

National Overview ~ *March 2004*

# Diabetes

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## **Diabetes**

# Introduction and Acknowledgements

NHS Quality Improvement Scotland (NHS QIS) was established as a Special Health Board on 1 January 2003 as a result of bringing together the Clinical Resource and Audit Group (CRAG), Clinical Standards Board for Scotland (CSBS), Health Technology Board for Scotland (HTBS), Nursing and Midwifery Practice Development Unit (NMPDU) and the Scottish Health Advisory Service (SHAS).

The purpose of NHS QIS is to improve the quality of healthcare in Scotland by setting standards and monitoring performance, and by providing NHSScotland with advice, guidance and support on effective clinical practice and service improvements.

A part of this remit is to develop and run a national system of quality assurance of clinical services. For each service, NHS QIS establishes a project group to:

- develop and consult on the standards and self-assessment framework;
- oversee the process of external peer review; and
- report findings to the NHS QIS Board.

The Diabetes Standards Subgroup was established in May 2001 under the chairmanship of Dr Malcolm Campbell, General Practitioner, Greater Glasgow, and Director of Quality Standards, Royal College of General Practitioners. Membership of the Subgroup is given in Appendix 1.

The *Clinical Standards for Diabetes* (2nd ed.) were developed by this Subgroup and published in October 2002 following extensive consultation. Copies of the standards are available on request from NHS QIS or on the website ([www.nhshealthquality.org](http://www.nhshealthquality.org)).

Peer review visits to all NHS Board areas in Scotland were conducted between February 2003 and September 2003 to assess performance against the standards. A local report on each NHS Board visit, including a detailed assessment of their performance against each standard, has also been published and is available on the website or on request from NHS QIS.

This report presents a national overview of diabetes services in Scotland, reporting on performance across Scotland against the standards and including relevant examples of local initiatives.

NHS QIS gratefully acknowledges the work of the Diabetes Standards Subgroup for overseeing the project from its inception to the publication of this report. In addition, the contribution made by every member of the peer review teams was crucial to the success of the visit programme. NHS QIS would like to thank, in particular, the review team leaders: Dr Malcolm Campbell, Dr Leslie Cruickshank, Dr John McKnight, Dr David Matthews, and Dr Mike Small.

To those NHSScotland staff who contributed to the peer review visits, NHS QIS wishes to record its thanks; in particular, the local review facilitators, liaison co-ordinators, and lead clinicians in NHS Board areas who were responsible for preparing staff locally for peer review visits and for the compilation of comprehensive self-assessment material prior to visits.

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# Executive Summary

## Introduction

Diabetes is a Greek word meaning literally 'passing through'. It was used to describe one of the more distressing symptoms of the condition, the passing of excessive amounts of urine, and the first references to the disease in medical texts were as long ago as 1425. At that time, the disease and its treatment were not well understood but it can now be treated very successfully, although as yet, it cannot be cured.

Over 150,000 people in Scotland have diabetes and it is estimated that up to a further 90,000 may have the disease but do not know it. It has been described as "...Scotland's epidemic for the 21st Century", and health statistics indicate that the number of people with diabetes is doubling every decade. Treating diabetes and its complications uses almost 10% of the total NHS budget. If diabetes is well managed, people can live a normal life. However, it is associated with many other problems, is the biggest cause of adult blindness in the working population, and is linked to early death from heart disease.

Diabetes is a condition that occurs when glucose (sugar) stays in the blood and cannot get into the body's cells. Glucose is the body's main fuel - everyone needs it to give them energy. It comes from digesting starchy foods, such as bread, rice or potatoes, from sugar and other sweet foods, and it is also made by the liver. The glucose then enters the cells that make up every organ and function of the body and provide the energy needed for them to thrive. In order for glucose to enter the cells, the pancreas produces a hormone called insulin. If somebody has diabetes, the glucose in their body cannot enter the cells and is not turned into energy, either because there is no insulin, or not enough in their body, or because the insulin that is produced is not working properly. The liver then tries to help by making even more glucose but the body still cannot turn the glucose into energy. It then starts to break down its stores of fat and protein to try and release more glucose, but still this glucose cannot be turned into energy. The unused glucose then passes into the urine and this is why many people with untreated diabetes pass large amounts of urine and are very thirsty. They also feel tired and often lose weight.

There are two types of diabetes:

- **Type 1 diabetes**, which is also known as insulin-dependent diabetes, develops if the body is unable to produce any insulin. Type 1 diabetes usually appears before the age of 40, but may occur at any age. It is not known why or how the insulin-producing cells in the pancreas get damaged, but the most likely cause is an abnormal reaction of the body to these cells, which may be triggered by a virus or other infection. Type 1 diabetes is treated by injections of insulin and a healthy diet.

- **Type 2 diabetes** develops when the body can still make some insulin, but not enough, or when the insulin that is made does not work properly (known as insulin resistance). This type of diabetes usually appears in people over the age of 40 and is sometimes referred to as 'maturity onset diabetes'. It is treated by diet and exercise alone, or by diet, exercise and tablets that help the pancreas to produce more insulin, or to make better use of the insulin it does produce. Many people with Type 2 diabetes eventually require insulin therapy.

The three main aims of treatment are:

- good glucose control;
- to decrease vascular risk; and
- inclusion in a screening programme.


People with diabetes carry out simple blood or urine tests to measure glucose levels and then adjust their insulin and diet accordingly. This, together with a healthy lifestyle, will protect against long-term damage to the eyes, kidneys, nerves, heart and major arteries.

### **Clinical Standards for Diabetes**

The care of people with diabetes is complex for two reasons:

- While routine care is needed, there is also an emphasis on continual checking up to make sure any damage is spotted early and treated. This level of care is about picking up and acting on early warnings, and about prevention - keeping the person with diabetes as healthy as possible, for as long as possible.
- Many different providers and specialties are involved, including GPs, diabetologists (physicians with specialist knowledge of diabetes), diabetes specialist nurses, podiatrists (feet), dietitians, ophthalmologists (eyes), cardiologists (heart), nephrologists (kidneys), pharmacists and psychologists. Information about each patient is collected from a number of sources and has to be continually sifted and monitored. If any part of the care-chain is left out, vital information may be missing and longer term damage could be caused.

Diabetes care in Scotland has a high profile and in 2001, the Scottish Executive Health Department (SEHD) set up the Scottish Diabetes Framework Working Group to develop a Framework for diabetes services. The *Scottish Diabetes Framework* was published in 2002, and high quality care is at the heart of each element of the Framework. One of the recommendations of the Group was that clinical standards were developed to allow the monitoring of care, and a multidisciplinary



subgroup was established to take this forward. Recognising the complexity of care, the standards they produced focused on the key elements of diabetes care:

- **Organisation - Clinical Management and the Co-ordination of Care** (Standards 1 & 2) which covers the systems that need to be in place to record information about people with diabetes to plan, provide, support and monitor co-ordinated and effective care;
- **Patient Focus** (Standard 3) which covers information and education for patients, as well as their involvement in their care; and
- **Clinical Review and Management** (Standards 4-10) which relates to the regular review of key indicators and management of any issues that are picked up, particularly in relation to eyes, cardiovascular status, feet, kidneys and acute management in the event of diabetic emergencies.

The standards were developed after wide consultation which was carried out in association with the Scottish arm of Diabetes UK. The standards mainly apply to adults, although the principles read across to diabetes in childhood. Each NHS Board area in Scotland has now been visited and their performance against these standards has been assessed. This executive summary highlights the key findings of these visits, describing the strengths and challenges across the three broad areas in which standards are set. More detailed findings are reported in Chapter 2 of this report.

Diabetes is a life-long condition. It affects people with diabetes and their families and friends and can result in serious health and psychological problems. Lifestyles have to be adapted to manage diabetes, including the patient's social life. Healthwise, diabetes can lead to blindness, loss of limbs, heart failure, kidney failure and sexual health issues. Managing diabetes well greatly reduces the risk of the above complications. Patients and those caring for them build long-term relationships and these are the platform for effective care. Generally, it was clear to the many healthcare professionals involved in the visits that people with diabetes in Scotland receive a high standard of care, and many examples of good practice were identified. However, there was a lot of variation in the way information is collected and performance is monitored locally and nationally, and this made it difficult on occasion to assess performance.

## Organisation - Clinical Management and the Co-ordination of Care (Standards 1 & 2)

NHS Boards are responsible for making sure that effective and high quality care is provided to all people with diabetes living in their area. As this involves a range of different services and specialties delivered in a variety of NHSScotland settings, co-ordination lies at the heart of diabetes care. **Standard 1** focuses on the need to register all people with diabetes on an up-to-date population-based electronic clinical management system. Without this basic first step, NHS Boards will not know who requires what treatment or whether they have received it. An exciting development is under way in Scotland - the Scottish Care Information - Diabetes Collaboration (SCI-DC: pronounced: 'sky'-DC). This system is shared across primary and secondary care and maintains an up-to-date shared record which includes core information on every patient and is available to all those involved in the care of that patient. It is web-based, and automated overnight transfers of information means that there is rapid, online access to test results and other information.

At the time of the visits only one NHS Board had SCI-DC in place, as there have been some delays in implementing it across Scotland. Whilst other NHS Boards had some form of register in place, these relied on multiple data entry across incompatible systems and did not support rapid access to up-to-date information. In some areas, data was nearly 2 years out of date. Most NHS Boards are participating in the Scottish Diabetes Survey, which was set up to record the number of cases of diabetes and the frequency of clinical reviews, although there was little evidence of NHS Boards using the information collected for audit or quality assurance. No NHS Board had in place a system for call and recall for screening/review and review of diabetic complications, although it is envisaged that SCI-DC will help to achieve this in time.

**Standard 2** focuses on the infrastructure supporting the delivery of care and the way in which this care is provided. Review teams found that few NHS Boards had a local strategy and implementation plan in place, although many were working on this. Whilst all NHS Boards had a Local Diabetes Service Advisory Group (LDSAG), not all of them were considered effective, and poor attendance at key meetings was highlighted in more than one NHS Board. Problems in establishing accountability and communications within the context of the wider NHS Board structure was proving a major barrier for several LDSAGs. The review visits also found a bewildering array of guidelines for shared care, referral and discharge between primary care and specialist diabetes teams.



## Strengths

- The development of a national system that, over time, will form a national register of everyone with diabetes, support their care by running call-recall for screening and review, and will collect information that can be shared on an online, rapid access basis.
- All patients have personal care plans.

## Challenges

- Implementing SCI-DC across Scotland.
- Implementing routine call-recall for screening and review.
- Using the data collected to improve the quality of care.
- Strengthening collaboration across primary and secondary care - SCI-DC should support this.
- Clarifying accountability of LDSAGs within the context of the NHS Board clinical governance structure.

## Recommendations

- All NHS Boards should put in place a detailed project plan to implement SCI-DC. This plan should be based on realistic timescales and include training and induction for all key staff.
- SEHD should ensure that the SCI-DC team are resourced to support full scale roll out of the system.
- NHS Boards should review the potential of patient-held care plans.
- NHS Boards should review the role and function of their LDSAGs.

## Patient Focus (Standard 3)

This standard is key to diabetes care. It covers access to information and support, education programmes, and patient's involvement in their care. There is good evidence that better outcomes can be achieved if people with diabetes are involved in their care and are provided with clear information about the condition and how to manage it. This is particularly true for children and effective education at that stage usually develops a confidence and assurance that reduces long-term problems.

While there was good evidence that a wealth of information, education and support is available, there was a lot of variation in the materials used, and ongoing education was not structured or routine. In some NHS Boards, mature and effective education programmes were in place. In others, the approach was reactionary and depended on the identification of problems. Every NHS Board reported problems with access to psychology and dietetic services. This must be addressed as these are two key areas that affect people with diabetes.

### Strength

- Extensive range of information available across Scotland.

### Challenges

- Standardising patient information across Scotland and within NHS Boards.
- Improving patient involvement in service development.


### Recommendations

- NHS Health Scotland should work with NHS Boards to standardise information leaflets for patients and their families and friends.
- NHS Education should develop a series of diabetes education programmes and provide supportive training programmes for staff providing diabetes care.

### Clinical Review and Management (Standards 4–10)

These standards encompass the core elements of the clinical management of diabetes. They include routine review meetings (also called *screening*) to monitor the management of patients with diabetes. Review meetings cover physical and lifestyle/well-being, and should consider everything from blood pressure and review of medication to weight, diet, exercise and sexual health.

No NHS Board could demonstrate that comprehensive reviews are carried out, mainly because these clinical/lifestyle indicators are not routinely recorded. This has to be a priority for NHS Boards during the implementation of SCI-DC. There was also concern that, in several areas, NHS Boards are not able to offer an annual review due to the number of people with diabetes; in some cases, annual reviews ranged from 12-24 months.



In terms of the clinical management of associated conditions, the majority of NHS Boards provide a very high standard of care. People with diabetes are at risk of a number of associated conditions including blindness, heart problems, renal (kidney) failure and nerve damage that can lead to amputation of limbs. Managing these risks is not easy for patients or those providing care, and review visits highlighted the many effective care pathways that have been developed.

In particular:

- All NHS Boards have consultant ophthalmologist-led services and every NHS Board offers laser treatment for people with active proliferative diabetic retinopathy.
- There is good access to podiatry services across Scotland.
- Specialised renal services are in place across Scotland.
- All NHS Boards are aware of the need to manage high blood pressure and cholesterol levels.

Diabetic emergencies are generally poorly monitored, although there was evidence that support is in place and that patients are well managed. Such emergencies are another 'early warning' and should inform overall patient care.

## Strengths

- Committed, specialist diabetes services are widely available.
- Good guidelines are in place for glycaemic control.

## Challenges

- Providing annual review (or more frequently, if required) for everyone with diabetes.
- Developing well co-ordinated services to avoid the risk of patients 'ping-ponging' between services.
- Putting in place protocols for the management of associated conditions, in particular for eyes, feet, kidneys and cardiovascular status.

## Recommendations

- NHS Boards should make sure that all patients are offered an annual review and that those who do not attend are followed up.
- NHS Boards should develop well co-ordinated, intra-service guidelines for clinical management, where information is shared and case review is routine.
- NHS Boards should develop and implement area-wide protocols for identified associated cardiovascular problems in people with diabetes.


## Conclusion

The care of people with diabetes in Scotland is generally of a very high quality and there are many examples of innovative and effective ways of working. While this review focused on services for adults, examples of materials used in educating children were provided and are to be commended.

In order to manage diabetes well, NHS Boards have to know who has diabetes, their current health status, and the effect of the care they are receiving. As diabetes care is provided across primary and secondary care by a range of different specialties, this is challenging and, at present, no NHS Board could demonstrate fully co-ordinated care and shared information systems. There is a tendency to compartmentalise care, which leads to fragmented services where the patient ‘ping-pongs’ from department to department, not always in the order intended. This makes it harder to provide the necessary education and information and can also lead to duplicate tests and delays. Every member of the teams that provide care for people with diabetes has a role to play, and not necessarily the obvious role. Diabetes specialist nurses can provide valuable psychological care, dietitians can offer glycaemic control advice and every member of the team can advise on weight reduction.

The SCI-DC system will help to make sure that each patient has one record that follows them through the system and that everyone has rapid access to up-to-date information. To make sure it is effective, NHS Boards need to review their current arrangements for the provision of care and ensure that the implementation of SCI-DC in their area reflects this. In particular, staff need to be trained in how best to use this system.

As well as developing information systems that support diabetes care, there is a need to develop the role of the patient in their care and in service design generally. People with diabetes are the most important determinants of the outcomes of their care. With access to the right information and care they can make informed decisions about their diabetes and become key partners of the healthcare team, promoting self-management, independence and confidence, and minimising the risks of long-term damage.



The vision in Scotland is to change practice from crisis intervention - reacting to each problem after it comes up - to active chronic disease management with the emphasis on early warning systems and risk management, with the patient at the heart of his/her care. To achieve this vision will not be easy, but there is already evidence that it is possible, and the service and those with diabetes are closely united in striving for this. The priority areas that need to be addressed first are described in the three key recommendations made below.

### **Key Recommendations**

- Every NHS Board has to implement SCI-DC. This will require careful project planning and management.
- NHS Boards should review the patient journey for people with diabetes, involving them in this process, with the aim of improving the co-ordination of care and the sharing of information.
- People with diabetes need to be fully involved in their own care and in the services they use. This is central to improving standards of care.



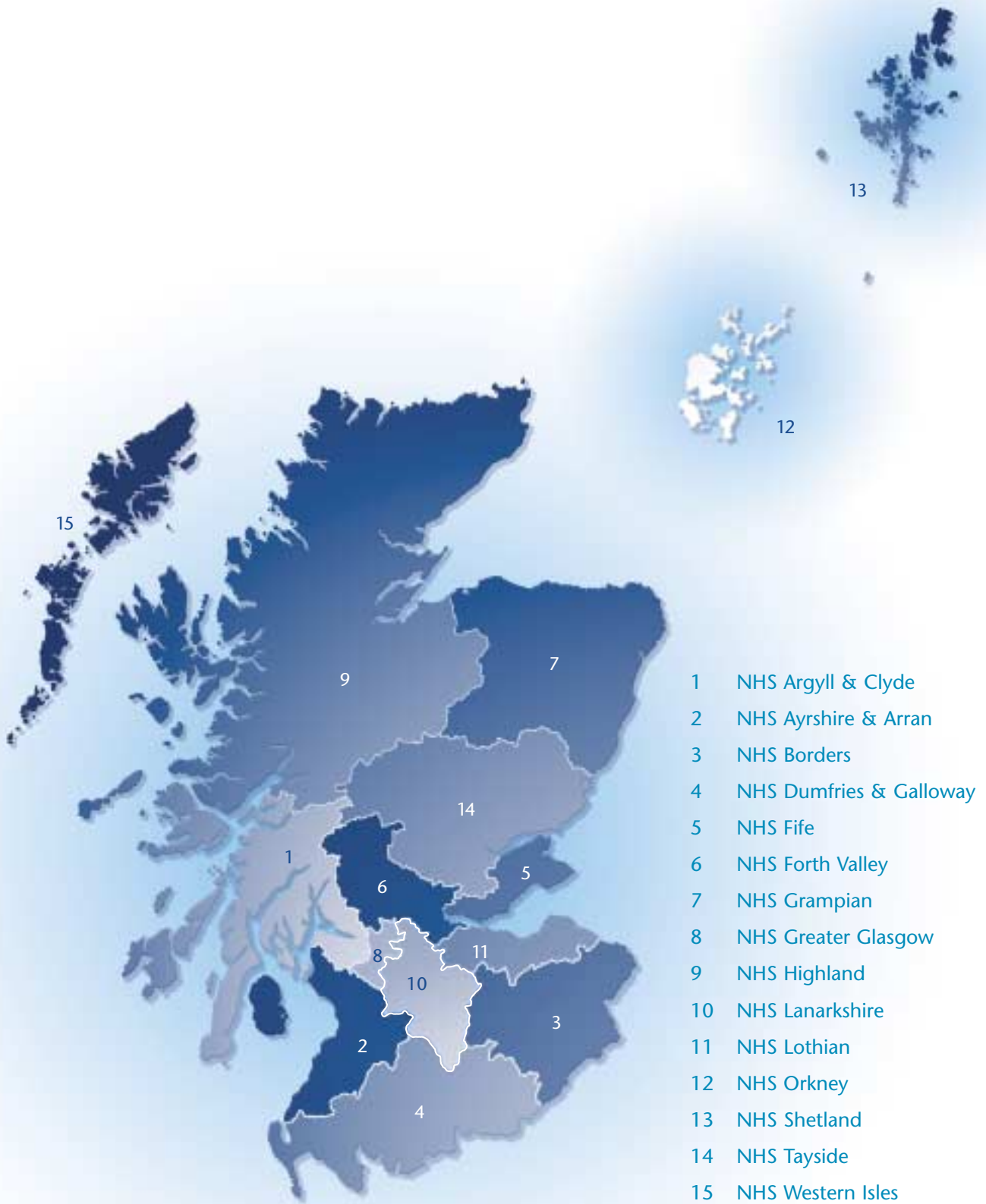
## Chapter 1

# Setting the Scene
















- [NHSScotland Regional Breakdown and Index of Visits](#)
- [The NHS Quality Improvement Scotland Approach to Assessment](#)
- [Background to the Clinical Standards for Diabetes](#)
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# 1. Setting the Scene

## 1.1 NHSScotland Regional Breakdown and Index of Visits



The following NHS Boards were reviewed during February 2003 - September 2003. Local reports, containing findings of each individual peer review visit and assessment against the standards, are available on the website ([www.nhshealthquality.org](http://www.nhshealthquality.org)) or in print format from NHS Quality Improvement Scotland (NHS QIS).



















<b>Local Report Area</b>  Estimated population <sup>1</sup>  Expected population with diabetes <sup>2</sup>  Registered people with diabetes <sup>3</sup>	<b>NHS Board Area Visited</b>
<b>1. Argyll &amp; Clyde</b>  423,500  12,940  9,522	NHS Argyll & Clyde
<b>2. Ayrshire &amp; Arran</b>  373,400  11,802  9,026	NHS Ayrshire & Arran
<b>3. Borders</b>  106,900  3,678  2,929	NHS Borders
<b>4. Dumfries &amp; Galloway</b>  145,800  5,057  5,150	NHS Dumfries & Galloway
















<sup>1</sup>. Source: Table 1 [page 11]; Expected Prevalence of Diabetes in Scotland 2002, Scottish Diabetes Survey 2002. Scottish Diabetes Survey Monitoring Group. Edinburgh: Scottish Executive (April 2003).

<sup>2</sup>. As above.

<sup>3</sup>. As above.

## 1. Setting the Scene

Local Report Area	NHS Board Area Visited
<b>5. Fife</b>  350,400  10,274  9,920	NHS Fife
<b>6. Forth Valley</b>  278,000  8,318  6,845	NHS Forth Valley
<b>7. Grampian</b>  523,400  15,309  5,726	NHS Grampian
<b>8. Greater Glasgow</b>  904,400  25,984  4,191	NHS Greater Glasgow
<b>9. Highland</b>  208,600  6,590  2,156	NHS Highland
<b>10. Lanarkshire</b>  562,000  16,027  16,358	NHS Lanarkshire

Local Report Area	NHS Board Area Visited
<b>11. Lothian</b>  783,600  22,268  18,917	NHS Lothian
<b>12. Orkney</b>  19,480  631  377	NHS Orkney
<b>13. Shetland</b>  22,440  634  608	NHS Shetland
<b>14. Tayside</b>  385,500  12,546  11,277	NHS Tayside
<b>15. Western Isles</b>  27,180  930  833	NHS Western Isles

### 1.2 The NHS Quality Improvement Scotland Approach to Assessment

NHS QIS uses a methodology which draws upon other quality assurance models to enable it, in partnership with healthcare professionals and members of the public, to develop standards for clinical services and to assess performance across NHSScotland against these standards.

Further information and definitions of the terms used in the standards and in the assessment of performance are contained in Appendix 2.

#### Assessment Categories

Each review team assesses performance using the categories 'met', 'not met' and 'not met (insufficient evidence)', as detailed below:

- **'Met'** applies where the evidence demonstrates the standard and/or criterion is being attained.
- **'Not met'** applies where the evidence demonstrates the standard and/or criterion is not being attained.
- **'Not met (insufficient evidence)'** applies where no evidence is available for the review team, or where the evidence available is insufficient to allow an assessment to be made.


A final category **'not applicable'** is used where a standard and/or criterion does not apply to the NHS Board area under review.

### 1.3 Background to the Clinical Standards for Diabetes

Meeting the needs of people with diabetes was identified as a priority area for NHSScotland with the publication of the Scottish Health Plan, *Our National Health: A Plan for Action, a Plan for Change (2002)*. The potential to make a significant impact on diabetes care was recognised with the inclusion of 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."*

The Scottish Diabetes Framework Working Group was established in April 2001; their remit was to draw together existing guidance and best



practice to address provision of diabetes care throughout the patient journey. The Group was multidisciplinary, including lay representation, and published key milestones in November 2001 followed by the full *Scottish Diabetes Framework* document in April 2002. The Framework sets out a proposed programme of diabetes care to be delivered over the next 5-10 years.

In partnership with the Scottish Diabetes Framework Working Group, a Diabetes Standards Subgroup was set up to identify clinical standards for diabetes services. The remit of the Diabetes Standards Subgroup was to direct the development of a core set of clinical standards for diabetes using the existing quality assurance and accreditation template developed by the Clinical Standards Board for Scotland (CSBS). Healthcare professionals and members of the public are represented, and the Subgroup drew on work already undertaken such as SIGN guidelines and the St Vincent Declaration.

The Diabetes Standards Subgroup identified several key standards specific to diabetes and also highlighted and incorporated applicable generic clinical governance standards. These standards complement and extend beyond the priorities identified in the *Scottish Diabetes Framework*.

## Consultation

A shared consultation period including both the Framework and the diabetes draft standards was successfully completed with valuable feedback received at open meetings and through a range of written comments. Focus groups were also held with the support of Diabetes UK. The responses were then considered by the Subgroup and many of the points raised were incorporated in the revised standards.

## Pilot Process

The standards were first published on World Diabetes Day in November 2001 to coincide with the publication of SIGN Guideline 55: *Management of Diabetes* and the key milestones of the *Scottish Diabetes Framework*. These standards were then piloted across three NHS Board areas in May 2002 - June 2002, resulting in minor changes to the standards and refinement of the accompanying self-assessment tool. The *Clinical Standards for Diabetes* (2nd ed.) are those against which performance of services around Scotland was reviewed during 2003.

Implementation of the work outlined in the *Scottish Diabetes Framework* is being taken forward through the Scottish Diabetes Group, chaired by Professor Andrew Morris, Reader in Medicine and Diabetes, University of Dundee.

### 1.4 Introduction to Diabetes

#### Basic Facts about 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 food, the blood glucose level rises and insulin is released into the blood. When the blood glucose level falls (eg 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.

**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, although can be seen in younger people.

#### The Symptoms of Diabetes

**The main symptoms of diabetes are:** increased thirst; going to the toilet a lot - especially at night; extreme tiredness; weight loss; genital itching or regular episodes of thrush; blurred vision.

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

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**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'.

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 have been 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 men and women are affected equally.

**Type 2 diabetes** used to be called 'maturity onset diabetes' because it generally 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.

**Other causes of diabetes.** There are some other causes of diabetes, including certain diseases of the pancreas, but they are very rare. Diabetes is not caused by an accident or an illness, however can be revealed by either.

### 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.

**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 help the pancreas to produce more insulin. Others 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. Through time, insulin may be required.

### 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 10-20 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, for those with diabetes mellitus, having regular medical check-ups at least annually, is so important.

*Adapted from a Diabetes UK publication: Understanding Diabetes: Your Key to Better Health. London: Diabetes UK (2000). Reproduced with permission.*

## Diabetes in Scotland

Approximately 150,000 people in Scotland have been diagnosed with diabetes and there are almost certainly many thousands more who are undiagnosed. Contrary to popular belief, diabetes is both progressive and life-threatening with potentially serious consequences for health. The complications of diabetes include a higher risk of heart disease, stroke, kidney failure, eye disease that can lead to blindness (diabetic retinopathy), 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.

Diabetes care requires the co-ordination and co-operation of many people working across a wide range of professions and organisations. Ensuring that high-quality services are available to everyone with diabetes will require a sustained effort over many years. While there are many examples of very good care in different parts of Scotland, there remains much to do and many issues to resolve.

### 1.5 The NHS Quality Improvement Scotland Standards and Your Care

#### Questions You Might Want to Ask

The diabetes standards have been summarised below and are shown in blue. Each standard is followed by relevant questions you might want to ask about your care.

#### Organisation

##### IM&T, Clinical Management Systems, Audit and Monitoring

*Details of all people with diabetes, with appropriate consent, are placed on a clinical management system.*

- Do I have to give consent for my details to be placed on a clinical management system?
- Does the NHS Board area that I live in participate in the Scottish Diabetes Survey?



*Photo courtesy of the National Kidney Research Fund.*

### **Pathway of Care, Teamworking and Integration of Services**

*There is a structured programme of care that defines diabetes care in a local area.*

- Will my plan of care be regularly reviewed?
- If I do not attend the diabetes clinic, will I be contacted with another appointment?

### **Patient Focus**

*All people with diabetes have access to information and education.*

- How can I be involved in how diabetes services are delivered in my area?
- Who will lead on my care?
- Where can I meet up with other people with diabetes?
- Where can I obtain information about diabetes and my treatment?

### **Clinical Review**

*All people with diabetes are offered an annual or more frequent examination to monitor the management and progression of their condition.*

- Will I be informed of all the results of the annual examination?
- How soon will my GP know the results of my annual examination?
- Who should I ask when I need help with trying to stop smoking?

### **Clinical Management**

#### **Eyes**

*All people with diabetes who have identified signs of developing diabetes-related, sight-threatening retinopathy are referred to an ophthalmologist.*

- What is diabetic retinopathy?
- How often should my eyes be checked?
- I have been told that I need laser treatment for my eyes. What does this mean?

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## Cardiovascular Status

*All people with diabetes with associated cardiovascular problems are appropriately managed.*

- How would I know if my blood pressure is high?
- What can be done to manage high cholesterol?

## Feet

*All people with diabetes with associated foot problems are appropriately managed.*

- Why do people with diabetes have to check their feet regularly?
- If I have a problem with my foot care, who should I contact?

## Glycaemia

*All people with diabetes have HbA1c measured and recorded.*

- How often will my HbA1c be measured?
- How long will it be before I am informed of the result of my HbA1c test?
- How can I keep a record of my glycaemic control to discuss with the diabetes team?
- Why is HbA1c measurement important when planning a pregnancy?

## Renal

*All people with diabetes with kidney problems have appropriate treatment.*

- How would I know that I have kidney problems?
- If I have kidney problems, will I need to be on a special diet?
- What other treatment will I need if I have kidney problems?

## Acute Management

*All people with diabetes with acute complications are rapidly assessed and managed.*

- Will the diabetes team be informed if I am admitted to hospital with an acute diabetic emergency?



## 1.6 Frequently Asked Questions

*Q. Can you catch diabetes from someone else?*

A. No, although we don't know exactly why some people get diabetes, we know that diabetes is not contagious - it can't be caught like a cold or flu. There seems to be some genetic link in diabetes, particularly Type 2 diabetes. But environmental factors also play a part.

*Q. Is Type 2 diabetes classed as mild diabetes?*

A. There is no such thing as mild or borderline diabetes. All diabetes is equally serious, and if not properly controlled can lead to serious complications.

*Q. If I have Type 2 diabetes, will members of my family also be at risk?*

A. Type 2 diabetes can be inherited. So if you've got Type 2 diabetes, other members of your family may also be at risk, particularly if they:

- are overweight.
- are usually over the age of 40.
- are of Asian or African-Caribbean origin.
- have a history of gestational diabetes (diabetes in pregnancy).

*Q. Will I go blind?*

A. Although diabetes is the leading cause of blindness in people of working age in the UK, research has proved you can reduce your chances of developing diabetes complications - such as damage to your eyes - if you:

- control your blood pressure and glucose levels.
- keep active.
- maintain your ideal body weight.
- give up smoking.

*Q. Can I eat sweets or chocolate?*

A. Sweets are no more out of bounds to people with diabetes than they are to the rest of us, if eaten as part of a healthy diet, or combined with exercise. People who take certain tablets or insulin to treat their diabetes may sometimes need to eat high-sugar foods to prevent their blood glucose levels falling too low.



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*Q. Should I eat special diabetic foods?*

A. The healthy diet for people with diabetes is the same as that recommended for everyone - low in fat, salt and sugar, with meals based on starchy foods like bread and pasta, and plenty of fruit and vegetables. Diabetic versions of sugar-containing foods offer no special benefit. They still raise blood glucose levels, are usually more expensive and can also have a laxative effect.

*Q. Why do I not attend the hospital diabetes clinic?*

A. This is likely to be because your GP/practice nurse is already looking after your diabetes, they are satisfied that that your diabetes is sufficiently well controlled, and that there are no other significant medical problems. Attendance at a hospital clinic may also depend upon whether your GP's surgery runs its own diabetes clinic.

*Q. How often should I see my doctor/nurse?*

A. **Annual check up:** You must be seen each year for an annual review of your diabetes. This is in order to make sure that your diabetic control is good enough, and to detect any complications which might be developing. This will include examination of the eyes, feet, and blood pressure. Blood and urine tests will also be carried out.

**Interim appointments:** The majority of patients will also benefit from seeing a healthcare professional on a far more regular basis. Therefore, many patients with diabetes are reviewed by their practice nurse, a hospital diabetes specialist nurse, or their GP at intervals of 3 months. Sometimes it may be necessary to make even more frequent visits, such as when repeated blood pressure measurements are required, or if blood glucose control is particularly poor. More frequent follow up is associated with improved diabetic control, and ultimately this reduces the risks of diabetic complications.

*Q. How often should I test my blood glucose?*

A. This varies from person to person, depending partly on your treatment, partly on your lifestyle and activities, and it also depends partly on how well controlled your blood glucose is. Even if you feel well, it is still necessary to undertake blood glucose tests, as careful diabetic control helps prevent the risk of developing long-term diabetic complications. There are some general principles that are helpful to remember.



**Type 1 (insulin-dependent) diabetes:** Patients treated with insulin are more likely to experience rapid swings in blood glucose levels, and to be at risk of hypoglycaemia (hypos). Insulin is usually given as between 2-4 injections per day, and dose adjustments are often required - although this depends upon many factors. At least one blood glucose test should be performed every day and recorded either in a diary (preferably) or left in the memory of your blood glucose meter. On different days the test should be performed at different times, preferably before meals and before bed. Over a period of time this builds up a good record of your blood glucose profile. If you are engaged in sport, strenuous physical activity, have an erratic lifestyle, are experiencing hypoglycaemic attacks, or have become unwell for any reason, you are likely to need to perform more frequent tests of blood glucose because these situations are likely to affect your diabetic control and may require adjustment of your insulin doses. The target level for blood glucose before a meal should be 4-7mmol/l.

**Type 2 (non-insulin-dependent) diabetes:** If you manage your diabetes by tablets and/or diet alone, a blood glucose test (finger prick) should be performed at least once a week, before breakfast and again 2 hours after the main meal of the day. Before breakfast your blood glucose should be in the range 4-7mmol/l, while 2 hours after a meal it should rise to no more than 9mmol/l.

## 1.7 Useful Contacts

The following organisations can provide information about diabetes. GPs and healthcare teams treating people with diabetes can also provide you with information about local support groups.

### 1. Child Diabetes - Scotland

The aim of this website is to bring together information about a variety of centres and initiatives working together to improve the care of children with diabetes in Scotland and beyond.

[www.diabetes-scotland.org](http://www.diabetes-scotland.org)

### 2. Diabetes in Scotland

Included on the site are publications, news items, a glossary, over 100 links to other sites of interest and details of the Scottish Diabetes Group and its subcommittees. Future development of the site will be guided by the needs of its users. The establishment of the site fulfils a commitment in the *Scottish Diabetes Framework* to launch a dedicated diabetes website.

[www.diabetesinscotland.org](http://www.diabetesinscotland.org)

### 3. Diabetes UK - Careline

If you need further information and support on any aspect of managing diabetes (eg medication, diet, exercise, employment, driving etc), you can contact one of the Diabetes UK Careline Counsellors. Please note Careline are unable to provide individual medical advice.

Tel: 020 7424 1030 (voice) or

020 7424 1031 (textphone)

E-mail: [careline@diabetes.org.uk](mailto:careline@diabetes.org.uk)

### 4. Diabetes UK Scotland

Diabetes UK is the leading charity working for people with diabetes. They fund research, campaigns and help people to live with the condition.

Diabetes UK Scotland  
Savoy House  
140 Sauchiehall Street  
GLASGOW  
G2 3DH

Tel: 0141 332 2700

Fax: 0141 332 4880

E-mail: [scotland@diabetes.org.uk](mailto:scotland@diabetes.org.uk)

**5. Juvenile Diabetes Research  
Foundation**

Juvenile Diabetes Research  
Foundation is dedicated to finding  
a cure for Type 1 (juvenile)  
diabetes and its complications  
through the support of research.

Juvenile Diabetes Research Foundation  
19 Angel Gate  
City Road  
LONDON  
EC1V 2PT

Tel: 020 7713 2030  
Fax: 020 7713 2031  
E-mail: [info@jdrf.org.uk](mailto:info@jdrf.org.uk)  
[www.jdrf.org.uk](http://www.jdrf.org.uk)

**6. RNIB Scotland (Royal National  
Institute of the Blind)**

RNIB Scotland promotes the  
interests of the 180,000 people in  
Scotland who have serious sight  
problems.

RNIB Scotland  
Dunedin House  
25 Ravelston Terrace  
EDINBURGH  
EH4 3TP

Tel: 0131 311 8500  
E-mail: [rnibscotland@rnib.org.uk](mailto:rnibscotland@rnib.org.uk)  
[www.rnib.org.uk](http://www.rnib.org.uk)



Chapter 2

# National Performance Against the Standards

## 2. National Performance Against the Standards

This section presents the findings across Scotland in terms of performance against individual standards. A number of examples of innovative local solutions and areas of good practice are highlighted in boxes throughout the text. These examples are not exhaustive - every review team noted examples of good practice during visits and these were often in place in more than one NHS Board area. Challenges are also listed and there is certainly scope for change and improvements in the process of care for people with diabetes. This is recognised by healthcare professionals and by patients and their friends and families, and whilst in the past there was limited patient involvement in diabetes care, there are now many examples of successful partnership working.

In common with many conditions, diabetes care is complex and most treatment is personally tailored to suit each patient's needs. This presents challenges when developing general patient information. It is not easy to achieve a balance between personal expectations and outcomes, and general information.

Feedback from those reviewed and those in review teams is sought after every visit and 207 people responded. Overwhelmingly, those involved in the review process report that the opportunity to network and the time to consider different ways of addressing shared issues has been valuable. Giving the public and the service the chance to review many aspects of the way in which care is provided has been fundamental to the approach taken and is a starting point for many activities including:

- identifying good practice;
- disseminating good practice;
- stimulating multidisciplinary working;
- involving those who use the service; and, perhaps most importantly,
- reviving the appetite to ensure that both the provision of patient care is balanced by the monitoring of that care against key performance standards, and that the quality of care is continually improved.

During the review of diabetes services, 15 NHS Board areas were reviewed to assess performance against the standards. This national overview summarises 15 local reports, as NHS Board-wide information was submitted by all of the NHS Boards reviewed. Accordingly, the findings presented reflect the number of instances where the standard criteria were met, based on the denominator of the 15 local reports (referred to in the text as NHS Boards).

## 2.1 Standard 1: Organisation: IM&T, Clinical Management Systems, Audit and Monitoring

### Standard Statement

*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.*

### Essential Criteria

1. There is an up-to-date population-based electronic clinical management system of all people with a recorded diagnosis of diabetes in the area which covers:
  - initial diabetes diagnosis;
  - development of significant diabetes micro- and macrovascular co-morbidities;
  - year of onset of co-morbidities;
  - measurement of ongoing modifiable risk factors;
  - long-term medication for diabetes and other chronic conditions.

**This criterion was met in 1/15 NHS Boards.**

The Scottish Care Information - Diabetes Collaboration (SCI-DC) is a Scottish Executive funded initiative, which aims to deliver effective IT solutions to diabetes services in NHSScotland. There has been a delay in the implementation of this national project which has impacted on the extent to which NHS Boards are progressing to establish up-to-date, population-based electronic clinical management systems for all people with diabetes. However, all NHS Boards have some form of area-wide register of people with a recorded diagnosis of diabetes, which are used to collect information on the number of people with the condition and their treatment.

One NHS Board met this criterion. The acute hospital sites in this NHS Board area used the SCI-DC Clinical system, which is an online electronic register of all hospital clinic attendees. SCI-DC Network, a similar system used to update information in primary care, was also in use within this NHS Board area. Automated nightly transfers of information were used to update the web-based SCI-DC systems. This allowed next-day rapid access to information for GP practices.

Across NHSScotland, local implementation of the SCI-DC systems continues to make good progress, with the SCI-DC Clinical system active in some other NHS Board areas. Live links had been implemented from the SCI-DC Clinical to the SCI-DC Network system in one other NHS Board. Some other NHS Boards were in the process of fully populating their SCI-DC Network databases with primary care data.

2. Data interfaces are in place between primary and acute care such that a single data entry covers all recording needs.

**This criterion was met in 0/15 NHS Boards.**

During the reviews, there were no NHS Boards with clinical management systems that spanned both primary and secondary care, allowing single data entry. However, until links to the SCI-DC system improve, no NHS Board will be in a position to meet this criterion.

3. The Board participates in the Scottish Diabetes Survey.

**This criterion was met in 14/15 NHS Boards.**

The Scottish Diabetes Survey is designed to measure the registered prevalence of diabetes, the frequency of clinical indicator screening and eventually clinical measures of quality of care in NHS Boards and across NHSScotland. All but one NHS Board were submitting information for the Scottish Diabetes Survey, now in its third year.

4. Data are collected using the clinical management system on a continuous basis to facilitate regular audit and quality assurance. The quality of the data is also regularly audited.

**This criterion was met in 1/15 NHS Boards.**

There was variation in the methods and frequency of data collection across NHSScotland. In some cases, GP practices submitted data electronically to populate central clinical management systems. Otherwise, this was done on a manual basis, for example by a diabetes facilitator manually collecting and validating primary care information. This could be a lengthy and time-consuming exercise, and in some NHS Board areas took up to 2 years.

In addition, there was variation in the quality assurance systems of data review. Ad hoc audits of the quality of data were undertaken, but not through a systematic, co-ordinated Board-wide approach.

## Desirable Criterion

5. The computerised clinical management system is Board-wide and incorporates call and recall systems for screening/review of complications.

**This criterion was met in 0/15 NHS Boards.**

No NHS Board had a clinical management system that incorporated call and recall for screening and review of diabetic complications. Call and recall functions were initiated separately at practice and hospital clinic level. Board-wide call-recall systems are essential to ensure that all patients are called for annual review. It is envisaged that the SCI-DC systems will facilitate Board-wide patient call and recall for screening/review of complications.

Systems to seek consent for patients to be placed on clinical management systems were not formalised and in place across all NHS Boards.

## Strengths

- Development of national IM&T systems, with uniform support, acceptance and engagement across NHSScotland.
- Advanced planning by some NHS Boards for the local implementation of SCI-DC.
- Submission of data for the annual Scottish Diabetes Survey.

## Challenges

- To improve local IT support for SCI-DC implementation.
- To ensure patient call and recall systems occur in all NHS Board areas.
- To use data collection for routine, regular audit and to identify those not receiving the recommended standards of care.
- To find solutions to bring data together from various sites through single data entry.
- To ensure all health professionals involved in diabetes care have access to a clinical management system.
- To ensure systematic quality assurance of captured data.

### Recommendation

- NHS Boards should develop a formal project plan for the local implementation of SCI-DC.

### Examples of local initiatives

#### NHS Lanarkshire

Monklands Hospital, Airdrie, has adopted a local system whereby an annual review appointment is generated and sent to the patient 6 weeks beforehand. As well as being an appointment reminder, this also highlights the need for a blood test and information relating to medication. It was reported that this letter has resulted in the rate of patients defaulting from the diabetes clinic decreasing from 20% to 6%.

#### NHS Tayside

An up-to-date population-based electronic clinical management system of people with a recorded diagnosis of diabetes exists through the automated nightly transfers of information from different sources, including clinics, GP practices, biochemistry laboratories and eye screening facilities. This allows next-day rapid access to information for GP practices.

## 2.2 Standard 2: Organisation: Pathway of Care, Teamworking and Integration of Services

### Standard Statement

*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.*

### Essential Criteria

1. There is a local strategy and implementation plan for diabetes services that covers diagnosis, screening for complications, treatment and care.

**This criterion was met in 4/15 NHS Boards.**

Definitive work to develop strategies and implementation plans for the delivery of diabetes care had taken place in a number of NHS Board areas. The NHS Boards that met this criterion had formal, Board-approved strategies and implementation plans in place.

Of those that did not meet the criterion, all were at various stages of strategic development and Board approval. An inclusive approach had been taken with the development of some of the strategies. Many of the approved or draft strategies were comprehensive and covered diagnosis, screening for complications, and treatment plans.

The development of managed clinical networks (MCNs) for diabetes was under way in some NHS Boards. It is envisaged that these networks will establish and evaluate services to improve communication, and co-ordinate diabetes care across traditional professional and NHS Board boundaries.

2. There is an effective, well-organised strategic planning group including stakeholders: a Local Diabetes Service Advisory Group (LDSAG), or equivalent, which is accountable to the NHS Board.

**This criterion was met in 7/15 NHS Boards.**

All NHS Board areas had a Local Diabetes Service Advisory Group (LDSAG), or equivalent. However, only some Groups were considered effective, had accountability to the Board and included sufficient multidisciplinary or stakeholder representation. Poor attendance at meetings was highlighted in some NHS Boards. For those that did not meet the criterion, there were problems either with the composition or effectiveness of the Group, with no clearly defined role within their NHS Board structure. This is a major barrier to the effectiveness of an LDSAG.

There was also a need to improve the training and support of the patient representatives serving on the Groups, to ensure that they were able to fully contribute in this environment.

3. There are agreed guidelines for shared care and referral and discharge between primary care teams and diabetes specialist care teams, which are regularly and jointly reviewed. These include protocols for the management of diabetes during other illnesses and procedures.

**This criterion was met in 4/15 NHS Boards.**

In most areas, there was good collaborative working between primary and secondary care diabetes teams, with guidelines in place. However, these were often not comprehensive, and within some NHS Board areas there were a number of different protocols covering the same or similar topics. Of the NHS Boards that undertook review of their protocols, there were a variety of mechanisms in place to do so, eg through the diabetes teams, LDSAGs and quality departments.

4. All people with diabetes have an individualised plan of care including mutually agreed targets based on Clinical Standards and the Scottish Diabetes Framework.

**This criterion was met in 15/15 NHS Boards.**

As part of their routine care, all people with diabetes had an individualised plan of care, including mutually agreed targets, albeit verbally agreed at the time of consultation with the patient and healthcare professional. In some cases, this was well documented in the patient casenotes, in others this may not have been routinely recorded. A small number of NHS Boards encouraged the use of patient-held records.

5. There are identified lead clinicians for diabetes in acute and primary care.

**This criterion was met in 14/15 NHS Boards.**

NHS Boards had identified lead clinicians who were responsible for the delivery of specific aspects of diabetes care, in primary and secondary care settings. One NHS Board did not have identified lead clinicians for diabetes within each of its Local Health Care Co-operatives (LHCCs).

6. There are robust fail-safe arrangements for identifying and following up people with diabetes who default from clinics, which take into account patient choice and responsibility for their care.

**This criterion was met in 10/15 NHS Boards.**

Arrangements to follow up patients who default from clinic visits were not robust across NHSScotland. Most mechanisms involved GPs, who were informed of patients who default from hospital clinic visits, and this triggered systems in many GP practices to contact these individuals. Overall, however, there were gaps in these systems. In some NHS Boards, formal protocols detailed principles to be followed for non-attendance by patients in both primary and secondary care.

Improved IT systems such as that of SCI-DC, would help to identify patients that have not received aspects of their care within a certain defined timeframe.

### Strengths

- Collaborative working across primary and secondary care in many areas.
- Identified lead clinicians for diabetes in primary and secondary care settings.
- Mechanisms were in place in many areas to identify patients who default from secondary care services and to inform GPs.

### Challenges

- To implement collaborative working and guidelines across the whole NHS Board area. Guidelines need to be widely distributed, effectively communicated and implemented.
- To develop diabetes services through the inclusive and effective working of the LDSAG, ensuring links, ownership and accountability to the Board.

### Recommendations

NHS Boards should:

- Be engaged in the strategic planning for diabetes services, through the development of MCNs for diabetes. There should be evidence of support from the Board, and incorporation into the Board's local health plan.
- Develop methods to routinely record and implement mutually agreed individual care plans for patients.



## Examples of local initiatives

### NHS Grampian

The *Grampian Guidelines for the Management of Diabetes Mellitus* were produced to facilitate diabetes care and to establish and implement common standards of care. The guidelines cover diagnosis, screening for complications, treatment and care. These guidelines are known to be used by other NHS Board areas.

### NHS Shetland

The LHCC Diabetes Quality Accord comprises a set of agreed clinical guidelines, patient care plans and a structured framework of both clinical and organisational practice to ensure a consistent and equitable high standard of care to all patients with diabetes. The Diabetes Quality Accord provides additional resources for GP practices, and is co-ordinated through the LDSAG.

### NHS Tayside

The diabetes network makes active use of online password-protected electronic clinical messaging through the SCI-DC system. This allows clinicians in primary care to send patient-specific clinical queries and messages to their diabetes specialist medical and nursing colleagues. This has been regarded as a real breakthrough in communication between primary and secondary care teams.

## 2.3 Standard 3: Patient Focus

### Standard Statement

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

### Essential Criteria

1. All people newly diagnosed with diabetes are offered at least one appropriately tailored formal educational session about their condition and are provided with written material to reinforce that education.

**This criterion was met in 10/15 NHS Boards.**

There was considerable variation in provision of initial diabetic education across NHSScotland, however, there were many examples of good quality individual and group diabetes educational programmes. There were also many examples of excellent patient information literature, but wide variation in the materials used between, and sometimes within, NHS Board areas.

Reasons for not meeting this criterion included: the lack of formal programmes of education for newly diagnosed patients with diabetes; inequitable access to the provision of education in primary care, with a lack of structured educational programmes for primary care staff providing new patient education; and limited availability of appropriate professionals in secondary care to facilitate educational sessions.

2. Educational programmes continue after diagnosis and include diet, foot care and eye care, as well as day-to-day management of diabetes.

**This criterion was met in 6/15 NHS Boards.**

All NHS Board areas did incorporate some ongoing education of people with diabetes into routine reviews on an ad hoc basis. Of the NHS Boards that met this criterion, there was structured additional education provided. This included the co-ordination of regular educational meetings for patients incorporating key components of diabetes care, outwith routine review appointments. Strong collaborative links had been established with Diabetes UK in these NHS Boards, ensuring further continual support and education was provided to the patient.

The NHS Board areas that did not meet this criterion did not have a formalised, structured programme for ongoing education, with continuing education in primary care proving a challenge. Ongoing provision of patient information, literature and access to diabetes specialist nursing services was variable.

Many areas identified lack of staff time as a barrier to organising formal continuing education programmes.

3. There are specific care programmes for different client groups in the population including children, adolescents, adults, elderly, preconceptional and pregnant women with diabetes, women with gestational diabetes, ethnic and vulnerable groups.

**This criterion was met in 13/15 NHS Boards**

All NHS Board areas had a wide range of specific care programmes for different patient groups in place. Of the two NHS Boards that did not meet this criterion, specific aspects of the care programmes for adolescent patients were not provided.

Services for children with diabetes were generally well supported throughout NHSScotland.

It was noted that not all NHS Board areas had specific programmes for ethnic groups and vulnerable people. Due to the small numbers involved in these NHS Board areas, cases were dealt with on an individual basis. Educational materials, including multilingual information sheets were available for these patient groups.

4. People with diabetes are involved in consultation on service development.

**This criterion was met in 11/15 NHS Boards.**

Many NHS Board areas had made significant efforts to enable patient and public involvement and support. Examples included involvement of Diabetes UK, Local Health Council, patient and carer representatives on LDSAGs and project groups and participation in healthcare workshops. The four NHS Board areas that did not meet this criterion all had some degree of patient/public representation on the local LDSAG, but no other formal process in place for wider consultation and involvement.

### Desirable Criteria

5. People with diabetes have appropriate access to identified key health professionals including state registered podiatry and dietetic, nursing and psychology services.

**This criterion was met in 2/15 NHS Boards.**

Overall, this criterion was not met due to specific access issues with psychology and dietetic services.

Provision of and access to podiatry services for people with diabetes was generally good across NHSScotland. Same or next day access to podiatry services for urgent podiatry problems was available in the majority of NHS Boards.

Access to dietetic services was variable, with limited access to dietetic staff in many NHS Boards. Consequently, several NHS Board areas provided a limited and inequitable dietetic service for people with diabetes across their area.

Access to diabetes specialist nursing services was variable, both between and within NHS Board areas. There was no diabetes specialist nurse in one NHS Board.

Access to clinical psychology services is generally limited throughout NHSScotland, and few areas had dedicated psychological services sessions for patients with diabetes. Consequently, patients with diabetes requiring psychology services in these areas were referred to the general psychology service, where extensive waiting times exist.

6. Members of the diabetes team who are involved in patient education, have access to a training programme.

**This criterion was met in 12/15 NHS Boards.**

Provision of training for members of the primary and secondary care diabetes teams was good across NHSScotland. The University of Warwick and the University of Bradford diabetes courses were popular and widely used. There was also a wide range of local training courses provided for both primary and secondary care staff. These local and national training initiatives enabled health professionals to be kept up to date with new developments in diabetes, as well as providing continuing professional development. Variable and ad hoc educational arrangements were in place within the NHS Boards that did not meet this criterion.



## Strengths

- Good quality individual and group diabetes education programmes exist.
- Extensive range of excellent patient information literature across Scotland.
- Provision of specific care programmes for different patient groups in most NHS Board areas.

## Challenges

- To rationalise and standardise patient educational information and literature.
- To develop formal ongoing diabetes education programmes for patients.
- To ensure consistent patient/public involvement and support across NHSScotland, particularly for consultation on diabetes service development.
- To ensure adequate dietetic, nursing and psychology service provision to meet the needs of patients with diabetes.
- Diabetes education needs to be culturally sensitive to the targeted communities.

## Recommendations

NHS Boards should:

- Work together to provide a comprehensive range of standardised diabetes patient information materials.
- Offer a programme of initial and continuing patient diabetic education, which should detail educational content, provider, and the initial and continuing training requirements for those delivering it.
- Ensure that all people with diabetes are offered advice about reducing the long-term complications of diabetes and about the purpose and importance of medication.
- Ensure that provision of dietetic, nursing and psychology services are such that they meet the needs of the local diabetic population.
- Ensure that effective staff training is provided to maintain standards of healthcare, and to ensure consistency in care delivery and education.

### Example of a local initiative

#### NHS Dumfries & Galloway

A diabetes educator has been appointed in Nithsdale and it is planned to establish this role in the remaining three LHCCs. The diabetes educators will support consultant-led diabetes clinics and work in the community thus maintaining their skill base and providing continuity and consistency of information provision across primary and secondary care. Education of primary care staff involved in treatment of diabetes is also an integral part of their role.

## 2.4 Standard 4: Clinical Review

### Standard Statement

*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.*

### Essential Criteria

1. There is a protocol to ensure that all people with diabetes are offered review of the following indicators on an annual basis, or more frequently where clinically indicated, from diagnosis.

#### Clinical

- Glycated haemoglobin (HbA1c).
- Blood pressure.
- Random total cholesterol.
- Eye examination for diabetic retinopathy according to HTBS recommendations.
- Urinalysis for microalbuminuria and proteinuria.
- Serum creatinine.
- Foot examination for ischaemia, neuropathy, and general foot care.
- Review of medication.

#### Lifestyle/Well-being

- Body Mass Index (BMI).
- Dietary intake.
- Physical activity.
- Tobacco consumption (smoking habit).
- Perception and understanding of condition.
- Psychological well-being.
- Sexual health.

**This criterion was met in 0/15 NHS Boards.**

This criterion was an extremely challenging aspect of care, taking into account review of eight clinical and a further seven lifestyle/well-being variables. Good quality information systems are essential as the input of data to the clinical management system should be recorded within the previous 12 months. All NHS Boards routinely reviewed and recorded a number of key clinical indicators, in particular HbA1c, blood pressure and cholesterol. However, NHS Boards were not recording all of the key indicators stated in the criterion on a routine basis. Consequently, no NHS Board met this criterion.

In many areas, the only available data was that produced for the Scottish Diabetes Survey, which did not provide information for the 12-month period prior to the peer review visits. It was reported that the overall level of testing and screening being performed as part of the annual review process was much higher than recorded. As IT systems improve, the Scottish Diabetes Survey will help to monitor the frequency of clinical indicator screening.

The number of people developing diabetes is rapidly increasing. Patient numbers are such that annual reviews in both primary and secondary care were offered at intervals of between 12-15 months. In one NHS Board, annual reviews ranged between 12-24 months.

Low returns for microalbuminuria screening were identified. This appeared to be a particular challenge for primary care.

Area-wide initiatives, such as smoking cessation services and exercise referral schemes, were in operation in some NHS Boards. These schemes augment the provision of specialist services to support and advise on lifestyle/well-being risk factors.

## General

2. Patients are informed of their results and offered support to manage lifestyle risk factor changes.

**This criterion was met in 9/15 NHS Boards.**

Most patients were informed of their abnormal blood test results and provided with good intervention to manage lifestyle changes. In many NHS Boards, pre-clinic blood testing or near patient testing was undertaken, allowing the opportunity for discussion of results with the patient at the clinic appointment.

The level and detail of information provided and feedback to patients was variable across NHSScotland, although work was in progress in a few NHS Board areas to standardise the process of informing patients of their results.

## Desirable Criterion

3. Referring practitioners (including optometrists, with patient consent) are given feedback regarding the outcome of their referrals.

**This criterion was met in 12/15 NHS Boards.**

In general there was good feedback to referring practitioners regarding the outcome of their referrals. However, in many NHS Boards, optometrists could only refer via the GP, and feedback was then only received by the GP. Of the NHS Board areas where optometrists could refer directly, they did not always receive feedback on their referrals.

## Strengths

- A number of key clinical indicators are reviewed on a routine basis, in particular HbA1c, blood pressure, and cholesterol.
- Progress on improving sedentary lifestyles receive a high priority in most NHS Boards with a variety of physical activity initiatives.
- Significant effort has been made to support the widespread take-up of smoking cessation advice/clinics.

## Challenges

- To improve the uptake/availability of microalbuminuria testing.
- Emphasis to be placed on informing patients of normal results, where pre-clinic blood testing or near patient testing is unavailable.
- To ensure adequate capacity within diabetes systems to cope with the needs of the local diabetes population, and projected population.
- To ensure lifestyle issues are consistently addressed in NHS Boards.

## Recommendations

- NHS Boards should provide a co-ordinated, structured, formalised annual review process for all people with diabetes. Clinical/lifestyle/well-being indicators may not necessarily need to be reviewed on the same day.
- All patients with diabetes should be informed of both normal and abnormal test results in a timely fashion.

## Examples of local initiatives

### NHS Ayrshire & Arran

Patients with diabetes are able to directly access the sexual dysfunction clinic and specialist nurse services. A helpline is also available for patients referred with sexual dysfunction alongside ongoing supervision and follow up.

### NHS Lothian

In the Western General Hospital, Edinburgh, results of all blood tests taken are available within 25 minutes. HbA1c results are available within 20 minutes in all other secondary care clinics in NHS Lothian.

## 2.5 Standard 5: Clinical Management: Eyes

### Standard Statement

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

### Essential Criteria

1. There is a referral process to a consultant ophthalmologist-led service for people with diabetes with identified signs of developing diabetes-related, sight-threatening retinopathy according to Health Technology Board for Scotland (HTBS) grading recommendations.

**This criterion was met in 3/15 NHS Boards.**

All NHS Boards had a consultant-led service for people with diabetes with identified signs of developing diabetes-related, sight-threatening retinopathy.

Three NHS Boards use HTBS grading recommendations to identify sight-threatening retinopathy, with planning or work to implement HTBS grading recommendations under way in the majority of NHS Boards. Although comparable systems were used in a small number of NHS Board areas, these did not incorporate HTBS grading recommendations.

2. All people whose eye examination has revealed retinopathy have their glycaemic control and blood pressure reviewed and treated as clinically indicated.

**This criterion was met in 11/15 NHS Boards.**

In the NHS Boards that met this criterion, mechanisms were in place to inform the practitioner primarily involved in a patient's diabetes management of the result of an ophthalmic assessment. In many NHS Boards, guidelines existed to encourage particular focus on blood pressure and glycaemic control in patients who had been found to have retinopathy. Primary and secondary care clinicians were involved in the review and treatment of blood pressure and glycaemic control in patients whose eye examination had revealed retinopathy.

3. All people with active proliferative diabetic retinopathy are offered laser treatment.

**This criterion was met in 15/15 NHS Boards.**

Where appropriate, laser treatment for proliferative diabetic retinopathy was offered to all patients across NHSScotland. If treatment was not given, the reasons for this were recorded in the patient casenotes. In some NHS Board areas, patients were often referred and treated on the same day as screening.

### Strengths

- Consultant ophthalmologist-led service in all NHS Boards.
- Where appropriate, people from all NHS Board areas with active proliferative diabetic retinopathy are offered laser treatment.

### Challenge

- Formalise and strengthen links between ophthalmic services and others in diabetes care, in particular with the diabetes care provider.

### Recommendation

- NHS Boards should implement HTBS grading recommendations.

### Example of a local initiative

#### NHS Grampian

As part of the diabetic retinopathy screening programme, patients living outwith city boundaries are offered the screening service at their local GP practice; a screening nurse attends the practice with a mobile camera to take the retinal photograph.

## 2.6 Standard 6: Clinical Management: Cardiovascular Status

### Standard Statement

*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.*

### Essential Criteria

1. Where blood pressure is consistently greater than 140 systolic and/or 80 diastolic (140/80mmHg), attempts are made to lower the blood pressure according to locally agreed protocols.

**This criterion was met in 9/15 NHS Boards.**

Over half of NHS Boards had locally agreed protocols in place for the management of hypertension in patients with diabetes, and in the majority of these NHS Board areas, this was detailed in the local diabetes handbook or equivalent. In a small number of NHS Board areas, differing protocols were in use across primary and secondary care, although these protocols may have reflected similar practice. In two cases, local protocols recommended initiation of blood pressure treatment at the level of 140/90mmHg.

Of the NHS Boards that did not meet this criterion, it was not evident that the protocols in place were being applied consistently across the NHS Board area, particularly across primary care. In one NHS Board area, work was in progress to develop a formalised protocol.

2. There is a local protocol for the management of consistently high cholesterol (>5mmol/l).

**This criterion was met in 12/15 NHS Boards.**

The majority of NHS Boards had locally agreed protocols in place for the management of consistently high cholesterol (>5mmol/l) in patients with diabetes, and in some of these NHS Board areas, this was detailed in the local diabetes handbook or equivalent. In a small number of NHS Board areas, differing protocols were in use across primary and secondary care, although the protocols may have reflected similar practice.

Of the NHS Boards that did not meet this criterion, it was not evident that the protocols in place were being applied consistently across the NHS Board area, particularly across primary care.

3. There is a local protocol for the management of angina.

**This criterion was met in 9/15 NHS Boards.**

There was no Board-wide protocol for the management of angina in six NHS Boards. One contributing factor for the criterion not being met was the absence of joint working in primary and secondary care to address the issue. In NHS Boards where there was no overall local protocol, there was evidence of the presence of protocols in specific locations such as coronary care units and LHCCs.

4. All people with diabetes who have been diagnosed with acute myocardial infarction are offered clinical care as detailed in the CSBS *Clinical Standards for Secondary Prevention following Acute Myocardial Infarction*.

**This criterion was met in 15/15 NHS Boards.**

Protocols were in place for the management of acute myocardial infarction and secondary prevention thereafter for people with diabetes across NHSScotland. Several NHS Boards had undertaken audits and developed action plans conforming to the National Coronary Heart Disease (CHD) action plan. In several NHS Boards, an integrated approach was being developed involving primary and secondary care; this included the development of MCNs for coronary heart disease.

5. The *Joint British Societies Coronary Risk Prediction Chart*, or recognised equivalent, is used to assess coronary heart disease risk in primary care.

**This criterion was met in 12/15 NHS Boards.**

In most NHS Boards, the *Joint British Societies Coronary Risk Prediction Chart* was used to assess coronary heart disease risk in primary care. In other cases, the *British National Formulary (BNF) Coronary Risk Prediction Chart* or the Clinical Decision Support Software (CDSS) calculator was used.

Most NHS Boards promoted the use of risk calculation. Of the NHS Boards that did not meet this criterion, there was no evidence that the protocols in place were being applied consistently across the NHS Board area, particularly across primary care.



## Strength

- The application of a local protocol for the management of consistently high cholesterol.

## Challenges

- The need to develop joint primary/secondary care working in some NHS Boards for cardiovascular management of people with diabetes.
- To ensure seamless working between the evolving diabetes and coronary heart disease managed clinical networks.

## Recommendation

- NHS Boards should implement area-wide protocols for identified associated cardiovascular problems in people with diabetes.

## Example of a local initiative

### NHS Borders

For people with diabetes without coronary heart disease, NHS Borders calculates the risk of a coronary heart disease event over a 10-year period, and starts statin treatment earlier than in non-diabetic patients.

## 2.7 Standard 7: Clinical Management: Feet

### Standard Statement

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

### Essential Criteria

1. There is a rapid referral process for people with diabetes with associated foot problems. The referral protocol states clearly whether referral is to primary or secondary care. In particular, conditions not responding to treatment provided by primary care are referred to secondary care.

**This criterion was met in 13/15 NHS Boards.**

All NHS Boards had a referral process in place for people with diabetes with associated foot problems. In the majority of NHS Board areas, there was a rapid referral system to specialist podiatry services prioritising people with diabetes, with referral to primary or secondary care varying across NHSScotland. In many cases, a podiatry assessment tool was used to identify high risk patients who were then typically referred to secondary care for management of their condition.

In many NHS Board areas, an open access service was available, allowing patients to self-refer for podiatry treatment.

2. All people with diabetes have appropriate access to state registered podiatry services.

**This criterion was met in 14/15 NHS Boards.**

In almost all NHS Boards, there was appropriate access to state registered podiatry services for people with diabetes. Access to podiatry services was variable across one NHS Board area.

3. There is a local protocol for drug and pressure relief treatment of diabetic foot disease.

**This criterion was met in 7/15 NHS Boards.**

Not all NHS Boards had protocols in place for both drug and pressure relief treatment of diabetic foot disease.

It was noted that national pressure relief guidance for the treatment of diabetic foot ulceration is under development.

## Desirable Criterion

4. All people with diabetic foot ulcers are reviewed by a diabetes foot specialist, using digital camera photographs for comparison.

**This criterion was met in 2/15 NHS Boards.**

In most cases, foot ulcer assessments were carried out by diabetic foot specialists. Although digital cameras were used in most NHS Board areas, access was such that digital photography was typically used to only monitor diabetic foot ulcers not responding to treatment. Consequently, the main reason NHS Boards did not meet this criterion was that not all people with diabetic foot ulcers were reviewed using digital camera photographs for comparison.

## Strength

- Good provision of podiatry services for patients with diabetes with associated foot problems.

## Challenges

- A significant proportion of NHS Boards require to have protocols for drug and pressure relief treatment of diabetic foot disease in place.
- To maintain service provision, in light of increased prevalence of people with diabetes.

## Recommendation

- NHS Boards should ensure digital photography is available for the monitoring of diabetic foot problems, and photographs are integrated into the patient record.

## Example of a local initiative

### NHS Highland

The diabetes team has designed a diabetes training course to be rolled out to all practice nurses. This covers basic foot examinations.

## 2.8 Standard 8: Clinical Management: Glycaemia

### Standard Statement

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

### Essential Criteria

1. Drug and insulin therapy is tailored to achieve the best possible glycaemic control without frequent or severe hypo/hyperglycaemia, and there is specific guidance for children and pregnant women.

**This criterion was met in 12/15 NHS Boards.**

In almost all NHS Board areas, clear guidelines or protocols were in place for the tailoring of drug and insulin therapy to achieve the best possible glycaemic control for patients with diabetes. In addition, there was generally good access to diabetes specialist nurses and physicians to facilitate this. Aside from routine clinic appointments, various mechanisms were in place to access specialist diabetes nursing services, including drop-in facilities at the diabetes clinic and out-of-hours answerphone services.

Two NHS Board areas did not meet this criterion due to identified issues regarding the access and availability of specialist nurses and physicians to tailor drug and insulin therapy. In the remaining NHS Board not to meet this criterion, guidelines were under review to incorporate information specific to children.

2. A Diabetes Control & Complications Trial (DCCT) compatible assay is used for the measurement of HbA1c.

**This criterion was met in 13/15 NHS Boards.**

In two NHS Boards, HbA1c measurement was not standardised across the NHS Board area using a Diabetes Control & Complications Trial (DCCT) compatible assay.

3. Sequential HbA1c measurements are used to identify people with diabetes who have poor glycaemic control. Specific targets are agreed for each individual patient.

**This criterion was met in 13/15 NHS Boards.**

In the majority of NHS Boards, sequential HbA1c measurements were widely used as an essential part of monitoring average glycaemic control. Pre-clinic blood testing or near patient testing of HbA1c occurred in a number of areas, allowing results to be available for discussion with the patient during the clinic visit. Poor glycaemic control was also identified through patient self-monitoring and self-referral to specialist diabetes nursing services.

In most cases, specific HbA1c targets to ensure good glycaemic control were agreed with individual patients.

4. The incidence of hypo/hyperglycaemia is monitored and the results are discussed with the patient.

**This criterion was met in 14/15 NHS Boards.**

In almost all NHS Board areas, patients were specifically questioned about incidences of hypo/hyperglycaemia at review visits and encouraged to self-refer to either the primary care team or diabetes specialist nurse during problem periods.

## Desirable Criterion

5. HbA1c measurements are made available to colleagues in the diabetes (primary and secondary care) team and sent to patients.

**This criterion was met in 8/15 NHS Boards.**

All NHS Board areas ensured that HbA1c measurements were available to members of the primary and secondary care diabetes teams. Methods for communicating HbA1c results were varied and included computer systems, patient casenotes, letters and multidisciplinary team meetings.

In NHS Board areas where pre-clinic blood testing or near patient testing of HbA1c was undertaken, results were usually available for discussion with the patient during the clinic visit. In some instances, patients would additionally be informed of their HbA1c results by letter following their clinic visit. In areas where this method of testing was not available, patients were not routinely informed by letter of both normal and abnormal results.

### Strengths

- Effective systems and good protocols/guidelines are widely in place for glycaemic control.
- Availability of near patient testing to allow immediate discussion of HbA1c test results with patient.

### Challenge

- DCCT compatible assays should be used for the measurement of HbA1c.

### Recommendations

NHS Boards should:

- Work towards establishing pre-clinic blood testing or near patient testing to allow HbA1c results to be made available to the patient at the time of the clinic appointment.
- Ensure that all patients with diabetes have access to specialist diabetes advice to ensure best possible glycaemic control is achieved.

### Examples of local initiatives

#### NHS Fife, NHS Forth Valley, NHS Tayside

Three NHS Boards are involved in DiabNet, a clinical network which aims to co-ordinate care for children and adolescents with diabetes. This network has developed guidelines on insulin adjustment and provides a 24-hour helpline for paediatric patients.

## 2.9 Standard 9: Clinical Management: Renal

### Standard Statement

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

### Essential Criteria

1. All people with identified abnormal renal function serum creatinine (greater than 150 micromols/l) are considered for referral to a renal clinic.

**This criterion was met in 9/15 NHS Boards.**

Nine NHS Boards had protocols in place to ensure patients with identified abnormal renal function serum creatinine (greater than 150 micromols/l) were considered for referral to a renal clinic. In some cases, although protocols were in place, the agreed serum creatinine level exceeded the identified threshold stated in the criterion. During the review visits, the identified level of serum creatinine whereby patients were considered for referral to a renal clinic ranged from 110 micromols/l to 500 micromols/l.

2. All people whose urinary albumin concentration is greater than 300mg/l (ie albuminuria which is thought to be due to diabetic nephropathy), have blood pressure, glycaemic control and serum cholesterol levels reviewed as clinically indicated.

**This criterion was met in 10/15 NHS Boards.**

Reasons for not meeting this criterion included variable frequency of renal clinic appointments; insufficient condition-specific guidance, or uncertainty as to what guidance was used in primary care.

The NHS Boards that had met this criterion had mechanisms in place to slow down the progression of established kidney failure. In a number of NHS Board areas, people whose urinary albumin concentration was greater than 300mg/l (ie albuminuria which is thought to be due to diabetic nephropathy), had blood pressure, glycaemic control and serum cholesterol levels reviewed at the renal and diabetes clinics. In some NHS Board areas, joint renal/diabetes clinics were held.

3. All people with Type 1 diabetes, with microalbuminuria as defined in a local protocol, are prescribed an ACE inhibitor unless there are contraindications.

**This criterion was met in 3/15 NHS Boards.**

Only a minority of NHS Boards had protocols in place to manage the earliest complications of diabetic kidney disease in those people with Type 1 diabetes.

Information was either not collected on the numbers of patients with Type 1 diabetes with microalbuminuria who are prescribed an angiotensin converting enzyme (ACE) inhibitor, or in instances where it was, no data were available to support that this occurred. This was due to limitations of current IT and monitoring systems to allow health professionals to access/extract the data. However, the prescribing of ACE inhibitors for all people with microalbuminuria was often reported to be standard practice in many NHS Board areas, and was stated in the local diabetes handbook or equivalent for the management of diabetic renal disease.

### Desirable Criterion

4. All people with proteinuria and a reduced glomerular filtration rate are offered dietetic intervention to review dietary protein intake and to assess the nutritional adequacy of their diet.

**This criterion was met in 11/15 NHS Boards.**

Generally, there was good access to dietetic services for people with diabetes-related renal failure across NHSScotland. Access to dietetic services was poor in the few NHS Board areas that did not meet this criterion.

### Strength

- Specialised renal services, including dietetic intervention for people with diabetes in Scotland, are good.

### Challenges

- To develop Board-wide management guidelines between renal and diabetes services to identify the pathway of care for patients with diabetes-related renal problems.
- To ensure consistency of referral to specialist renal services across an NHS Board area, particularly in relation to identified referral thresholds.



## **Recommendations**

NHS Boards should:

- Ensure that mechanisms are in place to identify and best manage people during early, established and late stages of diabetic renal disease.
- Define agreed management guidelines between renal and diabetes services to identify the pathway of care, ensuring consistency of referral.

## 2.10 Standard 10: Clinical Management: Acute Management

### Standard Statement

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

This standard was assessed during the peer review visits principally as a hospital-based service, although it is recognised that diabetic emergencies may also be managed in primary care.

### Essential Criteria

1. There is a local protocol for the acute management of people with diabetes who experience an acute diabetic emergency including severe hypoglycaemia, diabetic ketoacidosis (DKA) or hyperosmolar non-ketotic state.

**This criterion was met in 13/15 NHS Boards.**

The majority of NHS Boards had protocols and standardised practice for the management of patients presenting with an acute diabetic emergency. In a small number of NHS Board areas, differing protocols were in use across the main hospital sites within a single Trust, although the protocols did reflect similar practice. In some areas, closer integration with the A&E department was required.

2. People with diabetes who are admitted to hospital with diabetic ketoacidosis are reviewed by a specialist diabetes physician or nurse prior to discharge.

**This criterion was met in 10/15 NHS Boards.**

Most NHS Boards offered specialist review and follow up prior to discharge for patients with diabetes who are admitted to hospital with diabetic ketoacidosis, although it could not be guaranteed that this occurred for all patients. In a few areas where the diabetes team consisted of one or two individuals, limited cover for annual leave or sickness could result in the lack of any specialist attention for patients.

In the majority of NHS Board areas, paediatric patients were reviewed by the paediatric diabetes team, or a consultant paediatrician with a special interest in diabetes.

## Desirable Criteria

3. People with diabetes who experience severe hypoglycaemia are referred, on recovery, to specialist diabetes services for advice on psychological, clinical and lifestyle aspects of their care.

**This criterion was met in 11/15 NHS Boards.**

Following recovery from severe hypoglycaemia, most patients were referred for specialist advice on clinical and lifestyle aspects of their care. However, it was clear that a number of patients who were assessed in the A&E department, and who did not require admission to a medical or short-stay ward, were not always referred for review by the specialist diabetes services. Patients in primary care with severe hypoglycaemia were not routinely referred to specialist diabetes services.

Dedicated diabetes psychology sessions were not available in the majority of NHS Boards. However, it was accepted that the consultant diabetologist or diabetes specialist nurse were well placed to advise patients on psychological aspects contributing to, or following, metabolic upsets such as severe hypoglycaemia.

4. The rate of diabetic emergencies is monitored for all those with diabetes in the area.

**This criterion was met in 4/15 NHS Boards.**

The recording of diabetic emergencies within an NHS Board area was poorly monitored, and this was in part due to the lack of integrated IT systems. There was a dependence in some NHS Boards on data from the national Scottish Morbidity Record (SMR) system, but this system was deemed unreliable due to problems with inaccurate assigning of codes, and issues surrounding identification of the type of emergency presentation.

Localised systems for monitoring the rate of diabetic emergencies occurred in four NHS Board areas. This included the ongoing audit of adult patients presenting with diabetic emergencies undertaken by the diabetes specialist nurses; and in one of the smaller NHS Boards, patient casenotes and discharge letters containing the reason for admission were reviewed for audit purposes.

### Strength

- Protocols for the management of acute diabetic emergencies are well developed, ensuring standardised practice in many NHS Board areas.

### Challenges

- Closer integration between the A&E department and diabetes team to reinforce the need for, and importance of, specialist diabetes intervention to ensure review of all patients with diabetes prior to discharge.
- Educate/involve other clinical staff to ensure that patients admitted to hospital have access to appropriate advice, especially in areas with small diabetes teams.

### Recommendations

- NHS Boards should develop mechanisms whereby patients admitted to A&E departments with acute diabetic emergencies receive specialist diabetes review.
- NHS Boards should improve the audit and monitoring of diabetic emergencies, both at local and national level.
- To develop a link nurse network where diabetes teams of one or two individuals exist. These link nurses, although not expected to be experts in diabetes care, would be able to promote and facilitate the care of patients with diabetes as an additional support to the diabetes specialist nursing team.

### Examples of local initiatives

#### NHS Fife

Diabetes consultants visit each A&E department every 6 months to discuss the acute management diabetic emergencies booklet and provide training and medical education for new junior medical staff. The booklet is issued to all new junior medical staff, A&E and nursing staff, and covers acute complications with appropriate algorithms for the management of diabetic emergencies.



### **NHS Grampian**

There is a separate adult in-patient diabetes specialist nurse who covers both the wards and the A&E department. This hospital-based diabetes specialist nurse covers all referrals from wards in Aberdeen Royal Infirmary, including the A&E department, Royal Cornhill Hospital, Aberdeen, and Woodend Hospital, Aberdeen. The diabetes specialist nurse works closely with the diabetes registrar in advising wards on diabetes management during surgery or acute illness, and sees patients in A&E with short admission for hypoglycaemia.

### **NHS Lothian**

The Royal Hospital for Sick Children, Edinburgh, has developed a paediatric diabetic ketoacidosis integrated care pathway, which is followed as soon as the patient presents at the A&E department. This is a multidisciplinary plan of care, which forms the single clinical record of care for all healthcare professionals involved in the care and treatment of the patient.





Chapter 3

# Conclusions



### 3. Conclusions

This national overview sets out the performance of diabetes services in Scotland as a whole against the *Clinical Standards for Diabetes* (2nd ed.) published in October 2002. The accompanying local reports set out the performance of each NHS Board providing diabetes care against the same standards. A number of general themes have emerged which apply across the country.

Firstly, the review teams were struck by the commitment, dedication and hard work of the staff involved in providing diabetes services, frequently under considerable pressure. It is clear that these services seek, wherever possible, to be responsive to patient needs, and a number of innovative service developments were seen. However, many diabetes teams are currently reaching capacity and NHS Boards need to take this into account when planning services.

Secondly, there is much informal networking taking place across Scotland among those providing diabetes services. The reliance on the goodwill of staff has resulted in the development of comprehensive local knowledge, and effective working relationships with external colleagues. However, review teams noted a lack of formal procedures in place to support these arrangements, and felt that diabetes services would benefit from developing accredited managed clinical networks (MCNs). This would allow staff to share expertise, specialist resources and data, and would also prompt the development of innovative solutions to the variety of problems faced throughout the service.

Thirdly, members of the public have been involved at every stage of the diabetes services project. This has provided an invaluable perspective to the work of the Subgroup in setting the standards and on review visits. It has also given members of the public a chance to contribute to all aspects of the review process, rather than just receive a report prepared without their input.

NHS Quality Improvement Scotland (NHS QIS) looks to each NHS Board providing diabetes services to ensure that, in close collaboration with the staff responsible for providing the service, practice is reviewed in the light of this report's findings and recommendations, and appropriate action is taken.

### 3. Conclusions



Considerable momentum has been built up, and it is important to use this enthusiasm to progress the work on strengthening and improving diabetes services. The public, both locally and nationally, also has an important role to play in ensuring that these changes are made. NHS QIS reserves the right to revisit an NHS Board where it considers there are serious issues that need further external monitoring. NHS QIS intends periodically to review and raise these standards in light of the latest evidence about 'best practice' and the performance of the service, and to conduct further national and local reviews where appropriate, so as to encourage continuing quality improvement.



# Appendices

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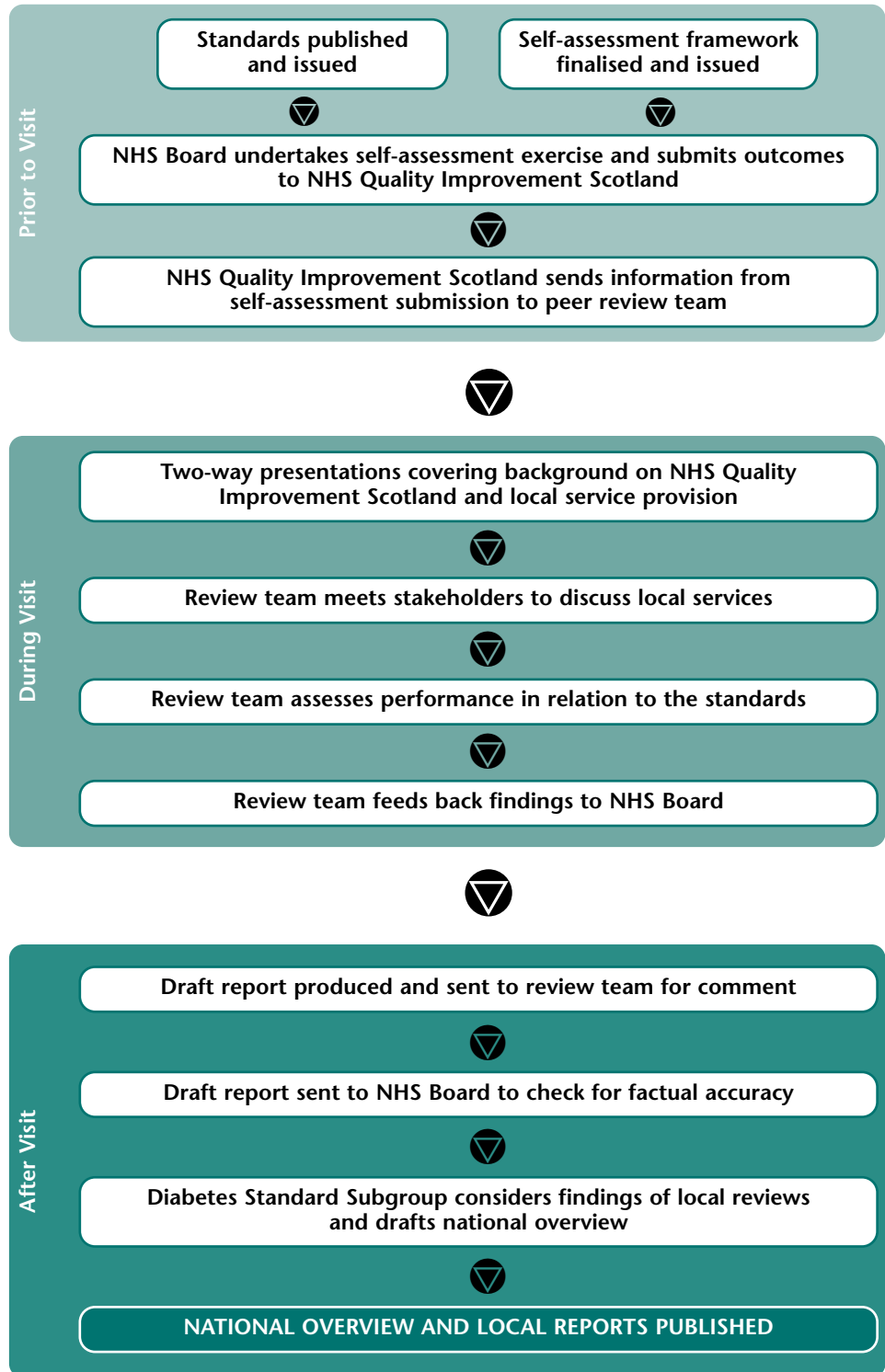
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## The Quality Assurance Process: Approach Used in this Review





## Standards

All standards set by NHS Quality Improvement Scotland (NHS QIS) comprise a standard statement and related criteria.

### Standard Statement

Describes the agreed performance for the specific area, determined by those who are involved in the delivery/receipt of the service.

### Criteria

State exactly what must be done for the standard to be reached.

Some criteria are **essential** as it is expected that they will be met wherever a service is provided. Others are **desirable/aspirational** in that they will promote continuous quality improvement as they are being met in some parts of the service and demonstrate levels of quality which other providers of a similar service should strive to achieve.

### Self-Assessment

Each set of clinical standards has an accompanying self-assessment framework. This framework gives guidance about the type of evidence required to demonstrate performance against the standards. It is completed and submitted to NHS QIS prior to a peer review visit, together with extensive additional documentation. The evidence obtained from this self-assessment exercise comprises the main source of written evidence considered by each peer review team.

### Peer Review

Peer review is the process by which a multidisciplinary review team, including members of the public, carries out an NHS Board visit to validate the quantitative data submitted through the self-assessment. This is done by means of gathering qualitative information through discussions with staff.

The composition of each review team varies, and all review team members come from outwith the geographical area they are reviewing. Although this presents challenges in achieving consistency of process, it promotes sharing of good practice and ensures that each review team assesses the performance of an NHS Board area against the standards, not by comparing one NHS Board area with another.

In order to determine whether a particular criterion is 'met' or 'not met', each review team requires to identify evidence on a variety of levels. For example, to demonstrate that a particular issue is addressed in a local protocol, evidence is sought during the peer review process as follows:

- description of the issue and how it should be managed in a local written protocol (submitted as part of the self-assessment);
- confirmation of awareness of the location and content of the protocol through staff interviews;
- evidence of a process in place for the protocol to be regularly updated; and
- collection of data through an integrated care pathway/audit sheet, leading to provision of collated audit data confirming compliance with the local protocol.


Until a legal interpretation of the Data Protection Act is made as to whether patient records can be accessed for purposes other than managing patient care, NHS QIS review teams are not scrutinising individual patient records. Therefore, in cases where it is stated that information is recorded in individual patient casenotes, and the claim is corroborated in staff interviews during the visit, an assessment of 'met' will be made.

During each diabetes review visit, the review team is guided by a team leader to ensure a multidisciplinary consensual assessment is reached. At the conclusion of the review, the review team provided feedback to the NHS Board giving a broad overview of its assessment, which is based on the written self-assessment, and on evidence obtained during the review visit.

To enhance the consistency of the process, an NHS QIS manager and project officer accompany each visit, both of whom provided the secretariat and developmental support for the Subgroup during the standard-setting phase of the project.

The schedule for a diabetes external peer review visit included:

- initial meeting with key personnel responsible for the service under review;
- dialogue with clinicians, audit staff and managers based on the written evidence;

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- scrutiny of documentation;
  - interviews with staff members;
  - regular team briefings throughout the day to assess progress and to compile the local report; and
  - feedback to the NHS Board representatives on conclusion of the visit.

In addition, the NHS QIS review team met with Local Health Council and patient representatives, GPs and representatives from the NHS Board area.

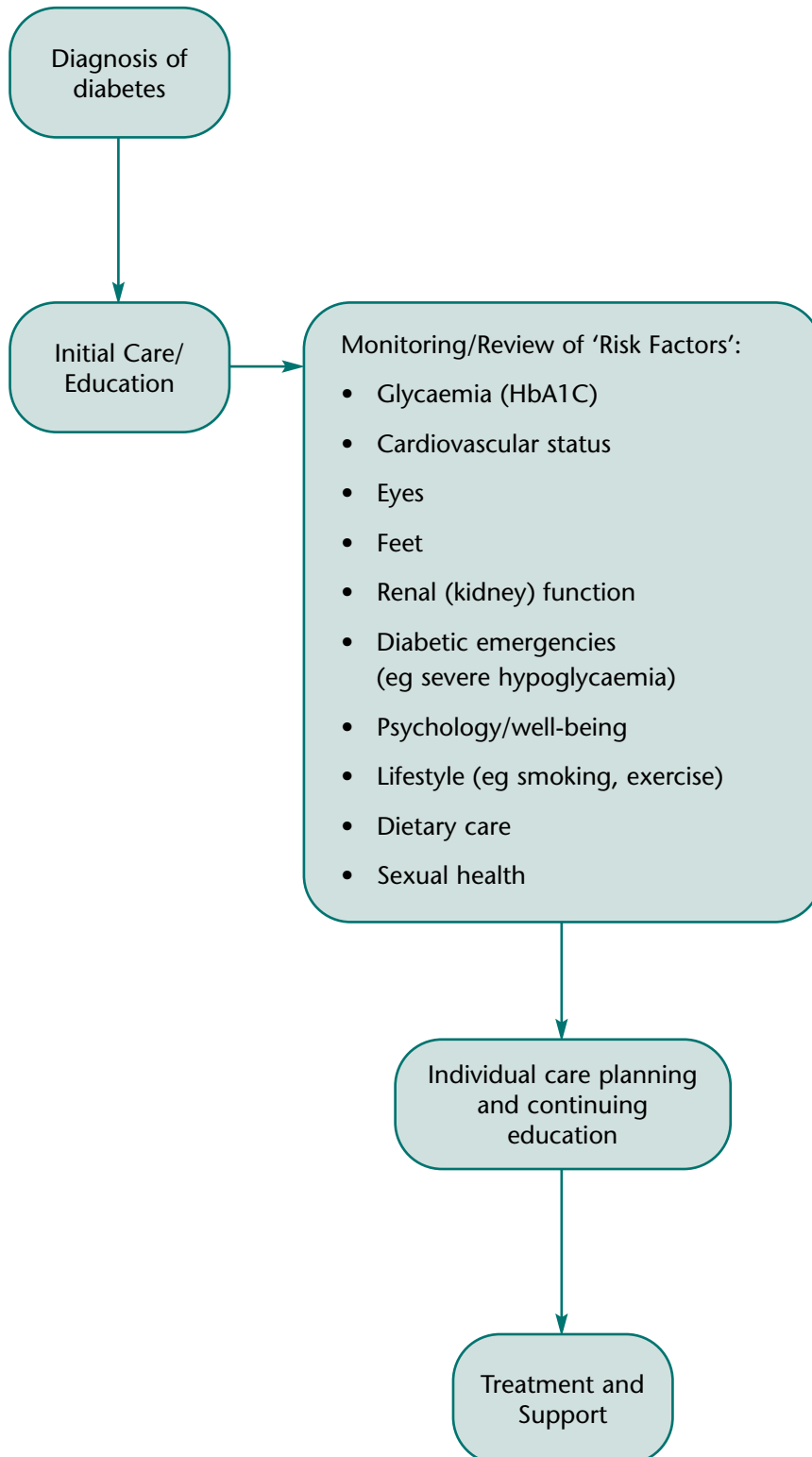
### **Reports**

A local written report is drafted following each visit by NHS QIS. The draft report is then circulated to the review team for comment, and to the NHS Board concerned to allow a check for factual accuracy.

On conclusion of the peer review programme, the Project Group is reconvened to study the findings and examine trends in order to draw conclusions and make recommendations to NHS QIS.

The responsibility of NHS QIS is to report whether the services provided by NHSScotland, both nationally and locally, meet agreed standards, but not to review individual cases or the work of individual healthcare professionals. In achieving this aim, variations in practice (and potential quality) within a service will be encountered. Where such variation exists between hospitals (eg between hospitals within an NHS Board area), this will be stated; treatment variations will also be reported, but will not identify patients or healthcare professionals.

## Pathway of Care for Diabetes Services



## Appendix 4

### Diabetes Review Team Members

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### Glossary of Terms

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 (AMI)	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.
AHP	See allied health professional.
allied health professions (AHPs)	Healthcare professionals directly involved in the provision of primary and secondary healthcare. Includes several groups such as physiotherapists, occupational therapists, dietitians, etc. Formerly known as professions allied to medicine (PAMs).
amputation	Surgical removal of part or all of a limb.
angina	Discomfort in the chest, jaw or arm which often occurs on exercising and which is due to a reduced blood supply to the heart.
angioplasty	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.
assay	Determination of the purity of a substance or the amount of any particular constituent of a mixture.
assessment	The process of measuring patients' needs and/or the quality of an activity, service or organisation.

<b>audit</b>	Systematic review of the procedures used for diagnosis, care, treatment and rehabilitation, examining how associated resources are used and investigating the effect care has on the outcome and quality of life for the patient.
<b>background (non-proliferative) diabetic retinopathy (BDR)</b>	Diabetes can cause blocking and subsequent damage to the small blood vessels in the retina. This can result in damaged vessels leaking small amounts of blood and the retina being starved of oxygen.
<b>BDR</b>	See background diabetic retinopathy.
<b>blood glucose</b>	A measurement of the amount of sugar in the blood.
<b>blood pressure (BP)</b>	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.
<b>BMI</b>	See body mass index.
<b>body mass index (BMI)</b>	A measurement of weight in relation to height.
<b>call-recall</b>	The process used to invite people for a screening test.
<b>carer</b>	A person who looks after family, partners or friends in need of help because they are ill, frail or have a disability. The care they provide is unpaid.
<b>casenotes</b>	Patient's notes; documentation of care.
<b>CDSS</b>	See Clinical Decision Support Software.
<b>CHI number</b>	The Community Health Index (CHI) is a unique patient identifier that is allocated to every patient registered with a GP in Scotland. It is entered onto a database that underpins a wide range of patient care processes in Scotland. There are strict controls on access to patient identifiable details.
<b>CHD</b>	See coronary heart disease.
<b>chronic</b>	Present over a long period of time. Diabetes is an example of chronic disease.
<b>circulation</b>	The flow of blood through the heart and blood vessels of the body.

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<b>Clinical Decision Support Software (CDSS)</b>	A clinical decision support system compares patient characteristics with a credible knowledge base and then guides a clinician by offering patient-specific and situation-specific advice. By incorporating evidence-based guidelines and a summary of the patient data or knowledge base, the clinical decision-making process is enhanced, thereby potentially improving the quality of care.
<b>clinical governance</b>	A framework through which NHS organisations are accountable for both 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. Management of clinical risk at an organisational level is an important aspect of clinical governance. Clinical risk management recognises that risk can arise at many points in a patient's journey, and that aspects of how organisations are managed can systematically influence the degree of risk.
<b>clinical management system (CMS)</b>	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.
<b>clinical review</b>	A method of detecting specified disease in a targeted population at a stage where the individuals have no symptoms.
<b>clinical service</b>	Service provided by healthcare professionals.
<b>Clinical Standards Board for Scotland (CSBS)</b>	The Clinical Standards Board for Scotland was a statutory body, established as a Special Health Board in April 1999. Its role was to develop and run a system of quality control of clinical services designed to promote public confidence that the services provided by the NHS met nationally agreed standards, and to demonstrate that, within the resources available, the NHS was delivering the highest possible standards of care. On 1 January 2003, CSBS was merged, along with four other clinical effectiveness bodies, to form NHS Quality Improvement Scotland (NHS QIS). See NHS Quality Improvement Scotland.


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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.
Community Health Index (CHI)	See CHI number.
co-morbidity	The presence of coexisting or additional diseases with reference to either an initial diagnosis or to 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.
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.
consultant in public health medicine	A qualified medical practitioner who specialises in the health of populations.
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.
criterion(s)/criteria(pl)	Provide the more detailed and practical information on how to achieve the standard, and relate to structure, process or outcome factors.
CSBS	See Clinical Standards Board for Scotland.
data source	The source of evidence to demonstrate whether a standard or criterion is being met.
DCCT compatible assay	See Diabetes Control and Complications Trial compatible assay.
default	Failure to participate in something which is required.
desirable (criterion/criteria)	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.

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Diabetes Control and Complications Trial (DCCT) compatible assay	A standardisation which allows comparison of glycated haemoglobin (HbA1c) results between different laboratories.
diabetes mellitus	A condition in which the amount of glucose (sugar) in the blood is too high because the body cannot use it properly.
Diabetes Mellitus Insulin Glucose Infusion in Acute Myocardial Infarction (DIGAMI)	Study which found that intensive insulin treatment of people with diabetes immediately following a heart attack significantly improved long term survival.
diabetes register	A list of people with diabetes, and a product of the clinical management system.
diabetic emergency	An acute diabetic episode including hypoglycaemia and diabetic ketoacidosis resulting in admission to hospital.
diabetic ketoacidosis (DKA)	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.
diabetic retinopathy	A complication of diabetes that affects the health and function of the retina by blocking off its small blood vessels.
diagnosis	Identification of an illness or health problem 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 kinds and amount of foods to eat.

DIGAMI	See Diabetes Mellitus Insulin Glucose Infusion in Acute Myocardial Infarction.
DKA	See diabetic ketoacidosis.
ECCI	See Electronic Clinical Communications Implementation.
Electronic Clinical Communications Implementation (ECCI)	The national programme to implement electronic clinical communication between primary and secondary care.
end organ damage	The results of a disease process that affects the structure and function of a number of body organs.
essential (criterion/criteria)	A criterion that should be met wherever a service is provided.
evidence-based medicine	Evidence-based clinical practice is an approach to decision making in which the clinician uses the best evidence available, in consultation with the patient, to decide upon the option which suits that patient best.
fundoscopy	Examination of the fundus (the retina) of the eye through the pupil using a handheld instrument.
gangrene	The death of body tissue. It is most often caused by a loss of blood flow, especially in the legs and feet.
General Practice Administration System for Scotland (GPASS)	The national primary care system for Scotland and one of Britain's leading general practice computer systems.
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 (HbA1c)	A test that sums up how well controlled diabetes has been in the preceding 3-4 months.
GP	General Practitioner.
GPASS	See General Practice Administration System for Scotland.
grader	The member of staff who interprets and records the appearance of a retinal photograph.
guidelines	Systematically developed statements which help in deciding how to treat particular conditions.



<b>HbA1c</b>	See glycated haemoglobin.
<b>Health Board</b>	See NHS Board.
<b>Health Council</b>	Each NHS Board area has a Health Council, an organisation whose aim is to promote public consultation and participation in health-related matters. Sometimes referred to as a Local Health Council.
<b>Health Department Letter (HDL)</b>	Health Department Letter (formerly known as Management Executive Letter - MEL), formal communications from the Scottish Executive Health Department to NHSScotland.
<b>Health Technology Board for Scotland (HTBS)</b>	The Health Technology Board for Scotland (HTBS) worked to improve Scotland's health by providing evidence-based advice to NHSScotland on the clinical and cost-effectiveness of new and existing health technologies (medicines, devices, clinical procedures and healthcare settings). On 1 January 2003, HTBS was merged, along with four other clinical effectiveness bodies, to form NHS Quality Improvement Scotland (NHS QIS). See NHS Quality Improvement Scotland.
<b>healthcare professional</b>	A person qualified in a health discipline.
<b>heart attack</b>	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 (see thrombosis).
<b>heart failure</b>	A condition in which the pumping action of the heart is impaired.
<b>hormone</b>	A circulating chemical messenger made in one part of the body and acting on other parts.
<b>HTBS</b>	See Health Technology Board for Scotland.
<b>hypercholesterolaemia</b>	Where abnormally high concentrations of cholesterol are present in the bloodstream. This can lead to heart disease, hardening of the arteries, heart attacks, and strokes.
<b>hyperglycaemia</b>	An excess of glucose in the bloodstream, which if untreated, may progress to diabetic coma.
<b>hyperlipidaemia</b>	High level of fats (lipids) in the blood.

<b>hyperosmolar non-ketotic state</b>	A complication of diabetes caused by a lack of insulin and dehydration. It is diagnosed when the patient has: <ol style="list-style-type: none"> <li>1. very high levels of glucose (sugar) in the blood.</li> <li>2. absence of ketoacidosis.</li> <li>3. severe dehydration.</li> <li>4. sleepy, confused, or comatose state.</li> </ol>
<b>hypertension</b>	High blood pressure which, if uncontrolled, can increase the risk of heart disease or a stroke.
<b>hypoglycaemia</b>	Hypoglycaemia (hypos) occur when blood glucose levels are low; below 4mmol/l, and can often cause confusion, light headedness and irritability.
<b>ICP</b>	See integrated care pathway.
<b>IM&amp;T</b>	Information management and technology.
<b>incidence</b>	The number of new cases of a disease within a defined group of people over a period of time.
<b>Information and Statistics Division (ISD)</b>	The Information and Statistics Division is part of the Common Services Agency, NHSScotland. Health service activity, manpower and finance data are collected, validated, interpreted and disseminated by the division. This data is received from NHS Boards, NHS Trusts and general practices. Website: <a href="http://www.show.scot.nhs.uk/isd/index.htm">www.show.scot.nhs.uk/isd/index.htm</a>
<b>informed consent</b>	The principle by which a patient/user is informed about the nature, purpose and likely effects of any treatment proposed, before being asked to consent to accepting it.
<b>in-patient</b>	A person who is admitted to hospital for observation, examination or treatment.
<b>insulin</b>	A hormone secreted by the pancreas. Insulin regulates the blood glucose level, and is important for growth and tissue repair.
<b>insulin therapy</b>	Treatment using insulin in patients with diabetes following trauma to the body such as a heart attack.

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**integrated care pathway (ICP)** An integrated care pathway is an explicit agreement by a local group, both multidisciplinary and multi-agency, of staff and workers to provide a comprehensive service to a clinical or care group on the basis of current views of good practice and any available evidence or guideline. It is important that the group agree on communication, record keeping and audit. There should be a mechanism to pick up when a patient has not received any care input specified by the pathway so that the omission can be remedied. The local group should be committed to continuous improvement of the integrated care pathway on the basis of new evidence of service developments or of problems in implementation.

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**integration** Shared or overlapping processes which result in a stronger whole. For example, a situation where all aspects of care are connected and clinicians are working together.

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**ischaemia** Reduced blood flow, usually because of narrowing or blockage of an artery.

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**Island NHS Board** There are three Island NHS Boards (Orkney, Shetland and the Western Isles). They have always had a combined strategic and operational role. See NHS Board.

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**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.

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**ketoacidosis** See diabetic ketoacidosis.

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**ketones** A breakdown product of fat that accumulates in the blood as a result of inadequate insulin or inadequate calorie intake.

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**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.

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**lay representation** The inclusion of a member(s) of the general public in a professional group.

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LDSAG	See Local Diabetes Service Advisory Group.
lead clinician	Clinician with administrative responsibilities for a specific service.
LHCC	See Local Health Care Co-operative.
Local Diabetes Service Advisory Group (LDSAG)	A strategic planning group of local diabetes service users, carers and providers who advise NHS Boards in matters relating to services for individuals with diabetes.
Local Health Care Co-operative (LHCC)	In Scotland, Local Health Care Co-operatives (LHCCs) are voluntary groupings of GPs and other local healthcare professionals intended to strengthen and support the primary health care team in delivering local care.
macro-vascular	Something that concerns large blood vessels.
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 network (MCN)	A formally organised network of clinicians. The main function is to audit performance on the basis of standards and guidelines, with the aim of improving healthcare across a wide geographic area, or for specific conditions.
MCN	See managed clinical network.
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 for the analysis of more than one randomised clinical trial.
microalbuminuria	Leakage of small amounts of protein (albumin) into the urine. An early warning of kidney damage.
micro-vascular	Something that concerns small blood vessels.
monitoring	The systematic process of collecting information on the performance of clinical or non-clinical activities, actions or systems. Monitoring may be intermittent or continuous. It may also be undertaken in relation to specific incidents of concern or to check key performance areas. Monitoring is used to appraise strengths, weaknesses, opportunities and threats.

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<b>morbidity</b>	A diseased condition or state. The incidence of a particular disease or group of diseases in a given population during a specified period of time.
<b>mortality (rate)</b>	The number of deaths in a given population during a specified period of time.
<b>multidisciplinary</b>	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.
<b>multidisciplinary system of working</b>	A method of working in a multidisciplinary team with protocols in place for most, if not all, eventualities.
<b>near patient testing</b>	Testing at site of care.
<b>nephropathy</b>	Kidney damage from any cause; quite often diabetes.
<b>neuropathy</b>	Disease of the nervous system. 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.
<b>NHS</b>	National Health Service.
<b>NHS Board</b>	NHS Boards are responsible for strategic planning, performance management and governance of each of Scotland's 15 local health systems. Most NHS Board areas (excluding Island NHS Boards) contain one Acute and one Primary Care Trust, with operational and employment responsibilities, but since 2001 they have operated within a strategic framework drawn up by the NHS Board. By 2004, Trusts will have been abolished and replaced by operating divisions of the NHS Board (see also NHS Trust).

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<b>NHS priorities</b>	The three national clinical priorities are mental health; coronary heart disease and stroke; and cancer.
<b>NHS QIS</b>	See NHS Quality Improvement Scotland.
<b>NHS Quality Improvement Scotland (NHS QIS)</b>	NHS Quality Improvement Scotland is a statutory body, established as a Special Health Board in January 2003. Its role is to focus on improving the quality of patient care and the health of patients. It will have a particular emphasis on the quality of care and the patient journey for vulnerable groups. NHS Quality Improvement Scotland has been created by the merger of five organisations: Clinical Standards Board for Scotland (CSBS); Health Technology Board for Scotland (HTBS); the Scottish Health Advisory Service (SHAS); Nursing and Midwifery Practice Development Unit (NMPDU), and the Clinical Resources and Audit Group (CRAG). Website: <a href="http://www.nhshealthquality.org">www.nhshealthquality.org</a>
<b>NHS Trust</b>	A Trust is an NHS organisation responsible for providing a group of healthcare services for the local population. An Acute hospital Trust provides hospital services. A Primary Care Trust provides primary care/community health services. Mental health services (both hospital and community based) are usually provided by Primary Care Trusts. Since 2001 Trusts have operated within an overall framework drawn up by their NHS Board. Subject to legislation, Trusts will be dissolved by April 2004, becoming operating divisions of the NHS Board. The NHS Board will be the single employer for the local system. In two areas - Borders and Dumfries & Galloway - since April 2003 there have been no Trusts or operating divisions with the NHS Board fulfilling a dual strategic and operational role (like the three Island Boards). The term 'Trust' is retained in NHS QIS publications during the period of Trust abolition. Where unification has occurred, the term 'Trust' should be taken to signify an operating division of the local NHS Board. See also NHS Board.
<b>NHSScotland</b>	The National Health Service in Scotland.




<b>obesity</b>	Condition of being grossly overweight, at least 20% heavier than the heaviest weight in the 'ideal' range for that person's height.
<b>oedema</b>	A collection of fluid. 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.
<b>ophthalmologist</b>	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.
<b>ophthalmology</b>	The study, diagnosis and treatment of diseases and defects of the eye.
<b>optician</b>	Fits, supplies and adjusts spectacles and contact lenses. An optician cannot examine the eyes or prescribe spectacles or medication.
<b>optometrist</b>	Although not a doctor of medicine, an optometrist is specifically trained to diagnose eye abnormalities and prescribe, supply and adjust spectacles and contact lenses.
<b>outcome</b>	The end result of care and treatment and/or rehabilitation. 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, and/or rehabilitation.
<b>out-patient</b>	A patient reviewed in a hospital but who does not need to be admitted to the hospital.
<b>patient</b>	A person who is receiving care or medical treatment. A person who is registered with a doctor, dentist, or other healthcare professional, and is treated by him/her when necessary. Sometimes referred to as a user.
<b>patient journey</b>	The pathway through the health services taken by the patient (the person who is receiving treatment), and as viewed by the patient.
<b>PCRG</b>	See Primary Care Reference Group.
<b>PCT</b>	Primary Care Trust. See NHS Trust and primary care.

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<b>PDR</b>	See proliferative diabetic retinopathy.
<b>peer review</b>	Review of a service by those with expertise and experience in that service, either as a provider, user or carer, but who are not involved in its provision in the area under review. In the NHS Quality Improvement Scotland approach, all members of a review team are equal.
<b>peripheral vascular disease</b>	Disorder affecting the blood vessels in the body preventing the ready supply of oxygenated blood to the peripheral parts of the body.
<b>photocoagulation</b>	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.
<b>physician</b>	A specialist in medicine.
<b>plan of care</b>	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.
<b>podiatrist/ chiroprapist</b>	Person with expert knowledge in foot care.
<b>prescription</b>	A set of written instructions from a doctor to a pharmacist regarding the preparation and dispensing of a drug, etc for a particular patient. The term can also be used to describe the drug, etc prescribed in this way, or a set of written instructions for an optician stating the type of lenses required to correct a patient's vision.
<b>pressure relief</b>	A means of redistributing gravitational force to prevent further tissue damage.
<b>primary care</b>	The conventional first point of contact between a patient and the NHS. This is the component of care delivered to patients outside hospitals and is typically, though by no means exclusively, delivered through general practices. Primary care services are the most frequently used of all services provided by the NHS. Primary care encompasses a range of family health services provided by family doctors, dentists, pharmacists, optometrists and ophthalmic medical practitioners.

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<b>Primary Care Reference Group (PCRG)</b>	Established to help the Clinical Standards Board for Scotland, and now NHS Quality Improvement Scotland, ensure that the component of care delivered to patients outside hospitals is included in its standards, and to promote the accreditation of general practices.
<b>primary prevention</b>	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.
<b>prognosis</b>	An assessment of the expected future course and outcome of a person's disease.
<b>proliferative diabetic retinopathy (PDR)</b>	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 that are prone to bleeding and pulling of the retina.
<b>prophylactic medication</b>	Drugs prescribed to prevent something happening.
<b>prophylaxis</b>	The prevention of disease; preventive treatment. Intervention to prevent an unwanted outcome.
<b>protein</b>	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.
<b>proteinuria</b>	Too much protein in the urine. This may be a sign of kidney damage.
<b>protocol</b>	A policy or strategy which defines appropriate action in specific circumstances. Protocols may be national, or agreed locally to take into account local requirements.
<b>psychological</b>	Relating to human behaviour.
<b>quality assurance (QA)</b>	Improving performance and preventing problems through planned and systematic activities including documentation, training and review.
<b>randomised</b>	Randomly allocated to one of more than one different choices.
<b>rationale</b>	Scientific/objective reason for taking specific action.

referral	The process whereby a patient is transferred from one professional to another, usually for specialist advice and/or treatment.
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.
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 has been associated with the increased rate of a subsequently occurring disease or health problem. Risk factors include aspects of personal behaviour, lifestyle, environmental exposure, or inborn or inherited characteristics, which are known to be associated with the disease.
Royal College of General Practitioners (RCGP)	Royal College of General Practitioners. Website: <a href="http://www.rcgp.org.uk/">www.rcgp.org.uk/</a>
SCI-DC	See Scottish Care Information - Diabetes Collaboration.
Scottish Care Information - Diabetes Collaboration (SCI-DC)	SCI (Scottish Care Information) is an integrated national programme of IM&T developments aimed at supporting the entire patient journey by developing and making available consistent IT systems and standards for use across Scotland to support clinical communication, which are owned collectively, developed and facilitated centrally. SCI-DC aims to deliver effective IT solutions to diabetes services in NHSScotland.

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<b>Scottish Diabetes Survey</b>	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.
<b>Scottish Executive Health Department (SEHD)</b>	The Scottish Executive Health Department is responsible for health policy and the administration of NHSScotland. Website: <a href="http://www.show.scot.nhs.uk/sehd">www.show.scot.nhs.uk/sehd</a>
<b>Scottish Intercollegiate Guidelines Network (SIGN)</b>	SIGN was established in 1993 by the Academy of Royal Colleges and Faculties in Scotland, to sponsor and support the development of evidence-based clinical guidelines for NHSScotland. Where a SIGN guideline exists for a specialty or service for which NHS QIS is setting standards, it will be referenced. For further information relating to SIGN guidelines or the methodology by which SIGN guidelines are developed, contact: SIGN Secretariat, Royal College of Physicians, 9 Queen Street, Edinburgh EH2 1JQ. Website: <a href="http://www.sign.ac.uk">www.sign.ac.uk</a>
<b>Scottish Morbidity Record (SMR)</b>	Data for individual patients are collected by the Information and Statistics Division (ISD) as a series of SMRs. These datasets are used for a range of purposes including epidemiological monitoring, health needs assessment, national and local planning, performance indicators, management information, costing, audit and research.
<b>screening</b>	Examination of people with no symptoms, to detect unsuspected disease.
<b>secondary care</b>	Care provided in an acute sector setting. See acute sector.
<b>secondary prevention</b>	All those factors that should be addressed, such as lifestyle changes or drugs, in order to reduce the likelihood of recurrence of, slowing or reversing the progression of disease.
<b>SEHD</b>	See Scottish Executive Health Department.
<b>self-assessment</b>	Assessment of performance against standards by individual/clinical team/Trust/NHS Board providing the service to which the standards are related.

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<b>serum creatinine</b>	A biochemical measurement or test of one of the body's waste products which is an indicator of renal function.
<b>side-effect</b>	An effect of treatment in addition to its desired therapeutic effect. A side-effect is usually unpleasant and unwanted.
<b>SIGN</b>	See Scottish Intercollegiate Guidelines Network.
<b>SIGN guideline</b>	Scottish Intercollegiate Guidelines Network guideline. See guidelines and Scottish Intercollegiate Guidelines Network.
<b>slit lamp</b>	A method of examining the structures of the eye using a special microscope.
<b>SMR</b>	See Scottish Morbidity Record.
<b>St Vincent Declaration</b>	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.
<b>standard statement</b>	An overall statement of agreed performance.
<b>statin</b>	Class of drug used to lower blood cholesterol.
<b>statutory</b>	Enacted by statute; depending on statute for its authority as a statutory provision. Required by law.
<b>systolic (blood pressure)</b>	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.
<b>thrombosis</b>	The formation of a blood clot in an artery blocking the blood supply. For example, a clot in a coronary artery can cause a heart attack.
<b>Trust</b>	See NHS Trust.
<b>Type 1 (insulin-dependent) diabetes</b>	Type 1 diabetes develops if the body is unable to produce any insulin. This type of diabetes usually appears before the age of 40. It is treated by insulin injections and diet.

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**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 it 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.

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**ulceration** Breaks or deep sores in the skin.

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**unified Board** See NHS Board.

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**Unified Health Board** See NHS Board.

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**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 body.

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**visual acuity** A measure of how well a person sees distant and close objects.

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## Our Commitment

Our work will be undertaken in line with the following values:

- **patient and public focus**
  - ~ promoting a patient-focused NHS that is responsive to the views of the public
- **independence**
  - ~ reaching our own conclusions and communicating what we find
- **partnership**
  - ~ involving patients, carers and the public in all parts of our work
  - ~ working with and supporting NHS staff in improving quality
  - ~ collaborating with other organisations such as public bodies, voluntary organisations and manufacturers to avoid duplication of effort
- **evidence-based**
  - ~ basing conclusions and recommendations on the best evidence available
- **openness and transparency**
  - ~ promoting understanding of our work
  - ~ explaining the rationale for our recommendations and conclusions
  - ~ communicating in language and formats that are easily accessible
- **quality assurance**
  - ~ aiming to focus our work on areas where significant improvements can be made
  - ~ ensuring that our work is subject to internal and external quality assurance and evaluation
- **professionalism**
  - ~ promoting excellence individually and as teams and ensuring value for money in the use of public resources (human and financial)
- **sensitivity**
  - ~ recognising the needs, opinions and beliefs of individuals and organisations and respecting and encouraging diversity

This document can be viewed on the NHS Quality Improvement Scotland website. It is also available, on request, from NHS Quality Improvement Scotland in the following formats:

- Electronic
- Audio cassette
- Large print

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