatry and psychological. Providing equitable access necessitates teamworking and an integrated approach to service delivery. Diabetes services are, in most areas, very complex and diffuse. Greater co-ordination and direction is needed to raise standards, reduce unacceptable variations and improve efficiency. This is particularly important given the increasing prevalence of diabetes.

Leadership

95. Effective diabetes services require clear strategic thinking, identifiable clinical and managerial leaders and structures which promote teamworking, collaboration and good communication. NHS boards are at different stages in terms of developing more integrated services and leadership styles will need to adapt and change as services develop. In identifying clinical leaders NHS boards and healthcare professionals will wish to consider the longer-term need for clear leadership of the Managed Clinical Network.

ACTION POINT

Clinical leaders should be identified at locality level to champion local integrated diabetes services in all NHS boards by June 2002.

96. Part of the leadership role is ensuring that the way services are organised and delivered reflect the needs and preferences of patients, not just those of the staff. Part of this task will be considering the scope for all specialist services and more general healthcare services to work together more effectively to care for people with diabetes. This will include contributing to the on-going professional training and development of staff in secondary and primary care settings.

97. It is clear that in addition to clinical leaders, those areas which have been able to make most progress towards increasing the integration of services have been the areas which have been able to call upon the skills of a diabetes co-ordinator or project manager. A service which can rely upon good communications, reliable data, well planned meetings and effective administration will significantly reduce pressures on healthcare professionals and so allow more time for patient care.

ACTION POINT

A dedicated 'diabetes co-ordinator' to improve communications within the local diabetes community and provide administrative support to enhance integrated care across primary and secondary care should be identified in all NHS boards by December 2002. The co-ordinator should be responsible to the LDSAG for strategy and implementation of policy at locality level.

Local Diabetes Service Advisory Groups

98. Action is needed at all levels and requires the commitment of all stakeholders. In the short term, organisations need to set up (or reinforce) local organisational structures which support integrated and co-ordinated diabetes care. In the longer term they need to make these structures work in order to nurture a culture which supports teamwork, inclusive planning and good communications. A 'whole systems approach' to diabetes care is essential. Many NHS boards already have the origins of effective clinical network activity in diabetes with the creation of multi-professional diabetes advisory groups (LDSAGs) with representation from both primary and secondary care, as well as in most cases service users or carers.

ACTION POINT

All NHS boards should establish an effective multi-professional Local Diabetes Service Advisory Group (or equivalent) with service user involvement by June 2002.

Table 18

Local Diabetes Service Advisory Groups

A Local Diabetes Service Advisory Group (or LDSAG) was an idea championed by Diabetes UK as a means of providing a coherent multi-disciplinary focus for the diffuse elements of diabetes care in an area. The idea caught on and LDSAGs were set up in many areas, albeit with differing roles, remits, memberships and degrees of effectiveness.

The Diabetes Framework seeks to re-energise and strengthen LDSAGs so that they become the main driver for change of diabetes services at regional level. A key recommendation of the Scottish Diabetes Framework is that all NHS boards put in place a group responsible for developing a local diabetes strategy and for advising on, and monitoring, the effects of that strategy. It should, in addition, oversee the agreement on priority setting for diabetes services locally and the development of systems to facilitate the achievement of targets and of user satisfaction and for monitoring and auditing the quality of the service against targets and standards.

LDSAGs should produce an annual report on developments and progress. As a minimum, the report should be presented to the local NHS board in public session.

Membership of the LDSAG should include all stakeholders of diabetes services; i.e. service users, representation from primary care clinicians, public health, managers specialist team(s) and commissioners of provider services, Diabetes UK, Local Health Councils and the local authority. There should also be consideration of co-opting relevant occasional members e.g. health promotion or social work.

Support and training should be available for all members of the LDSAG, but in particular for lay members. Consideration should be given by NHS boards to resourcing the core leadership team of the LDSAG. This would include protected sessional time for the network lead clinician, diabetes co-ordinator, and secretarial support. These individuals should be accountable to the LDSAG/clinical network.

LDSAGs represent a key step in the evolution of diabetes Managed Clinical Networks, and should form the core of the Managed Clinical Network's management arrangements.

Reporting Arrangements

99. Several NHS boards already publish a yearly report of diabetes activity. Such reports offer a valuable means of communicating to staff, patients and the public about recent achievements and developments, as well as providing a focus for those planning and managing services. It also provides a useful record for those agencies with a responsibility to monitor local services such as the Clinical Standards Board and the Scottish Executive. It is strongly recommended that this practice be followed by all NHS boards, in order to pave the way towards the annual report which the Managed Clinical Network will produce.

ACTION POINT

All NHS boards should publish an Annual Diabetes Report. A report for 2002/03 should be prepared and published by each LDSAG by June 2003.

Strategy and Implementation Plan

100. Clarity over objectives, a shared understanding of how the various elements of diabetes will interact and agreement about the resource and workforce implications of any proposed developments are essential if progress is to be made. This requires the delineation of a diabetes strategy, which, depending on local requirements may be a standalone document, or a part of the Local Health Plan. The LDSAG provides the logical forum to develop the strategy. Specific objectives and targets in the strategy and implementation plan should conform to the recommendations of the Scottish Diabetes Framework and strive to meet the clinical standards identified by the Clinical Standards Board. Local plans also need to be aligned with related developments such as in CHD, maternity services and primary care modernisation.

ACTION POINT

All NHS boards should publish a local diabetes strategy and implementation plan by April 2003.

Workforce Planning

101. Current pressures on diabetes services present a strong case for seeking to find more effective and efficient ways of organising and delivering care. However, even with improved organisational arrangements, increasing numbers of people with diabetes mean that NHS boards will need to look critically at the workforce implications of providing effective diabetes services. The Scottish Executive has already signalled in its response to *Planning Together*, the importance of workforce development and the need to ensure the integration of workforce planning and service planning. The Scottish Diabetes Group will need to establish close links with the new national and regional arrangements for workforce planning being developed by the Scottish Executive. It is anticipated that the Diabetes Collaborative Improvement Programme (outlined on page 67) will be helpful to NHS boards in examining the current and future workforce implications of the drive to improve diabetes services.

Table 19

Integrated Workforce Planning

Planning Together, the report of the Scottish Integrated Workforce Planning Group, set out a conceptual framework and a practical approach to building an effective workforce planning function for Scotland.

The report set out the key benefits of integrated workforce planning:

- Better match of teams to service delivery
- More effective use of existing and potential skills
- Minimised chance of service failure from workforce difficulties
- Greater flexibility to handle demand peaks
- Rationale to inform choice between service options
- Realistic basis for the timing of developments

Planning Together, Scottish Executive Health Department (January 2002)

ACTION POINT

A workforce survey of diabetes services in hospitals and the community (e.g. specialist nurses, podiatrists, dietitians, community nurses, general practitioners and consultants) will be commissioned by January 2003.

Diabetes Collaborative Improvement Programme

102. The implementation of the Scottish Diabetes Framework and in particular the strengthening of LDSAGs and the formation of managed clinical networks will be supported through the creation of a Collaborative Improvement Programme. The primary objective of the Collaborative is to raise the standard of diabetes care across Scotland. This will be achieved through the involvement of healthcare and other professions from all NHS board areas in a structured national service improvement programme.

MILESTONE

A Diabetes Collaborative Improvement Programme will be established by March 2002 to support the sharing of experience and best practice throughout Scotland to improve care and outcomes for people with diabetes.

Table 20

Diabetes Collaborative Improvement Programme

The Collaborative approach is a tried and tested systematic methodology, developed by the Institute for Healthcare Improvement (US), which has been successfully applied to improving healthcare in the US, Sweden and England.

The overall goal of the Collaborative is to:

- facilitate a structured, national response to clinical standards and guidelines;
- optimise the overall experience and outcomes of care for each patient by improving care delivery systems by reducing delays and removing constraints;
- support the development of long-term clinical networks.

In summary this approach involves:

- developing, through an Expert Panel, a set of principles, ideas and actions which would secure the greatest gain in a particular area of care if they were replicated across all those responsible for the delivery of that care;
- presenting these ideas in conjunction with change management methods to participating Trusts/Practices;
- enabling these sites to apply the learning to their own real life situation through rapid and intensive change management methods;
- sharing the learning across all participating sites to help support the broad roll out of ideas and practice.

The Programme will be structured over an 18-month period through a series of linked *Learning Sessions and Action Periods*. During 'Learning Sessions' Local Project Teams will be able to learn about relevant tools and techniques for the next Action Period, share experience and networking with other Project Teams, review performance from the previous Action Period and set the agenda/deliverables for the next Action Period. 'Action Periods' are the periods of activity (based on *PLAN – DO – STUDY – ACT* (PDSA) change cycles) in which the service improvement ideas defined during the Learning Sessions will be implemented.

The effective management of the programme is critical and participating sites will have the support of Programme Facilitators specifically trained to help clinical teams to implement the change management methods.

Managed Clinical Networks

103. The future of diabetes care is to move towards a whole systems approach and the establishment of Managed Clinical Networks. Some areas are already beginning to function along the lines of a network and all other areas should adopt a similar approach. LDSAGs represent important precursors of Managed Clinical Networks.

MILESTONE

Managed Clinical Networks for diabetes will be established in all NHS boards by September 2004.

Table 21

Managed Clinical Networks

The concept of Managed Clinical Networks (MCNs) arises from the work of the Acute Services Review. They offer a new and exciting way of delivering services to patients designed to lead to a focus on services and patients rather than upon buildings and organisations. In essence they involve clinical staff working across the boundaries between the different professions and parts of the health service. This should ensure that existing health service resources and staff are allowed to be focused on what matters – patients and their problems. The direct involvement of patients in these networks should ensure that the focus is not lost.

The definition of Managed Clinical Networks is *'linked groups of health professionals and organisations from primary, secondary and tertiary care, working in a co-ordinated manner, unconstrained by existing professional and Health Board boundaries, to ensure equitable provision of high quality clinically effective services throughout Scotland'.*

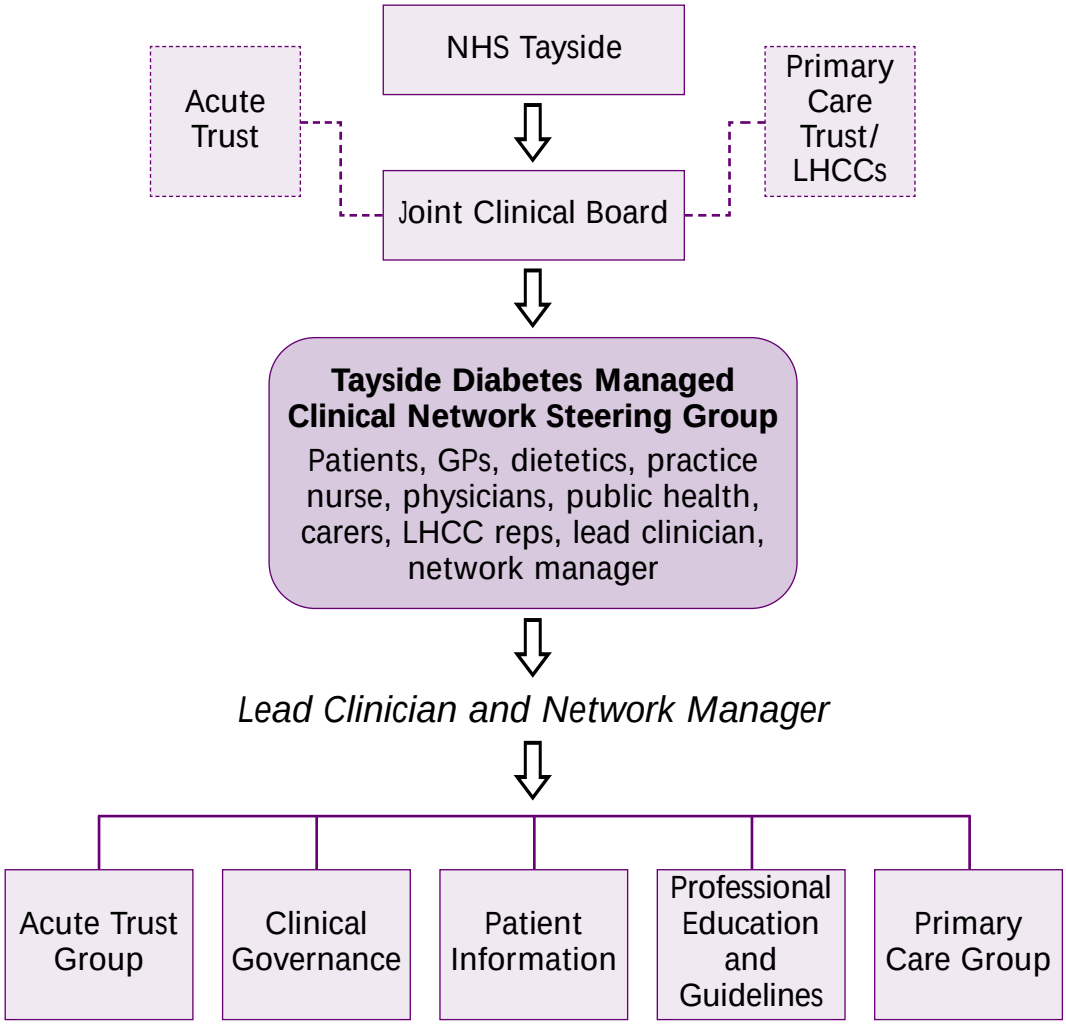
One of the main strengths of the concept is its flexibility. It can be applied to many different situations, but always to make sure the service is providing the response which is best suited to the interests of the patient who needs that particular service. That flexibility has meaning, however, only if the operation of each Network is governed by core principles. These were set out in MEL(1999)10, and can be summarised as follows:

- Each Network must be actively managed.
- The purpose of Network is to improve patient care in terms of quality, access and co-ordination.
- Patients must be involved in shaping the network.
- The work of the Network must be evidence-based.
- Outcomes need to be measured. Audit is integral.
- A quality assurance programme acceptable to Clinical Standards Boards of Scotland is required.
- The Network must produce an Annual Report.
- The Network must be genuinely multi-disciplinary.

Scottish Executive Health Department, Acute Services Review, June 1998

104. Tayside has pioneered a number of the proposals being put forward in this Framework. The Tayside Diabetes Managed Clinical Network has been built upon a consistent commitment to improving diabetes care over a number of years, combined with an inclusive approach to service development and innovative use of IT. The organisational structure being explored in Tayside may serve as a model for other areas.

Figure 4: Tayside Diabetes Managed Clinical Network



105. Another example of an important innovation in the delivery of diabetes services for children is DIABNET. This managed clinical network for 500 children with type 1 diabetes provides equity of service in diabetes specialist nursing, dietetics and clinical psychology across Fife, Forth Valley and Tayside. This network, the first of its type for children with chronic disease in NHS Scotland, has core elements of clinical governance (shared care pathways, clinical guidelines and protocols), formal evaluation and a particularly novel development of a network wide out of hours telephone support service for children and their families.

Teamworking

106. The basis of all Managed Clinical Networks is teamworking. The Managed Clinical Network must include not only the core team (in the practice or in the department) but also the wider team involving all those who contribute to the care or people with diabetes. Professions which should play a role in the diabetes Managed Clinical Network include optometrists, social workers and community pharmacists. Other groups with a potentially important role to play include universities, local authorities and the pharmaceutical industry.

107. An essential feature of Managed Clinical Networks is the involvement of patients in service planning and in the Network's management arrangements. Lay people who are expected to undertake this work are entitled to proper training, if required, both in respect of the condition itself and in relation to the workings of NHSScotland. In recognition of this, the Scottish Executive Health Department has awarded a grant to Diabetes UK (Scotland) to help promote training of lay people so that they can contribute effectively to diabetes Managed Clinical Networks (see paragraph 52).

Table 22

Community Pharmacy

The Right Medicine, the recently published strategy for pharmaceutical care in Scotland, highlights the important role which pharmacists can play in enhancing the care of people with diabetes. The strategy points to the need to recognise and increase the role of community pharmacists as members of the healthcare team.

'Community pharmacists are often patient's first point of contact, and for some their only contact, with a healthcare professional. This creates a unique opportunity to improve the gateways for signposting, accessing and providing services and information on health and health issues to a broad spectrum of the population. This includes the most vulnerable in our communities; older people, people with mental health problems, homeless people, travellers and drug users. All of these are people who might have difficulty, for lifestyle reasons, in accessing healthcare.' (p.6)

In the context of diabetes, the strategy suggests that community pharmacists could have an important role in developing screening, diagnostic and referral services, by promoting healthy lifestyles and screening for risk factors, as well as encouraging safe and appropriate self-medication. Also highlighted is the experience of pharmacists working in diabetes clinics to target patients with cardiovascular complications by conducting medication reviews and optimising secondary prevention treatment, including therapy for high blood pressure.

Scottish Executive Health Department, The Right Medicine: A Strategy for Pharmaceutical Care in Scotland (2002)

Table 23

Working with the Pharmaceutical Industry

'The Pharmaceutical Industry has expertise on how and why medicines are used and it is important to work with them. The [Pharmaceutical] Profession is keen to work in partnership with the Industry both to support existing services and develop new services. This includes the managed care of chronic condition, therapeutic drug monitoring and health promotion.

Action: The SEHD will produce guidance on joint working between NHSScotland and the Pharmaceutical Industry, which is transparent and improves patient care (December 2002).'

Scottish Executive Health Department, The Right Medicine: A Strategy for Pharmaceutical Care in Scotland (2002) (p.11)

Education and Training for Professionals

108. An effective diabetes service requires all clinical staff to be trained, competent and skilled in their components of diabetes care and able to work with other members of the multidisciplinary team needed to provide an integrated service to people with diabetes. Effective staff training is needed in order to maintain standards of health care; ensure consistency in care delivery; ensure relevant and appropriate information is delivered to staff and to patients; help professionals keep up to date with new developments in diabetes; and provide professional development.

109. During the fact-finding undertaken by Partners in Change (see Table 11), people with diabetes were asked to identify various ways in which they considered that staff training might help staff to provide better services. They suggested that staff should:

- be skilled in reaching out to people and asking them why they don't attend clinics be;
- be aware that people who are chronically ill find it hard to comment or complain. They depend on staff and so need encouragement to ask questions and make suggestions be;
- be equipped with listening skills and awareness of their body language;
- be knowledgeable about local community services and staff in other services;
- be skilled in raising difficult topics such as sexual problems; and
- remember that the person with diabetes knows about their own health and is the most important member of the team.

110. A number of professional associations and others produce educational materials and a wide range of courses and conferences are available to healthcare professionals who wish to learn more about diabetes. Most academic institutions in Scotland run a variety of short and longer courses on diabetes as well as teaching, counselling and computing courses. Much of the diabetes education currently available is very good, but overall it does not appear to be providing all that staff need. Many staff at the two open meetings held to discuss the Framework consultation paper identified more and better training as the thing which they most hoped that the Framework would deliver. The objective must be to find ways of maximising the opportunities for staff to access high quality learning programmes, most likely in the form of multi-disciplinary, flexible, accredited courses. An important first stage is to clarify in more detail what is already available, to quantify the educational gaps and to identify how best to address the training needs of staff.

111. In order to create a mechanism to fund the creation and delivery of educational material and to support innovation in diabetes training and education, the Working Group floated the idea of an educational trust. Discussions are continuing between the Scottish Diabetes Group, universities, Diabetes UK and the pharmaceutical industry about establishing such a Trust.

ACTION POINT

A short-life group will be established by the Scottish Diabetes Group to assess the availability and quality of existing diabetes education and training, to ascertain the training needs of staff, especially in primary care, and to make recommendations for meeting these needs. A report of this work will be published by December 2002.

112. NHS Education for Scotland, the new Special Health Board for education, will be established in April 2002 as the national body responsible for professional education. The Scottish Diabetes Group should work closely with this new body to ensure that the educational needs of those providing diabetes services are fully considered in the development of national educational programmes.

IM&T and Diabetes Registers

CSBS Standard 1 – Organisation: IM&T, Clinical Management Systems, Audit and Monitoring

All people with diabetes, with appropriate consent, are placed on a clinical management system which contains core information about their care and allows ongoing useful clinical information to be recorded for use in direct patient care and service audit.

113. Clinical data are at the core of diabetes care – for individual care, for service planning and for testing compliance with the St Vincent Declaration. Well managed integrated diabetes care needs to be underpinned by efficient and easy to use information technology. Good information management and technology (IM&T) can generate a dependable register, support clinical care, facilitate call-recall and provide robust and reliable audit and epidemiological data. Diabetes registers should not be sterile lists but dynamic resources created as a by-product of clinical care – wherever delivered. Registers are essential to underpin initiatives such as eye screening. Significant effort is required to ensure the appropriate level of patient consent and to establish and maintain the infrastructure to keep registers up to date.

114. Without robust and reliable information, it will be impossible to monitor the impact of the many initiatives outlined in this Framework. Care of individual patients is also compromised when appropriate information is not available, in timely fashion, to all of those involved in their care. This is especially true with the increasing emphasis on multidisciplinary care, often in several different settings. This model of care is particularly well developed for diabetes but increasingly is being applied elsewhere.

'You shouldn't have to tell your history over and over again.'

(Person with diabetes)

115. Diabetes is in a strong position to lead the way in developing a national IM&T solution because:

- There is broad agreement and a spirit of collaboration between medical, nursing and PAMS professionals about the way forward.
- A dataset, to support direct patient care, has been agreed and can be adapted/modified for this project with relative ease.
- Products that have been developed, tried and tested in Scotland can begin to deliver real benefits quickly.
- There is strong support from healthcare professionals, politicians and patients for a nationally co-ordinated national IM&T solution.
- A robust IM&T system is essential to underpin call-recall for eye screening in diabetes.
- There is an expectation that experience gained from the diabetes project can be applied in providing similar solutions for other chronic conditions.

116. Against this background the decision was taken to establish and fund SCI-DC (see Table 24) as a mechanism to deliver effective IT to diabetes services in Scotland. The SCI-DC Steering Group reports both to the Scottish Diabetes Group and to the IM&T Programme Board, the national planning and co-ordinating body for IM&T developments in Scotland.

MILESTONE

All hospital-based diabetes clinics will be supported by an effective IT system by December 2002.

MILESTONE

A national IT system to support all aspects of diabetes care will be fully implemented throughout Scotland by December 2005.

Table 24

SCI-DC: Developing a national clinical management system for diabetes

A Clinical Steering Group has been established to oversee the development and implementation of the Scottish Care Information Diabetes Collaboration (SCI-DC). A project manager has been appointed and programming, analysis, testing and support personnel are being recruited. The £1.5 million programme funded by the Scottish Executive will be co-ordinated by the Clinical Technology Centre in NHS Tayside.

The principal concept underpinning this initiative is the creation of a single shared record for use by all involved in the care of a patient. Ultimately, it is anticipated that the patient too will be able to access and contribute (appropriately) to his/her own record.

Work will be in several phases:

- Implementation of SCI-DC Clinical and SCI-DC Network. These products (previously known as the Lanarkshire Diabetes System and DARTS respectively) are being prepared for roll-out across the country. Detailed information has been sent to all NHS boards and Local Diabetes Service Advisory Groups in preparation for this work.
- Establishment of links with the broader SCI programme and the use of appropriate modules e.g. SCI-Gateway to facilitate communication with Primary Care.
- Collaboration with the GPASS development team to ensure seamless interchange with the principal primary care system in Scotland. The suppliers of other systems will also be appraised fully of the datasets and technical details.
- Development of educational and support content for use (via a web browser) by professionals and patients.
- Liaison with the Eye Screening Implementation Group to provide tools appropriate to support call-recall and image management.

This is an ambitious and complex project. Success will be dependent upon close working between all involved in diabetes care as well as upon the availability of resources. Patients may, of course, have other problems related or unrelated to their diabetes so it is vital that these developments proceed in such a way as to allow exchange of information beyond disease specific boundaries.

Local Diabetes Registers and the Scottish Diabetes Survey

117. NHS boards were asked in September 2000 (in HDL(2000)12) to ensure that each of them had a register of people with diabetes in their health board area. For many boards this acknowledged work already in hand, whilst for some others it raised significant organisational issues. NHS boards were also asked to submit aggregate data to the Scottish Diabetes Survey. This national snapshot survey represented the first attempt to collate comprehensive data on diabetes care in Scotland. By October 2001 data had been submitted by all 15 NHS boards. These data were compiled and analysed by the Scottish Diabetes Survey Monitoring Group and published in November 2001. Although considered to be a provisional survey (and the data were incomplete and do need to be treated with some caution), the 2001 survey marks an important and impressive first step in an ongoing process designed to understand and improve diabetes care across Scotland. The intention is that the survey will be repeated annually.

ACTION POINT

All NHS boards should submit data for the 2002 Scottish Diabetes Survey in September 2002.

ACTION POINT

A conference for those involved in developing and maintaining local diabetes registers will be held by Summer 2002 to update progress, and foster collaboration between all Scottish regions in the £1.5 million SCI-DC (SCI Diabetes Collaboration) programme.

Data protection and confidentiality

118. In recent years, NHSScotland has been increasingly aware of the need to tighten standards of data protection. These requirements are integral to the new diabetes IT and register developments.

Table 25

Data protection and patient confidentiality

The Data Protection Act (1997) and numerous professional guidance documents from bodies such as the General Medical Council have led to much debate over how the dissemination of clinical information is managed in healthcare.

At first sight there is an apparent tension between the necessity to share data and the requirements for data protection and confidentiality. However, all that is required is clarity over the purpose of a specific exchange of information and the rules relating to consent become apparent.

The physical security of information management and technology systems and their contained data is well understood and NHSScotland will continue to provide guidance. Rules on access control and the obtaining and recording of patient consent for data sharing have been subject to close scrutiny by the Confidentiality and Security Advisory Group Scotland. Detailed guidance will be forthcoming but it is understood that a distinction will be made between direct care, the use of information for operational management of the NHS (which would include quality control systems), and education or research. Meantime, the Scottish Executive is developing proposals to enable NHSScotland to comply with the law and best practice in this area. Part of this will be mechanisms to allow anonymised and aggregated data to be generated from clinical records to satisfy many of the requirements of management – a specific example is the Scottish Diabetes Survey.

As a matter of priority, a programme of education will be conducted by NHSScotland to improve staff awareness of confidentiality issues and patients' understanding and appreciation of what happens to their data. At the same time systems will be established to ensure that, wherever practicable, patients' wishes are respected.

Protecting Patient Confidentiality; A consultation paper (July 2001)

Patient Support

119. The involvement of people with diabetes in their own care is central to improving standards of care. At a population level too, the NHS needs to engage more proactively with the local people whom it serves. This includes improving communications, listening to and acting upon the views of people with diabetes and their carers, involving people with diabetes in the planning and monitoring of services, and assisting people and their families to support each other (e.g. Diabetes UK branches). These issues clearly overlap with the section above on 'Patient Information, Education and Empowerment' and the link to the work of Partners in Change and the new Patient Focus initiative is apparent. The reason for including a building block on 'Patient Support' was to emphasis the role of people with diabetes in the planning and managing of services as well as at a more individual level which is the primary concern of the section relating to care, monitoring and treatment.

Table 26

Volunteering

As a general rule, the NHS is not good at drawing in the skills and enthusiasm of the people who use its services, or in the wider community. Yet there is a wide range of ways in which people who have diabetes and their families can contribute their time to benefit other people. Examples include:

- people with diabetes acting as volunteer 'mentors' or 'buddies' for people who have had a recent diagnosis, or who are going through a period where they would like some additional advice or support;
- people with diabetes providing training for health care staff on how they live with diabetes and the types of responses and care they find helpful;
- families of people with diabetes helping to develop information packs for other families, and suggesting sources of information and support that are useful but which NHS staff might not think of;
- networks of people in local communities providing practical help and friendship to people with diabetes and people with other health problems – lifts to the shops, someone to go with you to the bowling club when your eyesight gets poorer, someone close to your own age who knows what it is like to be a teenager, or a new mum, who also has diabetes.

Guidance on volunteering in the NHS: Implementation, MEL(2004)4

Advocacy

120. Along with other people who have chronic health problems, people with diabetes may benefit from access to independent advocacy. There will be occasions when people with diabetes will be faced with difficult choices, and where their decision may not coincide with the view of the staff who provide their care. In these circumstances, support from someone to help the person say what they want can be invaluable for both the individual and for the staff. Sometimes a friend can take on this role, while other people will prefer to use the support of an independent advocacy service.

121. NHS boards, in their role as commissioners of advocacy services, should take account of the likely needs of people with diabetes: the Guide to Commissioners explains in more detail what is expected by the Scottish Executive. When LDSAGs and the NHS Boards are considering the range of local services for people with diabetes, access to independent advocacy should be included in that review. Information about availability of, and access to, independent advocacy should be part of the information given to individual patients and their relatives, and to any local support groups.

'It was only after [giving support and encouragement to other people with diabetes] I realised I could help somebody else, I had something to give.'

'People need time. This does not need to always be from a doctor or a nurse. Other people can give this.'

(People with diabetes interviewed by Partners in Change)

Research and Development

122. Research into the management and treatment of diabetes is carried out in various centres. Increasingly, pharmaceutical companies, universities and hospital research units share their expertise and the huge costs by working together. For example, whereas Diabetes UK can afford to fund research in its early stages, it depends upon collaboration with other groups, such as pharmaceutical companies, to take developments forward. During guideline development SIGN identify subject areas where there is little or no evidence. Funding of research into these areas would help to continue the advancement of knowledge in diabetic medicine and promote evidence-based medicine through supplying evidence to guideline programmes such as SIGN.

Table 27

Diabetes Research in Scotland

Since 1996 the Chief Scientist Office (CSO) has funded 14 projects relating to diabetes research, at a cost of £1,247,263. Several projects investigate the influence of birth weight on insulin resistance and risk factors for cardiovascular disease in the adult. One study involves the follow up of adults born to women who participated in controlled trials of weight manipulation during pregnancy. Another follow-up study uses monozygotic and dizygotic twin pairs to remove the effects of genetic and early socio-economic factors, to enable the effect of birth weight to be studied. The relationship between disease programming in the infant and maternal glycaemia and foetal size is also being studied in women with type 1 diabetes.

Two further projects aim to identify markers that can be used to screen for those diabetic patients most at risk from cardiovascular complications that would benefit from pharmacological intervention. One study is investigating serum B type natriuretic peptide and ECG changes to screen for left ventricular dysfunction, which is asymptomatic and precedes heart failure. The other is looking at QT dispersion and targeted intervention to reduce the incidence of sudden death.

> Of the remaining projects, several investigate strategies to improve quality of care and improve adherence and diabetic control as well as barriers to this as perceived by patients. Another is pioneering human pancreatic islet cell transplantation in diabetic patients undergoing renal transplantation, using a steroid-free immuno-suppressant regimen.
>
> *CSO Annual Report 2000-2001*

123. The range of research that is undertaken should include work on the strategies and interventions which help people live with diabetes and take on activities that are part of living in a community. It should include research around the mental wellbeing of people with diabetes – what helps to maintain positive mental health and what treatments and other responses are effective when people with diabetes experience depression.

Implementation

Implementation and Monitoring

124. Although the publication of a Framework is an important step forward, without effective implementation, the recommendations of the Diabetes Framework will have no impact. It is therefore essential that the Framework contains within it mechanisms to support implementation and systems to monitor progress. The challenge is to build upon best practice to ensure improvements in diabetes care are achieved consistently across Scotland, taking into account local needs and circumstances. This will require concerted effort both nationally and locally.

125. The Framework sets out a range of initiatives and ideas to support NHS boards and healthcare professionals to implement the recommendations. The main mechanism for supporting this work will be the Scottish Diabetes Group. This professionally-led expert group will provide leadership at national level, ensuring that diabetes services remain focused on the key objective – to improve care for people with diabetes. Delivering and sustaining improved standards in diabetes services will take a number of years and the Diabetes Framework itself will need to be revised and updated over the years if it is to remain a useful tool and if all aspects of diabetes care are to be addressed. The Scottish Diabetes Group will wish to monitor progress towards meeting the objectives of the Framework and to publish their findings.

126. In addition to the Scottish Diabetes Group, there will be four other mechanisms providing information about progress:

An action-focused reporting mechanism is an integral part of the **Diabetes Collaborative Improvement Programme**. Detailed information on progress will be available for the period that the Collaborative runs.

The **Clinical Standards Board for Scotland** has defined standards for the delivery of diabetes care and will be reviewing local services against those standards. The first CSBS report on diabetes services (in 2003) will provide a detailed and objective assessment of the quality of diabetes care in Scotland.

MILESTONE

The CSBS will publish an assessment of the standards of care provided by diabetes services in 2003.

The **Scottish Diabetes Survey** will provide an annual snapshot of some of the most important indicators of diabetes care. The Survey will provide an increasingly comprehensive and accurate picture of diabetes in Scotland. The next survey is due to be reported at the end of 2002 (see paragraph 117).

The **Performance Assessment Framework** (PAF) is the mandatory core framework for assessing the performance of the NHS in Scotland and forms the basis of the annual NHS Accountability Review. The PAF includes a number of indicators which are relevant to diabetes, in particular it stresses compliance with CSBS standards.

127. At a local level, the main drivers for securing implementation of the Framework objectives will be NHS boards (and their constituent parts) in conjunction with LDSAGs and managed clinical networks. Although the Framework sets out the broad objectives and the necessary scope of local developments (in particular in the 'Strategy, Leadership and Teamworking' section above), it is for local teams to work through the challenges and opportunities of their own circumstances to determine how best to proceed.

128. Other agencies, such as local authorities, schools and the pharmaceutical industry, need to consider their role and what contribution they might make to improving care and support available to people with diabetes.

Community Issues

Community Issues – Issues involving other agencies

129. In order to improve the lives of people with diabetes there is a need to focus not only on the role of the NHS and equal access to standards of health care, but on a range of 'community issues', which relate to living with diabetes. As a condition, diabetes can affect not just patients but those closest to patients – partners, parents, siblings, and friends. Diabetes also impacts on access to, for example, employment, leisure, transport, education, welfare benefits and social care services. Addressing 'community issues' is about taking a holistic view of diabetes and recognising that living with the condition is about much more than health care. These should not be seen as marginal issues. The Diabetes Framework has the potential to act as a catalyst in recognising and responding to these aspects of living with diabetes and as a means to inform different Executive agencies about community issues as they effect people with diabetes.

'It is unfair that diabetics have to apply for a driving licence every three years – why are we told we are as normal as can be by one person, then when it comes to something like our driving licence we are diabetic first, normal second?'

(Person with diabetes)

130. One of the examples of community issues raised by people with diabetes when asked by Partners in Change was food. Finding ways for people to be sure of access to reasonably priced fresh food was raised as a major issue by people in rural areas and by people in some larger housing estates. People thought there were ways in which the health services could work with other people to help people with diabetes – and everyone else in that community – live in a more healthy way, such as through food co-ops and vans in rural areas.

131. NHS organisations need to work more creatively with other agencies in order to address these issues, for example to ensure that health and social care provision for people with diabetes is as seamless as possible. The Community Planning process provides an important route for taking on many of the wider issues raised by people with diabetes and their families.

Scottish Diabetes Group

132. The Scottish Diabetes Framework Working Group was set up as a short-life group to deliver the Framework. Having delivered this report the Working Group now passes on the baton to the Scottish Diabetes Group which has been established to support and maintain the momentum of the Framework.

Table 28

Scottish Diabetes Group

The Scottish Diabetes Group will act as the national steering group to take forward the implementation of the Scottish Diabetes Framework. The following remit has been agreed:

'To act as a national steering group to co-ordinate and evaluate the implementation of the Scottish Diabetes Framework; to oversee the review and ongoing development of the national diabetes strategy; and to provide expert advice to the Department.'

The Group is chaired by Dr Andrew Morris, consultant diabetologist and Reader of Medicine at University of Dundee.

133. This Framework is not about centralist control of diabetes services – it is designed to support and promote the development of high quality diabetes services at locality level. The Scottish Diabetes Group aims to promote Scotland-wide collaboration, peer-support and dissemination of best practice. A website and an annual diabetes conference will be two mechanisms to support this.

ACTION POINT

A website to improve collation and dissemination of information about diabetes in Scotland – www.show.scot.nhs.uk/diabetes – will be established by the Scottish Diabetes Group by September 2002.

ACTION POINT

A conference to promote best practice in diabetes care (including service delivery and design, clinical IM&T, research and development, LDSAGs/managed clinical networks, and eye screening) will be hosted in Scotland in November 2002.

Conclusion

134. This Framework seeks to clarify the strategic direction for diabetes services in Scotland and to set in train a few key drivers to strengthen the infrastructure to underpin the sustained delivery of high quality care. Above all, the Framework is a pragmatic attempt to secure the support and enthusiasm of all those with an interest in diabetes. It is also a document for those who receive diabetes services – setting out the standards of care they should expect and offering opportunities to establish a model of care based upon partnership and empowerment. Teamworking is the key to improving diabetes services in Scotland. It is hoped that the strategic direction outlined will facilitate collaboration, co-operation and communication amongst the diabetes community in Scotland.

Scottish Diabetes Framework: **Annex A**

Scottish Diabetes Framework Working Group

Chairman: **Mrs Delia Henry,** National Manager, Diabetes UK Scotland

Dr David Alexander, General Practitioner, Dunfermline

Mr George Brechin, Chief Executive, Fife Primary Care NHS Trust

Dr Malcolm Campbell, General Practitioner, Kirkintilloch

Ms Sushee Dunn, Project Officer, Clinical Standards Board for Scotland

Dr Aileen Keel, Deputy Chief Medical Officer, Scottish Executive Health Department

Mr Ross Kerr, Person with diabetes, Fife

Dr Andrew Morris, Consultant Diabetologist, Tayside

Dr Moray Nairn, Programme Manager Scottish Intercollegiate Guidelines Network

Dr Lewis Reay, Consultant in Public Health Medicine, Health Technology Board for Scotland

Dr Kenneth Robertson, Consultant Paediatrician, Glasgow

Ms Mary Scott, Nurse/Diabetes Facilitator, Lothian

Ms Rona Smith, Senior Project Officer, Clinical Standards Board for Scotland

Dr Mike Small, Consultant – General Medicine, Glasgow

Ms Fiona Steven, Lead Therapist – Adult Dietetics, Edinburgh

Ms Jan Warner, Director of Reviews, Clinical Standards Board for Scotland

Secretariat: **Mr David Cline,** Scottish Executive Health Department

Ms Ruth Lockwood, Scottish Executive Health Department

Understanding Diabetes

Diabetes — or to give it its full name, ***diabetes mellitus*** — is a common condition in which the amount of glucose (sugar) in the blood is too high because the body is unable to use it properly. This is because the body's method of converting glucose into energy is not working as it should.

Normally, a hormone called insulin carefully controls the amount of glucose in our blood. Insulin is made by a gland called the pancreas, which lies just behind the stomach. It helps the glucose to enter the cells where it is used as fuel by the body.

We obtain glucose from the food that we eat, either from sweet foods or from the digestion of starchy foods such as bread or potatoes. The liver can also make glucose.

After a meal, the blood glucose level rises and insulin is released into the blood. When the blood glucose level falls (for example, during physical activity) the level of insulin falls. Insulin, therefore, plays a vital role in regulating the level of blood glucose and, in particular, in stopping the blood glucose from rising too high.

The two main types of diabetes

Type 1 diabetes (also known as insulin dependent diabetes) develops when there is a severe lack of insulin in the body because most or all of the cells in the pancreas that produce it have been destroyed. This type of diabetes usually appears in people under the age of 40, often in childhood. It is treated by insulin injections and diet.

Type 2 diabetes (also known as non-insulin dependent diabetes) develops when the body can still produce some insulin, though not enough for its needs, or when the insulin that the body produces does not work properly. This type of diabetes usually appears in people over the age of 40. It is treated by diet alone, or by a combination of diet and tablets, or by a combination of diet and insulin injections.

The symptoms of diabetes

The main symptoms of are: increased thirst; going to the loo all the time – especially at night; extreme tiredness; weight loss; genital itching or regular episodes of thrush; blurred vision.

Type 2 diabetes develops slowly and the symptoms are usually less severe. Some people may not notice any symptoms at all and their diabetes is only picked up in a routine medical check up. Some people may put the symptoms down to 'getting older' or 'overwork'.

Type 1 diabetes develops much more quickly, usually over a few weeks, and symptoms are normally very obvious.

In both types of diabetes, the symptoms are quickly relieved once the diabetes is treated. Early treatment will also reduce the chances of developing serious health problems.

Who gets diabetes and what causes it?

Although the condition can occur at any age, it is rare in infants and becomes more common as people get older.

Type 1 diabetes develops when the insulin-producing cells in the pancreas have been destroyed. Nobody knows for sure why these cells become damaged but the most likely cause is an abnormal reaction of the body to the cells. This may be triggered by a viral or other infection. This type of diabetes generally affects younger people. Both sexes are affected equally.

Type 2 diabetes used to be called 'maturity onset' diabetes because it usually appears in middle-aged or elderly people, although it does occasionally appear in younger people. The main causes are that the body no longer responds normally to its own insulin, and/or that the body does not produce enough insulin. People who are overweight are particularly likely to develop type 2 diabetes. It tends to run in families and is more common in Asian and African-Caribbean communities. Some people wrongly describe type 2 diabetes as 'mild' diabetes. There is no such thing as mild diabetes. All diabetes should be taken seriously and treated properly.

Other causes of diabetes. There are some other causes of diabetes, including certain diseases of the pancreas, but these are all very rare. Sometimes an accident or an illness may reveal diabetes if it is already there, but they do not cause it.

How is diabetes treated?

Although diabetes cannot be cured, it can be treated very successfully. Knowing why people with diabetes develop high blood glucose levels helps to understand how some of the treatments work.

Blood glucose levels. When sugar and starchy foods have been digested, they turn into glucose. If somebody has diabetes, the glucose in their body is not turned into energy, either because there is not enough insulin in their body, or because the insulin that the body produces is not working properly. This causes the liver to make more glucose than usual but the body still cannot turn the glucose into energy. The body then breaks down its stores of fat and protein to try to release more glucose but still this glucose cannot be turned into energy. This is why people with untreated diabetes often feel tired and lose weight. The unused glucose passes into the urine, which is why people with untreated diabetes pass large amounts of urine and are extremely thirsty.

Type 1 diabetes is treated by injections of insulin and a healthy diet. Type 2 diabetes is treated by a healthy diet or by a combination of a healthy diet and tablets. Sometimes people with type 2 diabetes also have insulin injections, although they are not totally 'dependent' on the insulin.

Treatments for Type 1 diabetes. People with type 1 diabetes need injections of insulin for the rest of their lives and also need to eat a healthy diet that contains the right balance of foods. Insulin cannot be taken by mouth because it is destroyed by the digestive juices in the stomach. People with this type of diabetes commonly take either two or four injections of insulin each day.

Treatments for Type 2 diabetes. People with type 2 diabetes need to eat a healthy diet that contains the right balance of foods. If diet alone is not enough to keep blood glucose levels normal, tablets may also be needed. There are several kinds of tablets for people with type 2 diabetes. Some kinds help the pancreas to produce more insulin. Other kinds help the body to make better use of the insulin that the pancreas does produce. Another type of tablet slows down the speed at which the body absorbs glucose from the intestine.

Reducing the risk of serious health problems

People with diabetes have a higher chance of developing certain serious health problems, including heart disease, stroke, high blood pressure, circulation problems, nerve damage, and damage to the kidneys and eyes. The risk is particularly high for people with diabetes who are also very overweight, who smoke or who are not physically active. The risk of developing any of these complications is greatly reduced by controlling blood glucose and blood pressure levels, and by eating healthily and doing regular physical activity.

Regular medical check-ups. In the last 10 to 20 years, the care for people with diabetes has improved dramatically. One of the most important developments has been improved methods of screening which help healthcare professionals to pick up any health problems at an early stage so they can be treated more successfully. This is why having regular medical check-ups, at least annually, is so important.

Adapted from a Diabetes UK publication. Reproduced with permission.

Scottish Diabetes Framework: **Annex C**

References and Further Reading

Amos AF, McCarty DJ, Zimmet P. 1997. The Rising Burden of Diabetes and its Complications: Estimates and Projections to the Year 2010. *Diabet Med,* 1997; **14**:S7-S85.

Clinical Resource and Audit Group. 1998. *Report of the Diabetes Registers and Diabetes IT Systems Steering Group.*
URL: http://www.show.scot.nhs.uk/crag/topics/diabetes/dsg01.htm.

Clinical Resource and Audit Group. 2000. *A Report by the Working Group on IT to Support Shared Care in Diabetes* (September 2000).

Clinical Standards Board for Scotland. 2001. *CSBS Standard for diabetes*. Edinburgh: Clinical Standards Board for Scotland (November 2001).
URL: http://www.clinicalstandards.org/pdf/Diabetes.pdf.

Cormack TG, Grant B, Macdonald MJ, Steel J, Campbell IW. 2001. Incidence of blindness due to diabetic eye disease in Fife 1990-9. *Br J Ophthalmol* 2001 Mar; **85**(3):354-6.

Currie CJ, Kraus D, Morgan CL, Gill L, Stott NCH, Peters JR. 1997. NHS acute sector expenditure for diabetes: The present, future and excess in-patient cost of care. *Diabet Med* 1997; **14**: 686-92.

Department of Health. 2001. *National Service Framework for Diabetes: Standards* (December 2001).

Diabetes UK. 2001. *What diabetes care to expect.* (June 2001).

Health Technology Board for Scotland. 2002. *Health Technology Assessment of Organisation of Services for Diabetic Retinopathy Screening* (April 2002).

Penney GC, Pearson D. 2000. A national audit to monitor and promote the uptake of clinical guidelines on the management of diabetes in pregnancy, *British Journal of Clinical Governance, 2000;* 5(**1**): 28-34.

Scottish Diabetes Framework Working Group. 2001. *Scottish Diabetes Framework: consultation paper.* Edinburgh: Scottish Executive Health Department (July 2001).

Scottish Executive Health Department. 1998. *Guidance on Clinical Governance.* NHS MEL(1998)75. Edinburgh: Scottish Executive Health Department (November 1998).

Scottish Executive Health Department. 1999. *Introduction of managed clinical networks within the NHS in Scotland.* NHS MEL(1999)10. Edinburgh: Scottish Executive Health Department (February 1999).

Scottish Executive Health Department. 1999. *Learning Together: A Strategy for Education, Training and Lifelong Learning for All Staff in the National Health Service in Scotland* (December 1999).

Scottish Executive Health Department. 2000. *Guidance on volunteering in the NHS: Implementation,* MEL(2000)4. Edinburgh: Scottish Executive Health Department (June 2000).

Scottish Executive Health Department. 2000. *Clinical Governance,* MEL(2000)29. Edinburgh: Scottish Executive Health Department (June 2000).

Scottish Executive Health Department. 2000. *Clinical negligence and other risks indemnity scheme (CNORIS).* MEL(2000)02. Edinburgh: Scottish Executive Health Department (August 2000).

Scottish Executive Health Department, Clinical Resource and Audit Group. 2000. *A report by the working group on IT to support shared care in diabetes.* Edinburgh: Clinical Resource and Audit Group (September 2000).

Scottish Executive Health Department. 2000. *Scottish diabetes survey.* HDL(2000)12. Edinburgh: Scottish Executive Health Department (September 2000).

Scottish Executive Health Department. 2000. *Our National Health: a plan for action, a plan for change.* Edinburgh: The Stationery Office (December 2000).

Scottish Executive Health Department. 2001. *Maternity Services Framework* (February 2001).

Scottish Executive Health Department 2001. *Protecting Patient Confidentiality: A consultation paper by the Confidentiality Security Advisory Group for Scotland (CSAGS)*. (July 2001).

Scottish Executive Health Department. 2001. *Coronary Heart Disease/Stroke Task Force Report*. (September 2001).

Scottish Executive Health Department. 2001. *Scottish Diabetes Framework: The blueprint for diabetes care in Scotland in the 21st century* (November 2001).

Scottish Executive Health Department. 2001. *Scottish Diabetes Survey 2001: Report by the Scottish Diabetes Survey Monitoring Group* (November 2001).

Scottish Executive Health Department. 2001. *Fair for all: Improving the Health of Ethnic Minority Groups and the Wider Community in Scotland* (December 2001).

Scottish Executive Health Department. 2001. *Patient Focus and Public Involvement* (December 2001).

Scottish Executive Health Department. 2002. *Planning Together: Final Report of the Scottish Integrated Workforce Planning Group and Response by Scottish Executive Health Department* (January 2002).

Scottish Executive Health Department. 2002. *Adding Life to Years: Report of the Expert Group on Healthcare of Older People* (January 2002).

Scottish Executive Health Department. 2002. *The Right Medicine: A Strategy for Pharmaceutical Care in Scotland* (February 2002).

Scottish Executive Health Department. Primary Care Modernisation Group. 2002. *Making the Connections: Developing best practice into common practice.* (March 2002).

Scottish Executive, Social Work Services Inspectorate. 2001. *Report of the Certification and Registration Working Group* (May 2001).

Scottish Intercollegiate Guidelines Network. 1998. *Report on a Recommended Minimum Dataset for Collection in People with Diabetes.* Edinburgh: SIGN (SIGN 25). (June 1998).

Scottish Intercollegiate Guidelines Network. 2001. *Management of diabetes: a national clinical guideline.* Edinburgh: SIGN (SIGN 55). (November 2001). URL: http://www.sign.ac.uk/pdf/sign55.pdf – *This essential synthesis of the evidence base of diabetes care includes 388 references.*

Scottish Office Department of Health. 1999. *Towards a Healthier Scotland – A White Paper on Health* (February 1999).

Scottish Office Department of Health. 1998. *Acute Services Review* (June 1998).

Scottish Office Department of Health. 1996. *Eating for Health: a Diet Action Plan for Scotland* (December 1996).

Scottish Study Group for the Care of Diabetes in the Young. 2001. Factors influencing glycaemic control in young people with type 1 diabetes in Scotland: a population-based study (DIABAUD2). *Diabetes Care* 2001; **24(2)**: 239-44.

St Vincent Joint Task Force for Diabetes. 1995. *The Report [Second report of the St Vincent Joint Task Force for Diabetes].* London: Department of Health; British Diabetic Association.

T²ARDIS (Type 2 diabetes – Accounting for a major Resource Demand in Society) Survey. 2000. *Implications for Seamless Care Provision in Type 2 Diabetes in the UK* (March 2000).

Williams R, Airey M, Gilworth G. 2001. *Integrating Diabetes Services – time to respond.* Nuffield Institute for Health, University of Leeds.

Williams R, Baxter H, Bottomley J, Biddy J, Burns E, Harvey J, Sheaves R, Young R. CODE-2 UK: our contribution to a European study of the costs of type 2 diabetes. *Pract Diab Int* 2001; **18**(7); 235-8.

World Health Organization (Europe) and International Diabetes Foundation (Europe). 1990. Diabetes care and research in Europe: the St Vincent Declaration. *Diabet Med* 1990; **7**; 360.

World Health Organization, Department of noncommunicable Disease Surveillance. 1999. Definition, diagnosis and classification of diabetes mellitus and its complications: report of a WHO consultation. Part 1: Diagnosis and classification of diabetes mellitus. Geneva: WHO (WHO/NCD/NCS/99.2).

Scottish Diabetes Framework: **Annex D**

Sources of Further Information

Scottish Executive Health Department – Scottish Diabetes Group

Contact: Chairman – Dr Andrew Morris, Reader in Medicine
University of Dundee, Ninewells Hospital, Dundee DD1 9SY

Secretary – Mr David Cline
St Andrew's House, Edinburgh EH1 3DG
Tel: 0131-244 2235
Email: david.cline@scotland.gsi.gov.uk

URL: www.show.scot.nhs.uk/diabetes

SCI-DC Steering Group (Scottish Care Information Diabetes Collaboration)

Contact: Chairman – Dr Kenneth J Robertson, Consultant Paediatrician
Yorkhill, Glasgow, G3 8SJ
Email: kjr@diabetes-scotland.org

Project Manager – Linda Napier
Trinity Park House, South Trinity Road, Edinburgh EH5 3SQ
Email: Linda.Napier@ppd.csa.scot.nhs.uk

Scottish Diabetes Survey Monitoring Group

Contact: Chairman – Dr John McKnight, Consultant Physician
Western General Hospital, Crewe Road, Edinburgh EH4 2XU
Email: john.mcknight@talk21.com

Diabetes UK

Contact: Ms Delia Henry, National Manager, Diabetes UK Scotland
Savoy House, 140 Sauchiehall Street, Glasgow G2 3DH
Tel: 0141-332 2700
Email: scotland@diabetes.org.uk

URL: www.diabetes.org.uk

CSBS – Clinical Standards Board for Scotland

Contact: Ms Jan Warner, Director of Reviews
Elliott House, 8-10 Hillside Crescent, Edinburgh EH7 5EA
Tel: 0131-623 4293
Email: comments@clinicalstandards.org

URL: www.clinicalstandards.org

SIGN – Scottish Intercollegiate Guidelines Network

Contact: Ms Juliet Miller, Director
Royal College of Physicians, 9 Queen Street, Edinburgh EH2 1JQ
Tel: 0131-247 3660

URL: www.sign.ac.uk

HTBS – Health Technology Board for Scotland

Contact: Professor Karen Facey, Director
Delta House, 50 West Nile Street, Glasgow G1 2NP
Tel: 0141-225 6999
Email: enquiries@htbs.org.uk

URL: www.htbs.org.uk

Tayside Regional Diabetes Network

Contact: Mrs Karen Hunter, Managed Clinical Network Co-ordinator
Ninewells Hospital, Dundee DD1 9SY
Email: : karen@memo.dundee.ac.uk

URL: www.diabetes-healthnet.ac.uk

Scottish Study Group for the Care of Diabetes in the Young

Contact: Secretary – Dr Kenneth J Robertson, Consultant Paediatrician
Yorkhill, Glasgow G3 8SJ

URL: www.diabetes-scotland.org

Scottish Diabetes Specialist Podiatrists Group

Contact: Chairman – Mr Duncan Stang, Chief Podiatrist
Hairmyres Hospital, Eaglesham Road, East Kilbride G75 8RG
Tel: 01355 220292
Email: duncan.stang@lanpct.scot.nhs.uk

SCI (Scottish Care Information)

Contact: Ms Anne Lamont, SCI Programme Co-ordinator
Trinity Park House, South Trinity Road, Edinburgh EH5 3SQ
Tel: 0131-551 8456

URL: www.show.scot.nhs.uk/sci

GPASS – General Practice Administration System for Scotland

Contact: Mr Martin Irving, GPASS Development Director
GPASS, Seaforth House, Seaforth Road, Hillington,
Glasgow G52 4SQ
Tel: 0141-882 9996

URL: www.show.scot.nhs.uk/gpass

Scottish Diabetes Framework

Clinical Effectiveness Programme in Practice Based Primary Care

Contact: Dr Colin Hunter, Chairman of Clinical Effectiveness Programme
Quality Department, RCGP Scotland, 25 Queen Street,
Edinburgh EH2 1JX
Tel: 0131-260 6800

URL: www.ceppc.org

SCIMP – Scottish Clinical Information Management in General Practice

Contact: Dr Libby Morris, Chairman SCIMP
Royal College of General Practitioners, 25 Queen Street,
Edinburgh EH2 1JX
Tel: 0131-260 6800

URL: www.show.scot.nhs.uk/scimp

CRAG – Clinical Resource and Audit Group

Contact: Dr Alison Bramley, Head of CRAG Secretariat
St Andrew's House, Edinburgh EH1 3DG
Tel: 0131-244 2353

URL: www.show.scot.nhs.uk/crag

CSO – Chief Scientist Office

Contact: Dr Roma Armstrong, Research Manager
St Andrew's House, Edinburgh EH1 3DG
Tel: 0131-244 2255

URL: www.show.scot.nhs.uk/cso

HEBS – Health Education Board for Scotland

Contact: Mr Graham Robertson, Acting Chief Executive
Woodburn House, Canaan Lane, Edinburgh EH10 4SG
Tel: 0131-536 5500

URL: www.hebs.scot.nhs.uk

ISD – Information and Statistics Division

Contact: Mr Richard Copland, Director
Trinity Park House, South Trinity Road, Edinburgh EH5 3SQ
Tel: 0131-551 8899 (Customer Liaison)

URL: www.show.scot.nhs.uk/isd

ABPI – Association of the British Pharmaceutical Industry Scotland

Contact: Kim Fellows
The Royal College of Physicians, 9 Queen Street, Edinburgh
EH2 1JQ
Tel: 0131-247 3688

URL: www.abpi.org.uk

Electronic Medicines Compendium

The eMC provides free access to up-to-date, comprehensive and reliable information about prescription and over-the-counter medicines available in the UK.

URL: http://emc.vhn.net

Clinical Security Advisory Group for Scotland (CSAGS)

The Group's remit is 'to provide advice on the confidentiality and security of personal health related information to the Scottish Executive, the Public and to Health Care Professionals'.

URL: www.show.scot.nhs.uk/csags

UK National Screening Committee (NSC)

UK organisation providing advice on all aspects of screening policy.

URL: www.nsc.nhs.uk

Scottish Diabetes Framework: **Annex E**

Glossary of Terms

Term	Definition
accountability	The process of reporting on discharge of responsibilities and tasks incurred by the position within an organisation.
accreditation	A process based on a system of external peer review using written standards, designed to assess the quality of an activity, service or organisation.
ACE inhibitors	Angiotensin Converting Enzyme inhibitors are a group of drugs which lower blood pressure and expand the blood vessels.
acute myocardial infarction	Scientific term for a heart attack, which occurs when a blood vessel to the heart becomes blocked, usually by a blood clot, resulting in damage to the heart muscle.
acute sector	Hospital-based health services which are provided on an in-patient or out-patient basis. Also known as 'secondary care'.
amputation	Surgical removal of part or all of a limb.
angina	Discomfort in the chest, jaw or arm which often occurs on exercise and which is due to a reduced blood supply to the heart.
angioplasty	Angioplasty is a method of treating patients suffering from arterial disease. In coronary angioplasty, narrowed or blocked arteries in or around the heart are opened by inflating a balloon at the tip of a catheter. Peripheral angioplasty is a similar procedure for the treatment of vascular disease in other areas of the body.
arteries	Blood vessels which carry blood away from the heart to supply the tissues.
aspirin	A medication which thins the blood to prevent clots forming. It is the most widely tested antiplatelet agent and inhibits cyclo-oxygenase-dependent platelet aggregation.
assay	Determination of the purity of a substance or the amount of any particular constituent of a mixture.
assessment	The process of measuring the quality of an activity, service or organisation.
audit	The process of setting or adopting standards and measuring performance against those standards with the aim of identifying both good and bad practice and implementing changes to achieve unmet standards.
BDR	Background Diabetic Retinopathy.

beta blocker	A group of drugs which can be used to treat raised blood pressure.
blood glucose	A measurement of the amount of sugar in the blood.
blood pressure	Blood pressure is related to the force of the heart pumping and the resistance to the flow of blood through the body. It is the pressure of the blood in the main arteries needed to push it through the smaller vessels of the circulation.
BMI	Body Mass Index. A measurement of weight in relation to height.
cardiologist	Specialist doctors who treat patients with heart conditions.
cardiovascular status	The status of the heart and blood vessels.
carer	A person, paid or unpaid, who regularly helps another person, often a relative or friend with all forms of care as a result of illness or disability. This term incorporates spouses, partners, parents, guardians, paid carers, other relatives, and voluntary carers who are not health professionals.
case record	Patient's notes; documentation of care.
CHD	See coronary heart disease.
cholesterol	Fatty substance needed by the body as a building block for tissues and chemical processes. Cholesterol is an important constituent of atheroma.
chronic	Present over a long period of time. Diabetes is an example of chronic disease.
circulation	The flow of blood through the heart and blood vessels of the body.
clinical governance	A framework through which NHS organisations are accountable for continuously improving the quality of their services and safeguarding high standards of care by creating an environment in which excellence in clinical care will flourish. *Source: DEPARTMENT OF HEALTH – NHS WHITE PAPER: A FIRST-CLASS SERVICE (1998).*
clinical management system	A collection of core information from individuals relating to their care which allows ongoing useful clinical information to be recorded for use in direct patient care and service audit. (See also Register).
clinical review	A method of detecting specified disease in a targeted population at a stage where the individuals have no symptoms.

clinical service	In some cases this means looking at the services provided for people with a particular condition or diagnosis (e.g. diabetes), in other cases, at those services relating to a range of manifestations (e.g. coronary heart disease).
clinical trial	Research study conducted with patients, usually to evaluate a new treatment or drug. Each trial is designed to answer scientific questions and to find better ways to treat individuals with a specific disease.
CNORIS	Clinical Negligence and Other Risk Indemnity Scheme. Has two principle aims: (1) financial efficiency through costs effectiveness risk pooling and claims management; (2) effective risk management by encouraging a rigorous approach to treatment of risk.
compliance	A measure of how conscientiously a person carries out advice tailored for that individual's benefit. For example, a situation where clinician and patient are in agreement about the best course of action and the patient carries out the plan by taking tablets or injections.
co-morbidity	The presence of co-existing or additional diseases with reference to either an initial diagnosis or the index condition that is the subject of study. Co-morbidity may affect the ability of affected individuals to function and also their survival; it may be used as a prognostic indicator for length of hospital stay, cost factors, and outcome or survival.
Contraindication	Any condition, past or present, which makes a particular line of treatment unsuitable or undesirable.
coronary arteries	The blood vessels that supply the blood and oxygen to the heart muscle.
coronary heart disease	CHD. Disease, such as angina, coronary thrombosis or heart attack, caused by the narrowing or blockage of the coronary arteries by atheroma.
CRAG	Clinical Resource and Audit Group.
criteria/criterion	Criteria provide the more detailed and practical information on how to achieve the standard and can be described as structure, process and outcome criteria.
CSBS	Clinical Standards Board for Scotland.
data source	The source of evidence to demonstrate whether a standard or criterion is being met.
DCCT compatible assay	Diabetes Control and Complications Trial compatible assay. A standardisation which allows comparison of glycated haemoglobin (HbA1c) results between different laboratories.

default	Failure to participate in something which is required.
desirable (criteria/ criterion)	Good practice that is being achieved in some parts of the service and demonstrates levels of quality to which other providers of a similar service should strive.
diabetes mellitus	A condition in which the amount of glucose (sugar) in the blood is too high because the body cannot use it properly.
diabetic emergency	An acute diabetic episode including hypoglycaemia and diabetic ketoacidosis resulting in admission to hospital.
diabetic ketoacidocis	A life-threatening metabolic emergency resulting from absolute insulin deficiency. Lack of insulin results in abnormal metabolism of carbohydrate and fat, and accumulation of by-products called ketones, which are acidic. The acidosis may lead to coma and death if not promptly treated.
diagnosis	Identification of an illness by means of its signs and symptoms. This involves ruling out other illnesses and causal factors for the symptoms.
diastolic (blood pressure)	Two levels of blood pressure are measured: the higher, or systolic, pressure, which occurs each time the heart pushes blood into the vessels, and the lower, or diastolic, pressure, which occurs when the heart rests. In a blood pressure reading of 120/80, for example, 120 is the systolic pressure and 80 is the diastolic pressure.
dietitian	An expert in nutrition who helps people with special health needs plan the types and amounts of foods to eat.
digital camera	A camera which captures images which can be digitised, stored and transmitted using microprocessor technology.
discharge summary	A letter, usually sent from a hospital to a patient's GP once the patient has been discharged, containing information relating to the patient's admission to hospital such as the reason for admission, diagnosis and what happened to the patient whilst in hospital.
DKA	See diabetic ketoacidocis.
end organ damage	The results of a disease process that affects the structure and function of a number of body organs.
end stage renal disease	When a person's kidneys fail to work. The treatment options for ESRD are: heamodialysis, peritoneal dialysis, and kidney transplantation. Untreated, severe renal disease leads to death. (See also 'nephropathy')

essential (criteria/ criterion)	A criterion that should be met wherever a service is provided.
evidence-based	The process of systematically finding, appraising, and using contemporary research findings as the basis for clinical decisions.
fibrovascular proliferation	One result of a disease process which affects blood vessels and surrounding tissue.
funduscopy	Examination of the fundus (the retina) of the eye through the pupil using a hand-held instrument.
gangrene	The death of body tissue. It is most often caused by a loss of blood flow, especially in the legs and feet.
generic standards	Standards that apply to most, if not all, clinical services.
gestational diabetes	A form of diabetes which begins during pregnancy and usually disappears following delivery.
glomerular filtration rate	Measure of the kidneys' ability to filter and remove waste products.
glycated haemoglobin	A test that sums up how well controlled diabetes has been in the preceding three to four months. (HbAlc)
GP	General Practitioner.
GPASS	General Practice Administration System for Scotland.
guideline	Systematically developed statements to guide treatment decisions.
HbA1c	See glycated haemoglobin.
HDL	Health Department Letter. Superseded previous series of MELs – Management Executive Letters.
healthcare professional	A person qualified in a health discipline.
heart attack	Non-medical term for a sudden serious disorder of the heart when part of the heart muscle can be damaged. Usually this refers to coronary thrombosis.
heart failure	A condition in which the pumping action of the heart is inadequate.
HEBS	Health Education Board for Scotland.
HTBS	Health Technology Board for Scotland.
hormone	A circulating chemical messenger made in one part of the body and acting on other parts.
hyper-cholesterolaemia	High level of cholesterol.

hyperlipidaemia	High level of fats (lipids) in the blood.
hyperosmolar non-ketotic state	A complication of diabetes caused by a lack of insulin and dehydration. It is diagnosed when the patient has: 1. very high levels of glucose (sugar) in the blood; 2. absence of ketoacidocis; 3. severe dehydration.
hypertension	High blood pressure which, if uncontrolled, can increase the risk of heart disease or stroke.
hypoglycaemia	Hypoglycaemia (hypo) occurs when blood glucose levels are low; below 4mmol/l.
IM&T	Information Management and Technology.
incidence	How often a disease occurs; the number of new cases of a disease among a certain group of people over a specific period of time.
infarct	Part of an organ which has died because its blood supply is cut off. Usually refers to the dead part of the heart muscle after a coronary thrombosis.
informed consent	Consent obtained freely and without coercion, after appropriate and understandable information has been given and questions answered.
insulin	A hormone secreted by the pancreas. Insulin regulates the blood glucose level, and is important for growth and tissue repair.
insulin therapy	Treatment using insulin in patients with diabetes following trauma to the body such as a heart attack.
integration	Shared or overlapping processes which result in a stronger whole. For example, a situation where all aspects of care are connected and all healthcare professionals are working together.
ischaemia	Poor blood supply, usually because of narrowing or blockage of an artery.
Joint British Societies Coronary Risk Prevention Chart	Validated information produced in the form of a chart which is used by healthcare professionals to predict a person's risk of developing coronary heart disease taking into account several different risk factors.
ketoacidosis	See diabetic ketoacidosis.
ketones	A breakdown product of fat that accumulates in the blood as a result of inadequate insulin or inadequate calorie intake.
laser treatment	Using a special strong beam of light of one colour (laser) to heal a damaged area. A person with diabetes might be treated with a laser beam to heal blood vessels in the eye.

lead consultant	Clinician with administrative responsibilities for a specific service.
LHCC	In Scotland, Local Health Care Co-operatives are voluntary groupings of GPs and other local health care professionals intended to strengthen and support the primary health care team in delivering local care.
Local diabetes service advisory group (LDSAG)	A strategic planning group of local diabetes service users, carers and providers who advise NHSScotland Boards in matters relating to services for individuals with diabetes.
macula	The area of the retina that is the centre of sight.
macular oedema	Fluid in the part of the retina that is at the centre of sight. It may be a result of leaking small vessels causing fluid to accumulate around the cells of the retina or may be a result of sick and dying cells ballooning up because they are starved of oxygen and food.
managed clinical networks	Linked groups of health professionals and organisations from primary, secondary and tertiary care, working in a co-ordinated manner, unconstrained by existing professional and NHS Board boundaries, to ensure equitable provision of high quality clinically effective services throughout Scotland.
medication	Drugs prescribed to treat a condition.
medicines management	Organisation of various medications involving the timing, frequency and period of treatment.
meta-analysis	Statistical method to combine the outcomes of more than one randomised clinical trial.
micro-albuminuria	Leakage of small amounts of protein (albumin) into the urine. An early warning of kidney damage.
micro-vascular	Something that concerns small blood vessels.
macro-vascular	Something that concerns large blood vessels.
mmhg	Millimetres of mercury: A measurement of blood pressure.
mmol/l	Millimoles per litre. Unit for measuring the concentration of glucose, lipids (fats) and other substances circulating in the blood.
morbidity	The incidence of a particular disease or group of diseases in a given population during a specified period of time.
mortality	The number of deaths in a given population during a specified period of time.

multidisciplinary	A multidisciplinary team is a group of people from different disciplines (both healthcare and non-healthcare) who work together to provide care for patients with a particular condition. The composition of multidisciplinary teams will vary according to many factors. These include: the specific condition, the scale of the service being provided and geographical/ socio-economic factors in the local area.
multidisciplinary system of working	A method of working in a multidisciplinary team with protocols in place for most, if not all, eventualities.
mydriasis	Dilation of the pupil of the eye by the insertion of drops.
nephropathy	Kidney damage from any cause; quite often diabetes. (See also 'end stage renal disease')
neuropathy	Nerve disease. Neuropathy is one of the long-term complications of diabetes. Nerve damage can affect many parts of the body. The most common form is called peripheral neuropathy, and usually affects the longest nerves first: those that supply the feet and legs. Neuropathy may cause numbness, tingling or pain in the feet or legs. Other types of neuropathy may impair digestive or sexual function, or cause pain.
NHS 24	National, nurse-led triage and health information service.
NHS boards	The role of NHS boards is to ensure the efficient, effective and accountable governance of the local NHS system. There are 15 NHS boards in Scotland.
obesity	Condition of being grossly overweight at least 20% heavier than the heaviest weight in the 'ideal' range for that person's height. Obesity is defined as BMI greater than 25 kg/m^2 or waist greater than 32" for women, 37" for men.
oedema	A collection of fluid.
ophthalmologist	A medical doctor specially trained to diagnose and treat disorders of the eye. An ophthalmologist is qualified to prescribe medication, prescribe and adjust spectacles and contact lenses and is usually qualified to perform laser treatment and surgery.
optician	Fits, supplies and adjusts spectacles and contact lenses. An optician cannot examine the eyes or prescribe spectacles or medication.
optometrist	Although not a doctor of medicine, an optometrist is specifically trained to diagnose eye abnormalities and prescribe, supply and adjust spectacles and contact lenses.

outcome	The end result of care and treatment. In other words, the change in health, functional ability, symptoms or situation of a person, which can be used to measure the effectiveness of care and treatment.
outpatient	A patient reviewed in a hospital but who does not need to be admitted to the hospital.
PAF	Performance Assessment Framework.
PAM	See professions allied to medicine.
Partners in Change	A programme of national and local projects designed to promote the involvement of patients throughout NHSScotland.
patient	A person who is receiving medical treatment (especially in a hospital). Also, a person who is registered with a doctor, dentist, etc and is treated by him/her when necessary. Sometimes referred to as user.
patient journey	The pathway taken through the healthcare system by the patient and as viewed by the patient.
PCMG	Primary Care Modernisation Group. Scottish Executive group supporting the development of LHCCs.
PCRG	Primary Care Reference Group. Established to help the CSBS ensure that the component of care delivered to patients outside hospitals is included in its standards and to promote the accreditation of general practices.
PCT	Primary Care Trust.
peer review	Review of a service by those with expertise and experience in that service, either as a provider, user or carer.
peripheral vascular disease	Disorder affecting the blood vessels in the body preventing the ready supply of oxygenated blood to the peripheral parts of the body.
photo-coagulation	Using a special strong beam of light (laser) to seal off bleeding blood vessels such as in the eye. The laser can also burn away blood vessels that should not have grown in the eye. This is the main treatment for diabetic retinopathy.
placebo	Dummy treatment which is given to some of the volunteers participating in a clinical trial. Patients can feel better even when the treatment they are given is a ‘sugar pill’ or placebo.
plan of care	A written agreement which is developed with the user, and which details the roles and responsibilities of all individuals involved in the person’s care and when their care arrangements are to be reviewed.

podiatrist/ chiropodist	Person with expert knowledge in foot care.
polyuria	The passing of large volumes of urine usually due to excess glucose in the bloodstream. It is hence a symptom of untreated diabetes.
prescription	Usually a written recipe of treatment.
pressure relief	A means of redistributing gravitational force to prevent further tissue damage.
prevalence	The number of existing cases of a disease among a detain group of people, usually at a specified point in time.
primary care	The conventional first point of contact between a patient and the NHS. This is the component of care delivered to patients outside hospitals. It is typically, though by no means exclusively, delivered through general practices, and is the service most often used by a patient.
primary prevention	The prevention of the development of a condition, such as coronary heart disease, by avoidance of factors known to contribute to its development, for example, smoking and lack of exercise.
professions allied to medicine	Healthcare professionals directly involved in the provision of primary and secondary healthcare. Includes several groups such as physiotherapists, occupational therapists, dietitians, etc.
prognosis	An assessment of the expected future course and outcome of a person's disease.
proliferative retinopathy	Diabetes can cause small blood vessels to block off resulting in the retina being starved of food and oxygen. If enough small blood vessels block, then the eye tries to grow new blood vessels (proliferative retinopathy) that are prone to bleeding and pulling of the retina.
prophylactic medication	Drugs prescribed to prevent something happening.
prophylaxis	The prevention of disease; preventive treatment.
protein	One of the three main classes of food. Proteins are made of amino acids, which are called the building blocks of the cells. The cells need proteins to grow and to mend themselves. Protein is found in many foods such as meat, fish, poultry, and eggs.
proteinuria	Too much protein in the urine. This may be a sign of kidney damage.

protocol	A policy or strategy which defines appropriate action. Also covers the adoption, by all staff, of national or local guidelines to meet local requirements in a specified way.
psychological	Relating to human behaviour.
quality assurance	Improving performance and preventing problems through planned and systematic activities including documentation, training and review.
randomised	Randomly allocated to one of more than one different choices.
rationale	Scientific/objective reason for taking specific action.
RCGP	Royal College of General Practitioners.
RCT	Randomised, controlled trial
referral	The process by which a patient is transferred from one professional to another, usually for specialist advice.
register	At its simplest, a list. However, the term is often used interchangeably in 'clinical management system'.
renal	A term that means relating to the kidneys.
renal failure	An abnormality resulting from the inability of the kidneys to function and resulting in a build-up of poisons in the body.
renal function	A measure of how well a person's kidneys are working to remove waste products from the body.
renal impairment	A reduction in the ability of the kidneys to carry out their functions.
retinal photography	Use of a camera to take pictures of the surface of the retina.
retinopathy	Damage to the retina at the back of the eye. Retinopathy is one of the possible long-term complications of diabetes. The retina contains many small blood vessels that can be injured by high blood glucose and high blood pressure.
risk factor	A clearly defined occurrence or characteristic that increases the possibility that a person will get a disease.
SCI-DC	Scottish Clinical Information Diabetes Collaboration.
Scottish Diabetes Survey	A Scottish Executive initiative attempting to build a national register of people with diabetes and to monitor diabetes care, with the aim of facilitating better healthcare.

Scottish Executive	The devolved government for Scotland. It is responsible for most of the issues of day-to-day concern to the people of Scotland, including health, education, justice, rural affairs and transport.
secondary prevention	Encompasses the identification and modification of risk factors following an acute event, in order to reduce the likelihood of recurrence.
SEHD	Scottish Executive Health Department.
self-assessment	Assessment of performance against standards by individual clinical teams and/or Trusts providing the service to which the standards are related.
serum creatinine	A biochemical measurement or test of one of the body's waste products which is an indicator of renal function.
side-effect	A side-effect is an unpleasant and unwanted effect of drug treatment.
SIGN	Scottish Intercollegiate Guidelines Network.
slit lamp	A method of examining the structures of the eye using a special microscope.
SPICE-PC	Scottish Programme for Improving Clinical Effectiveness in Primary Care.
standard statement	An overall statement of desired performance.
statutory	Enacted by statute; depending on statute for its authority; as a statutory provision.
St Vincent Declaration	The main aim of the St Vincent Declaration is to reduce the serious health problems linked to diabetes, such as blindness, renal failure, amputation and coronary heart disease, through governmental and healthcare team initiatives.
systolic (blood pressure)	Two levels of blood pressure are measured: the higher, or systolic, pressure, which occurs each time the heart pushes blood into the vessels, and the lower, or diastolic, pressure, which occurs when the heart rests. In a blood pressure reading of 120/80, for example, 120 is the systolic pressure and 80 is the diastolic pressure.
tractional retinal detachment	When the surface of the back of the eye becomes separated from the underlying structures by new blood vessels.
type 1 (insulin-dependent) diabetes	Type 1 diabetes develops if the body is unable to produce any insulin. This type of diabetes usually presents before the age of 40. It is treated by insulin injections and diet.

type 2 (non-insulin-dependent) diabetes	Type 2 diabetes develops when the body can still make some insulin, but not enough, or when insulin that is produced does not work properly (known as insulin resistance). This type of diabetes usually appears in people over the age of 40, though often appears before the age of 40 in the South Asian and African-Caribbean population. It is treated by diet alone or by diet and tablets or, sometimes, by diet and insulin injections.
ulceration	Breaks or deep sores in the skin.
urinary albumin concentration	A measure of how much albumin (protein) leaks from the blood into urine as a result of one or more disease processes in the kidneys.
visual acuity	A measure of how well a person sees distant and close objects.
vitrectomy	An operation to remove the blood that sometimes collects at the back of the eyes when a person has eye disease.
vitreous haemorrhage	Bleeding into the fluid in the middle of the eye from new blood vessels arising from a disease process at the back of the eye.