

National Overview Follow-up Report ~ *March 2008*

Diabetes

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“ I do a hard day’s work but
diabetes doesn’t stop me. ”

Barry McGrory

Introduction and acknowledgements

NHS Quality Improvement Scotland (NHS QIS) was set up by the Scottish Parliament in 2003 to take the lead in improving the quality of care and treatment delivered by NHSScotland. NHS QIS does this by setting standards, by monitoring performance, and by providing NHSScotland with advice, guidance and support on effective clinical practice and service improvements.

A part of the remit of NHS QIS 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 NHS QIS Clinical Standards for Diabetes (2nd ed.)¹ were published in October 2002. Peer review visits to all NHS board areas in Scotland were conducted in 2003 to assess performance against the standards. A local report on each NHS board and national overview of service provision were published in March 2004. Copies of these reports, and the diabetes standards, are available on request from NHS QIS or on the website (www.nhshealthquality.org).


An NHS QIS diabetes steering group was established in May 2006 to provide advice and support to NHS QIS in developing and undertaking follow-up review visits against the existing diabetes standards. The group is chaired by Dr Mike Small, Consultant Physician, NHS Greater Glasgow and Clyde. Membership of this group is given in Appendix 2.

This report, based on the NHS QIS follow-up reports for each NHS board area, presents a national overview of diabetes services within NHSScotland, reporting on the performance across Scotland against the standards and including relevant examples of local initiatives.

NHS QIS gratefully acknowledges the work of the diabetes steering group for overseeing the follow-up process 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.

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

1 NHS Quality Improvement Scotland. Clinical Standards for Diabetes (2nd ed.). Edinburgh: 2002



To support the work of the follow-up reviews, NHS QIS commissioned Diabetes UK Scotland to review the care experience of people living with diabetes, as noted in the Scottish Diabetes Framework Action Plan². To this end, Diabetes UK Scotland facilitated patient focus groups in each NHS board area across Scotland, and reported the findings in local reports. A summary of Diabetes UK Scotland's findings from these reviews can be found in Chapter 3.

The overall purpose of the review undertaken by Diabetes UK Scotland was to support the work of NHS QIS by ensuring the voice of people with diabetes and their families was also heard. Specific NHS board feedback has already been published in a series of local reports and is available on the Diabetes UK website (www.diabetes.org.uk).

Diabetes UK Scotland would like to acknowledge the investment by NHS QIS in this process. Thanks also go to the people who made the time to attend focus group discussions across Scotland; to the young people who completed survey forms; to staff from local managed clinical networks and local Diabetes UK Scotland voluntary groups who helped to promote the focus groups; to Sarah Goldsworthy for support and design of the methodology; and to all of the staff of Diabetes UK Scotland who facilitated the focus groups and wrote up the local and national reports.

Finally, NHS QIS would like to thank Diabetes UK Scotland and all those who attended the focus groups for their contribution to ensuring the views and experiences of people living with diabetes have been captured.

2 Scottish Executive. Scottish Diabetes Framework Action Plan. Edinburgh: 2006.
Available from:
<http://www.scotland.gov.uk/Resource/Doc/129328/0030795.pdf>

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Joint foreword

NHS QIS and Diabetes UK Scotland first worked together in 2000 when NHS QIS developed clinical standards for the care of people with diabetes. Performance against these standards was then reviewed in every NHS board in Scotland and Diabetes UK Scotland took part in many of the review visits. In 2004, NHS QIS published the first ever comprehensive review of diabetes services across NHSScotland and pledged to review these services again in 2007. This report builds on that work, updating the profile of Scotland's diabetes services and this time, taking into account the experience of people living with diabetes. It is the result of effective partnership working: as NHS QIS gathered information and data from service providers, Diabetes UK Scotland, in a parallel process, focused on the voices of people living with diabetes.

There is no doubt that NHS boards have made changes since the first review, and that these changes have improved services. Most NHS boards are meeting significantly more criteria now than in 2003–2004 and there is good evidence that those using these services are increasingly involved in planning and developing them. This is the backdrop against which we also looked at the experience of patients and not surprisingly, the views of patients are, at times, at odds with the information provided by healthcare professionals. Despite this, healthcare professionals are well aware of the lifelong impact of this disease on every aspect of everyday life and are clearly committed to using this review to learn how they could further improve the services they provide. Those living with diabetes were in turn very appreciative of the high standards of care provided and were very constructive about ways of working together to make this even better.

The value derived from this joint exercise rests in linking the two main stakeholder elements 'in the real world' where services and patients interact. As one patient said of her practice nurse, "she is informed, reasonable and lives in the real world." In other words, when expectations and understanding are shared between patients and staff, the experience is more likely to be positive. In turn, maintaining good health and reducing the risk of complications can be achieved.

Better Health, Better Care³ stresses the importance of a proactive and positive approach to healthcare and patient experience now informs that approach more than ever before. This is the first report NHS QIS and Diabetes UK Scotland have published together: we believe that by working in this way, we are charting a new way forward for providing healthcare for people living with long-term conditions. We are very

3 Scottish Government. Better Health, Better Care: Action Plan. Edinburgh: 2007. Available from: <http://www.scotland.gov.uk/Resource/Doc/206458/0054871.pdf>

grateful to the openness and constructive feedback provided by those providing services and those living with diabetes: without their candour – and their examples of success and challenge – it would not be possible to further improve services together. We are committed to learning from, and sharing, our experiences of this process with the aim of improving the quality of life and the quality of care for people living with diabetes in Scotland.

Audrey Birt
Director
Diabetes UK Scotland

David Steel
Chief Executive
NHS Quality Improvement Scotland

Introduction

Approximately 197,000⁴ people in Scotland have been diagnosed as having diabetes and as many as 90,000 may have the disease, but do not know it. The number of people diagnosed with diabetes is doubling every decade and treating the disease and its complications uses about 10% of the total NHS budget; over £1 billion every year. Over 80% of people with diabetes in Scotland are overweight or obese.

Diabetes is a life-long condition that generally gets worse over time. It is now:

- a major cause of stroke and coronary heart disease, and resulting deaths from these conditions
- the leading cause of blindness in people aged 20–74
- a leading cause of renal failure
- the leading cause of amputation of a lower limb, and
- a contributor to poor outcomes in pregnancy.

Clinical standards for diabetes

The care of people with diabetes is complex for the following reasons.

- As glucose control can deteriorate with time, people with diabetes need continual, regular clinical review and their need for treatment often increases over time. There are also a number of other measurable factors such as blood pressure which may require treatment. Regular screening to pick up developing complications at an early stage is important as early intervention improves outcome.
- Many different healthcare professionals and specialties are involved, including GPs, diabetologists (physicians with a specialist knowledge of diabetes), nurses, podiatrists (feet), dietitians, ophthalmologists (eyes), nephrologists (kidneys), pharmacists and psychologists. Information about each patient is collected from a number of sources and brought together as a comprehensive profile of a patient's health. If any part of this shared care is left out, vital information could be missing and this could result in poorer health.
- Perhaps, most importantly of all, is the need for patients to have a high level of self-care. In a disease where lifestyle factors are so important, patients need to develop an expertise in: diet therapy, how exercise might influence diabetic control, how to carry out home glucose testing and understand HbA1c tests, and the complexities surrounding insulin administration. Patients are also required to have an understanding of the need for and compliance with the many drugs routinely used in clinical practice.

⁴ Provisional figures taken from unpublished Scottish Diabetes Survey 2006. Latest published Scottish Diabetes Survey 2005 can be found at www.diabetesinscotland.org/diabetes/publications.asp

In 2002, national standards were set by the then Clinical Standards Board for Scotland. During 2003, every NHS board was visited to assess performance against these standards and, in 2004, NHS QIS published the findings of this review. At that time, we found high standards of clinical care and many examples of innovative and effective ways of working. We also identified a number of challenges for NHS boards and we made recommendations to address these. The priority areas for action included:

- full implementation of the national diabetic register across Scotland (Standards 1–2)
- improvements to patient involvement and information (Standard 3), and
- co-ordinating services and ensuring an annual review of all necessary parameters for people living with diabetes (Standards 4–10).

We made a commitment at that time to follow up on progress and, during 2006–2007, we visited NHS boards for a second time. This executive summary highlights the key findings of this follow-up and describes progress towards improving performance against the standards. In order to support greater involvement of people in their own care, we also commissioned the Scottish arm of Diabetes UK to run a series of focus groups across NHSScotland to learn more about people's experience of their diabetes care. Detailed findings from these focus groups are presented in Chapter 3 of this report.



Key findings of follow-up assessment against the NHS QIS clinical standards for diabetes

General

All NHS boards have made changes to their diabetes services since we first reviewed performance against these standards and there was good evidence that these changes have improved the services provided. In particular, Scotland was one of the first countries in the world to introduce a national diabetic retinopathy screening programme and NHS boards are on schedule in implementing this. Feedback on patient experience reflects the high standards of care provided and signals a shared willingness to be constructive about different ways of further improving services together. Notably, there has been an increased shift to move the care of patients with uncomplicated Type 2 diabetes from secondary to primary care.

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 services and specialties delivered in a variety of settings, co-ordination lies at the heart of diabetes care. In Scotland, an electronic shared record has been developed to support a co-ordinated approach and this maintains an up-to-date record about every patient with diabetes that can be used by all those involved in their care. This system is called the Scottish Care Information – Diabetes Collaboration (SCI-DC, pronounced ‘sky’-DC).

At the time of the initial round of review visits, only one NHS board had SCI-DC in place and whilst other NHS boards had some form of register in place, these generally did not support rapid access to up-to-date information. SCI-DC has now been rolled out across NHSScotland, with all NHS boards using this to some degree, although not all are entering data ‘real time’ – that is, during a clinic appointment. Eight NHS boards are now using SCI-DC fully. This is very encouraging, but further work is still needed on the electronic transfer of information from SCI-DC to GP practices. We also found that a very small number of GP practices still do not permit extraction of data to SCI-DC and NHS boards are encouraged to discuss this further with these practices and to make sure they have effective alternatives in place.

Of most concern was the continued lack of data interfaces that would allow one data entry to populate primary and secondary care systems. In many cases, double entry of data is needed at more than one stage and this increases the risk of errors and of missing data.

Much has been learned since SCI-DC was first implemented, and it has become clear that whereas it was originally intended to collect and provide information at the point of care, it is more effective if used as an information store that feeds a variety of local IT systems. Developing interfaces that allow systems to talk to each other and data to flow both ways has been a complex and at times frustrating process and NHS boards feel they have little control over this. We concluded that further urgent development and full roll-out of the SCI-DC system remains a priority action. This would give front-line staff and patients the information they need to plan, manage and develop all aspects of care. We **recommend** that NHS National Services Scotland focuses on this priority over the next 2 years, working closely with NHS boards as experience so far confirms it is achievable to have SCI-DC rolled out and working in real time across Scotland by 2010.

Standard 2 focuses on the way diabetes services are organised and on the infrastructure in place to support these. At the time the standards were developed, NHS boards co-ordinated diabetes services through local diabetes service advisory groups (LDSAGs) and, since then, these have matured and evolved. NHS boards now have diabetes managed clinical networks (MCNs) and these have facilitated clearer links to, and support from, NHS boards. The introduction of MCNs has supported the development of diabetes strategies and implementation plans. While few NHS boards had these in place when we first visited, most now have well-developed plans. There is also evidence of input into the NHS boards' local delivery plans. We **recommend** that NHS boards continue to build on the good work of their MCNs in improving care for patients with diabetes across their whole population.

Patient focus (Standard 3)

There is good evidence that better outcomes can be achieved if people with diabetes are fully involved in their care and are provided with clear information about how to manage their condition. Information and education can be provided in many different ways: group meetings, one-to-one sessions, information and education packs, during appointments and within a community pharmacy setting. Generally we found that NHS boards provide education to people with diabetes, both at the time of diagnosis and on an ongoing basis. However, the variety of settings in which information is given presents its own challenges and patients reported that it is not always consistent.

We found a significant improvement and willingness in the approach NHS boards use to seek patient opinions and to involve them in service development, very much supported by the setting up of MCN patient subgroups. We **recommend** that NHS boards, through their diabetes MCNs, evaluate the effectiveness of the information that is provided and the way in which it is provided.

Clinical review and management (Standards 4–10)

These standards cover the core elements of the clinical management of diabetes. They also include routine review meetings to monitor the general health and management of people with diabetes.

When we first reviewed NHS boards against the annual review criteria, we found that no NHS board could demonstrate that they carried out comprehensive annual reviews, mainly because data on lifestyle is not routinely collected. We also noted that some NHS boards were unable to offer an annual review and in some cases these were carried out at 24 months rather than 12 months. Progress has been made on this front and four NHS boards now meet these criteria. Others continue to have problems with data collection and again the introduction of SCI-DC would support the collection of this information and make it available to all those providing care.

We found good evidence that NHS boards continue to provide a very high standard of clinical care and, in particular, the number of NHS boards with a referral system for people with signs of diabetes-related retinopathy according to Health Technology Board for Scotland (HTBS) grading recommendations has risen from three in 2004 to 12 in 2006–2007. This is in line with the Scottish Government policy to roll out a national diabetic retinopathy screening programme across Scotland and to comply with the NHS QIS Clinical Standards for Diabetic Retinopathy Screening⁵.

Most NHS boards now meet all the criteria covered in the clinical management standards and we commend them for the progress that has been made. Inclusion of the Quality and Outcomes Framework (QOF) in the new General Medical Services (nGMS) contract has undoubtedly provided a welcome boost to the routine collection of the necessary data and this in turn should contribute to improved healthcare monitoring of patients with diabetes.

We **recommend** that NHS boards continue to focus on making sure that comprehensive annual reviews are carried out and that the information gathered during these reviews is recorded. Full implementation of SCI-DC will support this.



5 NHS Quality Improvement Scotland. Clinical Standards for Diabetic Retinopathy Screening. Edinburgh: 2004

Conclusion

NHSScotland has a track record of innovative and groundbreaking healthcare in diabetes. We were the first UK country to introduce a national register which collects data in real time for acute and primary care services (SCI-DC). We were one of the first countries to introduce a national diabetic retinopathy screening programme to tackle diabetes-related blindness. We were the first UK country to introduce and monitor performance against national clinical standards for diabetes, not once but with a follow-up review across Scotland as well. These investments have paid off and we found that every NHS board has improved their performance against the standards, some significantly. In particular, the standard of clinical care is more consistent than it has been in the past and is generally of a very high standard.

The incidence of diabetes continues to rise in Scotland, as in other countries, and it is now one of the most common long-term conditions. Diabetes is a progressive condition. At present, there is no cure, but there are a number of very effective steps that can be taken to prevent and manage the risk of associated conditions. In NHSScotland, we have good evidence that the following clinical steps are being taken: blood glucose and HbA1c levels are monitored; screening for kidney disease, eye disease and foot problems are performed; regular blood pressure and cholesterol levels are checked as tests of cardiovascular health, while smoking is actively discouraged. We need to ensure that these interventions which are happening for the great majority of patients in Scotland are provided to all patients. We also know that diet and lifestyle are critical and the NHS is working hard to provide the support people may need to change their lifestyles and improve their diabetes management. To ensure that these life-saving checks are being offered to everyone with diabetes, we need to know who has diabetes and we need ongoing information about their health.





Key recommendations

The establishment of MCNs has assisted in the continued development of structures and services to help support and influence the quality improvement of patient care. SCI-DC is one of the key background services which provides information that healthcare professionals need in order to provide care in a joined-up way and that meets the needs of the patients. As a result, our **key recommendations** are two-fold:

- NHS boards, together with their MCNs, should consider the gaps in the diabetes service that have been identified during their follow-up review and put systems in place to address these to demonstrate continuous service improvement.
- NHS National Services Scotland should continue to ensure the implementation of SCI-DC by 2010. This will require collaboration with NHS boards through the MCNs to make sure the necessary interfaces between systems are put in place. SCI-DC can then be used as intended – to fully support patients and front-line clinical staff in providing world class care for patients in Scotland with diabetes.





Chapter 1

Setting the scene

1 Setting the scene

1.1 Introduction to diabetes

Basic facts about diabetes⁶

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.

⁶ Adapted from: Diabetes UK. Understanding Diabetes: Your Key to Better Health. London: 2000. Reproduced with permission.

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, it 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.

Diabetes in Scotland

Approximately 197,000 people in Scotland have been diagnosed with diabetes and there are almost certainly many thousands more who are undiagnosed. As noted in the Scottish Diabetes Framework Action Plan, the prevalence of diabetes continues to rise, particularly for Type 2 diabetes which is often associated with unhealthy bodyweight. It is possible that within 25 years, one in 10 people in Scotland will have diabetes.

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.



1.2 Follow-up performance assessment review – approach taken by NHS QIS

Following the peer review visits in 2003 to assess performance against the Clinical Standards for Diabetes (2nd ed.) (October 2002), the resulting NHS board local reports were well received by both healthcare staff and patients involved in the process, and created a valuable overview and baseline of where the service stood in relation to diabetes care in Scotland in 2003–2004. In order to maintain the momentum generated from this process, NHS QIS committed to undertake a round of follow-up reviews. The Scottish Diabetes Group took a role in overseeing implementation of the updated Scottish Diabetes Framework Action Plan, which was published in June 2006. The framework stated that NHS QIS would ‘undertake a round of streamlined visits to all NHS boards to review progress in implementing diabetes standards.’

An NHS QIS diabetes steering group was established in May 2006 to provide advice and support to NHS QIS in developing and undertaking follow-up review visits against the existing diabetes standards. The group is chaired by Dr Mike Small, Consultant Physician, NHS Greater Glasgow and Clyde. Membership of this group is given in Appendix 2.

The follow-up review visits, conducted between October 2006–August 2007, primarily focused on all criteria assessed as either ‘not met’ or ‘not met (insufficient evidence)’ during the 2003 reviews, whilst ensuring that those criteria previously assessed as ‘met’ remained ‘met’.

Assessment categories

Each review team assessed performance using the following categories:

- ‘**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, and
- ‘**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.



1.3 Diabetes UK Scotland patient experience methodology

The Scottish Diabetes Framework Action Plan reported that NHS QIS ‘will work with Diabetes UK to review the care experience of people living with diabetes.’ NHS QIS commissioned Diabetes UK Scotland to facilitate this area of work. Diabetes UK Scotland organised focus group meetings involving people living with diabetes in each NHS board area in Scotland. These meetings took place between November 2006–April 2007. Attendance and participation from people with diabetes was sought through engaging with local healthcare systems such as managed clinical networks, specialist clinics, primary care staff and public involvement workers. Recruitment was also sought through the patient focus implementation group, a subgroup of the Scottish Diabetes Group, NHS QIS public partners, local Diabetes UK members, voluntary groups and local media.

Diabetes UK Scotland staff facilitated the focus groups to ensure that objectives were achieved and to collect the information received. People’s experiences were captured through individual questionnaires and group work. A process mapping exercise was undertaken to invite people to reflect on their personal experiences throughout the various stages of their journey of care, resulting in a visual representation of experiences within which gaps, delays, duplications, etc could be readily identified. The three process maps covered: healthcare professionals working together; information; and positive stories and unmet needs. Each map had seven steps: symptoms, diagnosis, assessment, treatment, information, education and review.

Data subsequently collated from the questionnaires, process maps and from information gathered at the focus group meetings were compiled into local reports for each NHS board, and a national patient perspective summary report which has been incorporated within this report.

NHS QIS acknowledges the work undertaken by Diabetes UK Scotland to review the care experience of people living with diabetes. There are approximately 197,000 people diagnosed with diabetes in Scotland. Approximately 450 of them fed into the focus groups and contributed to a survey held across Scotland. Their contribution to this report reflects the real experiences of the individuals involved.

1 Setting the scene





Chapter 2

**Findings and progress
since 2004**

2 Findings and progress since 2004

During the follow-up review of diabetes services, 14 NHS boards were reviewed to assess continued performance against the standards. It should be noted that, following the dissolution of NHS Argyll & Clyde on 31 March 2006, the administrative boundaries of NHS Greater Glasgow and NHS Highland altered to allow them to take over the responsibility for managing the delivery of health services in the former Argyll and Clyde area. Information covering Argyll and Clyde has subsequently been incorporated into the relevant NHS board follow-up report: Argyll & Bute has been incorporated into the NHS Highland follow-up report and Clyde has been incorporated into the NHS Greater Glasgow and Clyde follow-up report.

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 featured at the end of each standard section. 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. Challenges are also listed and there is certainly scope for continued 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 diabetic care, there are now many examples of successful partnership working.

2.1 Detailed findings against the standards

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.

Assessment category	NHS boards	
	2004	2007
met	1	8
not met	14	6
not met (insufficient evidence)	-	-

In 2004, all NHS boards had some form of area-wide register of people with a recorded diagnosis of diabetes. However, there had been a delay in the implementation of the national project, SCI-DC, which had impacted on the extent to which NHS boards could fully establish up-to-date, population-based electronic clinical management systems for all people with diabetes. The extraction of accurate figures from the various IT systems in use across primary and secondary care was problematic.

SCI-DC Clinical (hospital-based system) and SCI-DC Network (a web-based clinical support system) have since been rolled out for use across

NHSScotland. There was, however, variability in the use of SCI-DC as to whether information was being entered real time during the clinic appointment, or entered onto the system after the clinic by medical or administrative staff.

About half of GP practices use General Practice Administration System for Scotland (GPASS), which is a practice-based IT system. Data entered into GPASS automatically populates SCI-DC Network. For GP practices not using GPASS (ie those using systems such as EMIS, Vision), work was ongoing nationally to establish links to electronically transfer information to SCI-DC Network to allow continuous data collection. By the end of the follow-up reviews, some systems had this electronic link in place. However, for those GP practices still without a link, it was necessary for primary care staff to manually input data.

There were a very small number of GP practices which do not permit the extraction of data to SCI-DC due to patient consent and confidentiality issues. As a result, not all patients registered with diabetes in these NHS board areas were recorded on SCI-DC.

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

Assessment category	NHS boards	
	2004	2007
met	-	-
not met	15	14
not met (insufficient evidence)	-	-

In 2004, there were no data interfaces in place so that one single data entry populated the primary and secondary care information systems. This system remains unchanged. Double data entry was still required for some non-GPASS practices where electronic links are not in place for the automatic transfer of data to SCI-DC Network. There was also no facility to back-populate data from SCI-DC Clinical into primary care systems. In addition, links between SCI Store (which holds X-ray and laboratory test results) and SCI-DC were not nationally available, resulting in double data entry of test results.

As a result, this criterion will not be 'met' across Scotland until the national SCI-DC Network system fully interfaces with all other relevant NHS information systems.

3 The Board participates in the Scottish Diabetes Survey.

Assessment category	NHS boards	
	2004	2007
met	14	14
not met	1	-
not met (insufficient evidence)	-	-

The follow-up reviews confirmed that all NHS boards now participate in the Scottish Diabetes Survey.

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.

Assessment category	NHS boards	
	2004	2007
met	1	3
not met	14	11
not met (insufficient evidence)	-	-

Specific examples were presented during the follow-up reviews of data extracted from SCI-DC being used for service planning and development purposes. Some NHS boards were still at the stages of verifying the reliability of data before using for audit purposes. In many NHS boards, processes were variable in relation to data quality assurance and validation, aside from the use of data value parameter checks within SCI-DC. In addition, not all NHS boards were able to collect data on a continuous basis as a result of the need to manually input data into SCI-DC. Timescales for manual input varied considerably. This issue will be resolved once system links are in place to allow electronic transfer of information to SCI-DC Network from non-GPASS practices. However, some NHS boards commented that local, dedicated IT support continued to be an issue.

Access to SCI-DC can be variable, particularly for healthcare professionals working in the community and not attached to a GP practice.

Desirable Criterion

5 The computerised clinical management system is Board-wide and incorporates call and recall systems for screening/review of complications.		
Assessment category	NHS boards	
	2004	2007
met	-	-
not met	15	14
not met (insufficient evidence)	-	-

In 2004, there were no NHS board-wide clinical management systems in place, resulting in no NHS boards meeting this criterion. Although the national SCI-DC system has now been implemented across NHSScotland, it has no call and recall function; as a consequence, this criterion cannot be 'met'. NHS boards use their own local call-recall systems.

Strengths

- SCI-DC is accessible across NHSScotland.
- The continued submission of data by NHS boards for the Scottish Diabetes Survey.
- Continuous data collection from the majority of GP practices, with system links being established for the remaining non-GPASS practices to allow electronic transfer of information to SCI-DC Network.
- The use of SCI-DC data for service planning and service development.

Challenges

- The implementation of formal processes for data quality assurance and validation, and to facilitate regular audit of data.
- The continued roll-out of electronic links to SCI-DC Network for the remaining non-GPASS practices.
- The continued provision of local, dedicated SCI-DC IT support.



Recommendations

NHS National Services Scotland to:

- address national issues with SCI-DC, including the further development of IT links to SCI-DC Network to facilitate sharing of patient information and to reduce the need for double data entry across the primary and secondary care information systems.

NHS boards to:

- provide local, dedicated SCI-DC IT support.

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.

Assessment category	NHS boards	
	2004	2007
met	4	10
not met	11	4
not met (insufficient evidence)	-	-

The follow-up reviews demonstrated significant improvement, with most NHS boards having a local diabetes strategy and implementation plan in place. This has been strengthened by the introduction of diabetes MCNs, which has facilitated clear links to, and support from, the NHS board. Through the MCNs and formal diabetes strategies, there has been evidence of input into NHS boards' local health plans.

For those NHS boards not meeting this criterion, diabetes strategies and implementation plans were either unclear or were in draft format.

- 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.

Assessment category	NHS boards	
	2004	2007
met	7	13
not met	8	1
not met (insufficient evidence)	-	-

In most NHS boards, the previous LDSAGs have since evolved into diabetes MCNs. These MCN strategic groups report to and are accountable to the NHS board through clinical governance reporting structures. Most MCNs had various operational subgroups identified to target and progress specific areas of work. In the one NHS board not to meet this criterion, the MCN steering group had not convened for some time due to the absence of a lead clinician in diabetes.

- 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.

Assessment category	NHS boards	
	2004	2007
met	4	8
not met	11	5
not met (insufficient evidence)	-	1

Shared care arrangements and referral pathways, although not always formal, are in place in all NHS boards, with recognition and clear awareness of where care is delivered and where patients are seen. However, in some NHS boards, where formal guidelines are in place, it was not evident that there was appropriate distribution of, and access to, the guidelines, particularly across primary care.

There had been a notable shift to move the care of patients with uncomplicated Type 2 diabetes back into primary care, allowing specialist staff in secondary care to focus on the treatment of patients with more complex medical problems. In a few NHS boards, diabetes local enhanced services have been introduced whereby GPs receive additional monies for delivering an enhanced diabetes service in primary care.

More use was being made of staff intranets and local diabetes websites through the NHS boards, allowing both staff and patients access to, for example guidelines, patient information and literature.

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

Assessment category	NHS boards	
	2004	2007
met	15	14
not met	-	-
not met (insufficient evidence)	-	-

The follow-up reviews confirmed that all patients continued to have individualised plans of care. Small disparate areas used specific patient-held records, for example in some GP practices or for select patient groups, eg obstetric patients. Following the launch of the SCI-DC patient-held summary record, some NHS boards had commenced using this facility, as highlighted in the Scottish Diabetes Framework Action Plan. This will allow patients to obtain a printed summary of their personal information held within their SCI-DC patient record, including results and agreed patient targets.

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

Assessment category	NHS boards	
	2004	2007
met	14	12
not met	1	2
not met (insufficient evidence)	-	-

All but two NHS boards had identified lead clinicians for diabetes in primary and secondary care. In the two NHS boards not to meet this criterion, the position of lead clinician was vacant at the time of the follow-up review, although an appointment had been made in one of the areas.

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.

Assessment category	NHS boards	
	2004	2007
met	10	14
not met	3	-
not met (insufficient evidence)	2	-

The follow-up reviews demonstrated that all NHS boards now have systems in place across primary and secondary care for the management of patients who default from clinics.

Strengths

- Most NHS boards have a diabetes strategy and implementation plan which feed into NHS boards' local health plans.
- The establishment of effective diabetes MCN strategic groups which report to and are accountable to the NHS board through clinical governance reporting structures.
- The transfer of care of patients with uncomplicated Type 2 diabetes back into primary care/introduction of diabetes local enhanced services.

Challenge

- Formalising patient referral pathways in all areas, particularly with the shift in care from secondary to primary care.

Recommendations

NHS boards to:

- develop clear patient pathways and referral guidelines between primary and secondary care.
- commence using the SCI-DC patient-held summary record.

Example of a local initiative

NHS Greater Glasgow and Clyde

The MCN primary care/secondary care interface subgroup has been established which deals with patient management issues across primary and secondary care. This group has been responsible for several initiatives, including the development of clear referral protocols across primary and secondary care and an agreed microalbuminuria guideline which is applied across primary and secondary care.

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.

Assessment category	NHS boards	
	2004	2007
met	10	12
not met	3	2
not met (insufficient evidence)	2	-

The majority of NHS boards had well-established systems in place for the provision of formal educational sessions to patients newly diagnosed with diabetes. This was through the use of educational checklists, standardised information and education packs and individual or structured group education sessions, held as appropriate. A number of NHS boards had implemented Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (DESMOND). This is a structured multidisciplinary, national education programme for patients newly diagnosed with Type 2 diabetes, and was identified in the Scottish Diabetes Framework Action Plan as one means of ensuring access to structured education sessions.

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

Assessment category	NHS boards	
	2004	2007
met	6	9
not met	9	5
not met (insufficient evidence)	-	-

There was recognition that patients receive education on an ongoing basis during review appointments across primary and secondary care. However, in some NHS boards, the provision of additional ongoing education and initiatives was variable. Difficulties were noted in the logistics of running group educational events in rural areas due to population and geographical constraints.

During the follow-up reviews, a successful pilot was being undertaken across three NHS board areas implementing Dose Adjustment for Normal Eating (DAFNE), an education programme for patients with Type 1 diabetes. This was identified in the Scottish Diabetes Framework Action Plan as one means of improving the quality of education available to people with Type 1 diabetes. Across NHS boards, other locally adopted education courses were also available.

A number of NHS boards had undertaken educational events such as hosting patient conferences and awareness-raising sessions. Several NHS boards had invited a theatre company to run local performances of a play considering the different aspects of having and living with Type 2 diabetes. Educational events were also being undertaken in collaboration with other local condition-specific MCNs.

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.

Assessment category	NHS boards	
	2004	2007
met	13	14
not met	2	-
not met (insufficient evidence)	-	-

The follow-up reviews demonstrated that specific care programmes continue to exist for different patient groups across all NHS boards. It was particularly evident that care programmes for paediatric patients, pre-pregnancy and pregnant women were well covered, and there has been a notable increase in the provision of comprehensive adolescent and transitional care clinics.

Additionally, greater awareness and consideration was being given to the requirements of ethnic minority patients with diabetes through the establishment of specific clinics in areas where there are large ethnic populations, and the use of translated literature and educational materials.

Much work was also under way in relation to the needs of people with diabetes who live in nursing or residential homes, through the provision of link nurse networks to provide further education and support.

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

Assessment category	NHS boards	
	2004	2007
met	11	13
not met	4	1
not met (insufficient evidence)	-	-

The follow-up reviews indicated a major improvement and willingness in relation to seeking patient opinions and consulting on service development. This has been assisted with the development of MCN patient subgroups and forums.

Some NHS boards were working across other local condition-specific MCNs to provide training and develop induction packs and information for use by representatives on MCN strategic groups.

Desirable Criteria

5 People with diabetes have appropriate access to identified key health professionals including state registered podiatry and dietetic, nursing and psychology services.		
Assessment category	NHS boards	
	2004	2007
met	2	2
not met	13	12
not met (insufficient evidence)	-	-

In the majority of NHS boards, there was appropriate access to podiatry, dietetic and specialist nursing services. However, some NHS boards were undertaking service redesigns, particularly in relation to dietetic and podiatry services, in recognition of the need for more effective use of resources and to identify required changes to referral and treatment pathways. In several NHS boards, lack of access to community dietetics was highlighted as an issue.

Additionally, although a small number of NHS boards had made progress since 2004, issues remain in relation to the provision of dedicated diabetes clinical psychology support, particularly for adult patients.

Many NHS boards were providing additional training for staff to increase skills in psychological interventions and motivational techniques such as cognitive behavioural therapies. This was identified in the Scottish Diabetes Framework Action Plan as a means of improving access to psychological and emotional support for people with diabetes.

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

Assessment category	NHS boards	
	2004	2007
met	12	13
not met	2	1
not met (insufficient evidence)	1	-

The follow-up reviews confirmed that members of the diabetes team continued to have appropriate access to training courses, including the provision of update education sessions from formal accredited courses such as those delivered from the universities of Warwick and Bradford.

There was recognition, particularly in smaller NHS boards, of resource implications for staff attending formal diabetes courses. To combat this, some NHS boards had developed their own local diabetes accredited courses to provide educational opportunities to more staff.

As identified in the Scottish Diabetes Framework Action Plan, many NHS boards were undertaking training needs analyses to establish the diabetes educational needs of staff across primary and secondary care, and to identify and target educational gaps.

Strengths

- Well-established systems are in place for the provision of education to patients newly diagnosed with diabetes.
- There is continued provision of specific care programmes for different patient groups across all NHS boards.
- There has been an increase in the provision of comprehensive adolescent and transitional care clinics.
- There is greater awareness and consideration being given to the requirements of ethnic minority patients with diabetes.
- There has been an improvement in the willingness to seek patient opinions and consult on service development.
- Diabetes MCNs are linking with other local condition-specific MCNs.

Challenges

- The provision of formal ongoing education.
- There are resource implications for staff attending formal diabetes courses or for provision of education for patients.

Recommendations

NHS boards to:

- continue with service redesign planning, particularly in relation to dietetic and podiatry services, in recognition of the need for more effective use of resources and to identify required changes to referral and treatment pathways.
- develop packages of ongoing education for patients after diagnosis.
- ensure the provision of dedicated diabetes clinical psychology support, particularly for adult patients.

Examples of local initiatives

NHS Dumfries & Galloway

A joint adolescent and young adult evening clinic is held every 2 months in Dumfries. This is a 4-year transition clinic for patients aged 16–20 years. As well as proving a successful and beneficial service to patients, the clinic has provided the opportunity for increased staff learning and sharing of best practice. Staff alternate to ensure an appropriate skill mix. Patients will either see the adult consultant diabetologist and a paediatric diabetes specialist nurse, or the consultant paediatrician with an adult diabetes specialist nurse.

NHS Forth Valley

The ‘Way to Go’ initiative is being implemented in NHS Forth Valley. This pilot project was funded by the Scottish Diabetes Group for 2 years to ensure people with Type 2 diabetes receive a full range of effective dietary advice in primary care while making the best use of dietitians’ time. Recommendations from the pilot project are now being used in primary care to train staff on the dietary treatment of patients with Type 2 diabetes. This will provide a support and advice service, allowing more complex patients to be seen as appropriate by a dietitian. This will also inform a redesign of the dietetic service for patients with Type 2 diabetes.

NHS Grampian

An innovative training programme, the Aberdeen Introductory Course in Teaching and Training for Diabetes Healthcare Professionals, has been developed and piloted. This in-house course has been designed for staff who are interested in extending their knowledge and skills in teaching and training, with a view to enhancing contributions to patient and staff support.



NHS Greater Glasgow and Clyde

Staff across the NHS board area have been undertaking Urdu classes at the University of Strathclyde to learn basic conversational phrases through the 'Languages for Health' partnership between the University of Strathclyde and NHS Greater Glasgow and Clyde. This is aimed at increasing cultural awareness among healthcare professionals and was reported to have proved very successful.

NHS Lanarkshire

A patient education strategy is under development which includes patient education pathways for patients with Type 1 or Type 2 diabetes, from initial diagnosis through to ongoing education.

NHS Tayside

A centralised booking system for patient education is in operation through SCI-DC, whereby any healthcare professional in the GP practice can book patients onto an education session. This online booking system is being further developed to improve functionality and also to provide information on attendance rates and waiting times.

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.

Assessment category	NHS boards	
	2004	2007
met	-	4
not met	15	10
not met (insufficient evidence)	-	-



In 2004, problems surrounding poor data collection had resulted in difficulties in relation to the recording of data for clinical factors. Consequently, no NHS board met this criterion. Annual reviews in both primary and secondary care were offered at intervals of between 12–15 months, although in one NHS board annual reviews ranged between 12–24 months.

Since publication of the NHS Quality Improvement Scotland (NHS QIS) Clinical Standards for Diabetes (2nd ed.), it should be noted that QOF, part of the nGMS contract, allows a 15-month period for annual patient review. During the follow-up reviews, one NHS board was identified as requiring to actively manage the annual review process as it remained outwith the nGMS contract stipulations.

The QOF, introduced in 2004, is a system to remunerate general practices for providing good quality care to their patients and to help support work to further improve the quality of healthcare delivered. QOF includes evidence-based indicators and disease prevalence rates for specific diseases or conditions. This includes 18 diabetes clinical indicators which relate to patients with Type 1 or Type 2 diabetes. For the purposes of the follow-up reviews, QOF data were used to assess and support the recording of the relevant indicators noted in this criterion. It was agreed that a 90% recording achievement rate would be acceptable, with the exception of retinal screening which should be assessed at 80% in line with the NHS QIS Clinical Standards for Diabetic Retinopathy Screening.

During the follow-up reviews, NHS boards were able to demonstrate over 90% achievement rates for most of the relevant diabetes clinical indicators. However, for those NHS boards that did not meet the criterion, difficulties predominantly lay in achieving over 90% for microalbuminuria testing and foot screening although, in the main, figures for both these clinical indicators were over 80%. Improving the uptake/availability of microalbuminuria testing was identified as a challenge in the previous NHS QIS diabetes national overview (March 2004). Although the actual uptake for microalbuminuria testing has improved, challenges remain as a result of issues with IT.

There remained appropriate initiatives in place to discuss and manage lifestyle and well-being factors, such as smoking cessation services and exercise referral prescription schemes.

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

Assessment category	NHS boards	
	2004	2007
met	9	10
not met	4	4
not met (insufficient evidence)	2	-

The follow-up reviews demonstrated an increase in the availability of near patient testing or pre-clinic blood testing which allows results, both normal and abnormal, to be available at the time of the patient's consultation. However, for those NHS boards that did not meet this criterion, patients were not being routinely or proactively informed of normal results until their next appointment, particularly in relation to important clinical diabetes parameters, for example HbA1c and cholesterol.

Desirable Criterion

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

Assessment category	NHS boards	
	2004	2007
met	12	12
not met	3	2
not met (insufficient evidence)	-	-

The follow-up reviews demonstrated that, in the vast majority of cases, referring practitioners were given feedback regarding the outcome of their referrals. This had been aided by the implementation of SCI-DC.



Strengths

- The use of QOF data to assess and support the recording of the relevant diabetes clinical indicators.
- There is an increasing emphasis on appropriate lifestyle and well-being initiatives, such as smoking cessation services and exercise referral prescription schemes.
- The increase in the availability of near patient testing or pre-clinic blood testing.

Challenge

- In the absence of near patient testing or pre-clinic blood testing, routinely and proactively informing patients of normal results, particularly in relation to important clinical diabetes parameters, for example HbA1c and cholesterol.

Recommendation

NHS boards to:

- improve patient uptake of microalbuminuria testing and implement better recording systems to capture these results.

Example of a local initiative

NHS Borders

The lifestyle advisor and support service is a new service which supports and assists patients to make changes to their lifestyles to promote and protect their health for the future. This service is already available to people with diabetes in Kelso and Hawick and will be rolled out across NHS Borders over a 2-year period.

Standard 5 Clinical management: Eyes

Standard Statement

All people with diabetes who have identified signs of developing diabetes-related, sight-threatening retinopathy, according to Health Technology Board for Scotland (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.

Assessment category	NHS boards	
	2004	2007
met	3	12
not met	12	2
not met (insufficient evidence)	-	-

A national diabetic retinal screening programme is available across NHSScotland. This is the first such national screening service in the UK and should ensure that all people with diabetes have access to effective retinopathy screening, through use of either fixed camera sites and/or mobile screening services. This was identified as a priority in the Scottish Diabetes Framework Action Plan. However, IT difficulties do remain in some NHS boards. It is anticipated that the screening programme will be fully implemented in all areas by March 2008, pending resolution of national software issues.

There remained direct referral processes to consultant ophthalmologists in accordance with HTBS grading recommendations.

As identified in Criterion 4.1, QOF data indicated that, in all NHS boards, over 80% of patients with diabetes had a record of retinal screening in line with the NHS QIS Clinical Standards for Diabetic Retinopathy Screening. However, across several NHS boards, it was reported that there were issues in relation to high non-attendance rates to retinal screening services.

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

Assessment category	NHS boards	
	2004	2007
met	11	13
not met	2	1
not met (insufficient evidence)	2	-

In the vast majority of areas, mechanisms were in place to ensure that all people whose eye examination has revealed retinopathy have their glycaemic control and blood pressure reviewed and treated as clinically indicated. Generally, copies of patients' retinopathy screening reports were sent to the appropriate clinician to ensure heightened management and review of targets for glycaemic control and blood pressure.

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

Assessment category	NHS boards	
	2004	2007
met	15	14
not met	-	-
not met (insufficient evidence)	-	-

The follow-up reviews confirmed that all people with active proliferative diabetic retinopathy continue to be offered laser treatment.

Strength

- The national diabetic retinal screening programme is available across NHSScotland.

Challenge

- The full roll-out of national diabetic retinal screening programme across NHSScotland.

Recommendation

Scottish Diabetes Retinopathy Screening (DRS)

Collaborative to:

- resolve national software issues in relation to the diabetic retinal screening programme.

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.

Assessment category	NHS boards	
	2004	2007
met	9	12
not met	4	1
not met (insufficient evidence)	2	1

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

Assessment category	NHS boards	
	2004	2007
met	12	12
not met	1	1
not met (insufficient evidence)	2	1

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

Assessment category	NHS boards	
	2004	2007
met	9	12
not met	6	2
not met (insufficient evidence)	-	-

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 Infarction⁷.


Assessment category	NHS boards	
	2004	2007
met	15	13
not met	-	-
not met (insufficient evidence)	-	1

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

Assessment category	NHS boards	
	2004	2007
met	12	12
not met	1	1
not met (insufficient evidence)	2	1

⁷ Clinical Standards Board for Scotland (CSBS). Clinical Standards for Secondary Prevention following Acute Myocardial Infarction. Edinburgh: 2000

The vast majority of NHS boards had the required protocols in place for the management of cardiovascular problems in people with diabetes, although there were some inconsistencies in relation to dissemination and implementation of guidelines, particularly across primary care.



NHS boards reported that there were plans to review and update local cardiovascular guidelines following publication in February 2007 of the updated Scottish Intercollegiate Guidelines Network (SIGN) angina guideline⁸.

Strength

- There are protocols for the management of cardiovascular problems in people with diabetes.

Challenge

- Ensuring the dissemination and implementation of protocols across primary care.

Recommendation

NHS boards to:

- give consideration to the provision of dedicated cardiovascular risk clinics, which could be nurse or pharmacy-led.

Example of a local initiative

NHS Lothian

Cardiovascular risk clinics, run by pharmacists, have been provided throughout the NHS board area. These clinics, which assess patients' ability to take their medication and offer lifestyle advice, have been shown to be effective in reducing blood pressure and cholesterol levels.

8 Scottish Intercollegiate Guidelines Network (SIGN). SIGN Guideline 96: Management of Stable Angina. Edinburgh: 2007

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.

Assessment category	NHS boards	
	2004	2007
met	13	14
not met	2	-
not met (insufficient evidence)	-	-

The follow-up reviews confirmed that there were rapid referral processes in place in all NHS boards for people with diabetes with associated foot problems.

In some NHS boards, a review of podiatry services and the implementation of risk stratification strategies had resulted in changes to referral and treatment pathways. Following appropriate training, routine foot screening of low risk patients was increasingly being undertaken in the community by practice nurses. Additionally, in some NHS boards, low and moderate risk patients were being referred back for management in primary care, with the opportunity to rapidly refer patients to specialist secondary care services when required.

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

Assessment category	NHS boards	
	2004	2007
met	14	13
not met	1	1
not met (insufficient evidence)	-	-

Please refer to Criterion 3.5. Almost all NHS boards had appropriate access to state registered podiatry services.

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

Assessment category	NHS boards	
	2004	2007
met	7	10
not met	7	4
not met (insufficient evidence)	1	-

Most NHS boards had protocols for both drug and pressure relief treatment of diabetic foot disease. For those NHS boards that had no drug or antibiotic protocol in place, antibiotics were prescribed in primary care at the request of podiatry staff.

Work is under way by the Scottish Diabetes Specialist Podiatrist Group to develop national guidance in both areas.

Desirable Criterion

4 All people with diabetic foot ulcers are reviewed by a diabetes foot specialist, using digital camera photographs for comparison.		
Assessment category	NHS boards	
	2004	2007
met	2	10
not met	13	4
not met (insufficient evidence)	-	-

In all NHS boards, patients with diabetic foot ulcers were referred into secondary care and assessed by a specialist podiatrist. Digital cameras were widely available in secondary care to photograph diabetic foot ulcers for comparison and monitoring purposes, but were less readily available in primary care. For a small number of NHS boards with access to digital photography, it was not always routine practice to photograph all diabetic foot ulcers.

In the main, digital images were printed off and held in the patient record as there is currently no mechanism to link digital images to SCI-DC.

Strengths

- The review of podiatry services and implementation of risk stratification strategies which are resulting in changes to referral and treatment pathways.
- There are rapid referral processes for people with diabetes with associated foot problems.
- The use of digital cameras to photograph diabetic foot ulcers for comparison and monitoring purposes.
- Routine foot screening of low risk patients is being undertaken in the community.

Challenges

- Ensuring routine practice to photograph all diabetic foot ulcers.
- Availability and access to digital cameras in primary care.

Recommendations

NHS boards to:

- encourage implementation of national foot risk assessment scoring systems.

SCI-DC Steering Group to:

- ensure that mechanisms are in place to link digital images to SCI-DC to allow sharing with other healthcare professionals.

Example of a local initiative

NHS Western Isles

A dual retinal/podiatry screening programme was undertaken in 2004. This was a one-off pilot exercise to ensure capture of all patients with diabetes. Annual foot screening was undertaken by a podiatrist within a 6-week timeframe at adjacent GP practices in conjunction with patients undergoing retinal screening with the Tayside mobile retinal screening unit.

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.

Assessment category	NHS boards	
	2004	2007
met	12	13
not met	3	1
not met (insufficient evidence)	-	-

All NHS boards had protocols and guidance in place to ensure drug and insulin therapy is individually tailored to achieve the best possible glycaemic control. However, in one NHS board there was not specific guidance for children to ensure appropriate tailoring of insulin; children were managed in accordance with general guidance.

In many NHS boards, there was a shift to provide insulin initiation and adjustment for patients in primary care, with support from diabetes specialist nurses when required. In two NHS boards, there were a number of community diabetes specialist nurses who work across the community health partnerships to support primary care.

Work was under way in many NHS boards to produce and implement local insulin strategy documents, as recommended in the Scottish Diabetes Framework Action Plan. Additionally, most NHS boards were developing an insulin pump therapy service, in accordance with national guidelines.

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

Assessment category	NHS boards	
	2004	2007
met	13	14
not met	2	-
not met (insufficient evidence)	-	-

The follow-up reviews confirmed that HbA1c measurements were standardised in each NHS board using a Diabetes Control and 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.

Assessment category	NHS boards	
	2004	2007
met	13	14
not met	2	-
not met (insufficient evidence)	-	-

Through the implementation of SCI-DC and QOF, there was a raised awareness and increased reliability of data surrounding HbA1c measurements.

Sequential HbA1c measurements can be extracted from SCI-DC to identify people with diabetes who have poor glycaemic control, including a graph charting facility. Additionally, measurements and specific targets can be provided through the SCI-DC patient-held summary record.

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

Assessment category	NHS boards	
	2004	2007
met	14	14
not met	-	-
not met (insufficient evidence)	1	-

In all NHS boards, patients were encouraged to self-monitor hypo/hyperglycaemia events through, for example, patient diaries or self-referral to the diabetes team. These clinical events are then discussed at routine review appointments.

However, issues were apparent in relation to patients being treated at home by Scottish Ambulance Service staff or being treated and discharged through the accident and emergency (A&E) department. There is a lack of cohesion and information-sharing between these agencies and the diabetes service.

Desirable Criterion

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

Assessment category	NHS boards	
	2004	2007
met	8	12
not met	7	1
not met (insufficient evidence)	-	1

The follow-up reviews demonstrated an increase in the availability of near patient testing or pre-clinic blood testing for HbA1c which allows results, both normal and abnormal, to be available at the time of the patient's consultation. However, for two NHS boards there was no evidence to demonstrate that patients were routinely or proactively informed of normal results until their next appointment.

Additionally, with the implementation of SCI Store, healthcare professionals have easier access to patient results.

Strengths

- The availability of sequential HbA1c measurements.
- There has been an increase in the availability of HbA1c near patient testing or pre-clinic blood testing.
- The development of local insulin strategy documents.
- Insulin initiation and management for patients in primary care.
- The continued development of insulin pump therapy services.
- The use of community diabetes specialist nurses who work across the community health partnerships to support primary care.

Challenges

- Routinely and proactively informing patients of normal HbA1c results in the absence of near patient testing or pre-clinic blood testing.
- Ensuring adequate provision of insulin pump therapy services for suitable patients.

Recommendation

NHS boards and Scottish Ambulance Service to:

- ensure better recording of diabetic emergencies through collaboration and information-sharing between A&E, the Scottish Ambulance Service and the diabetes service.

Examples of local initiatives

NHS Fife

A new post of diabetes ward liaison nurse is being trialled at Victoria Hospital, Kirkcaldy, for one year, which the review team commended. The diabetes ward liaison nurse undertakes daily visits to all medical wards, monitoring and providing advice to patients with regard to modification of insulin, identifying potential problems and providing education to patients and staff. This proactive role has been well received by patients, nursing, medical and pharmaceutical staff. As a direct result of the introduction of this post, critical incidents involving patients with diabetes have reduced from 17% to 5%.

NHS Lanarkshire

An insulin dose prescription chart was fully implemented across all three hospital sites in January 2007. The chart also includes guidance on the suggested treatment of confirmed hypoglycaemia. It was reported that a small audit on usage of the chart has since been undertaken.

NHS Orkney

Diabetes specialist staff maintain regular contact with adolescent patients with diabetes by text messaging to their mobile telephones. Staff and patients have used this method of communication for over 5 years in Orkney.

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.

Assessment category	NHS boards	
	2004	2007
met	9	12
not met	6	1
not met (insufficient evidence)	-	1

All NHS boards had renal referral guidelines in place which, in most areas, were being updated and revised to reflect estimated glomerular filtration rate (eGFR) referral criteria as a standard measurement of renal function. This greater assisted in the referral between diabetes and renal services and was increasingly being reported as standard by laboratories. The Scottish Diabetes Framework Action Plan has placed greater emphasis on the recording of eGFR for patients.

Generally, there appeared to be close working relationships between renal and diabetes staff in the NHS board areas. Joint diabetes/renal clinics were available in some NHS boards.

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.

Assessment category	NHS boards	
	2004	2007
met	10	12
not met	2	-
not met (insufficient evidence)	3	2

Most NHS boards had arrangements in place to ensure more frequent review of blood pressure, glycaemic control and serum cholesterol levels, when required, as part of ongoing diabetes management.

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

Assessment category	NHS boards	
	2004	2007
met	3	1
not met	1	-
not met (insufficient evidence)	11	13

In 2004, there were problems with collecting and accessing information on numbers of angiotensin converting enzyme (ACE) inhibitors prescribed. Information on the number of people with microalbuminuria or proteinuria who have been prescribed an ACE inhibitor is now collected as part of QOF data. The majority of QOF data submissions from the NHS boards recorded over 80% of eligible patients being prescribed an ACE inhibitor. It was noted that QOF requires exception reporting for patients not prescribed an ACE inhibitor. However, it was recognised that QOF data are unable to distinguish between patients with Type 1 or Type 2 diabetes.

In one NHS board, a specific audit had been undertaken through data on SCI-DC to demonstrate that patients with Type 1 diabetes had been prescribed an ACE inhibitor.

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.

Assessment category	NHS boards	
	2004	2007
met	11	12
not met	4	2
not met (insufficient evidence)	-	-

The majority of NHS boards had good access to dietetic services for people with diabetes-related renal problems. However, in two NHS boards there was limited availability to renal dietetic services to ensure appropriate dietetic intervention for all patients.

Strength

- The use of eGFR referral criteria as a standard measurement of renal function to aid referral between diabetes and renal services.

Challenges

- The availability of renal dietetic services to ensure appropriate dietetic intervention for all patients.
- QOF data are unable to distinguish between patients with Type 1 or Type 2 diabetes.
- Use of SCI-DC data to audit required information on patients being prescribed ACE inhibitors.

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 initial and follow-up 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.

Assessment category	NHS boards	
	2004	2007
met	13	14
not met	2	-
not met (insufficient evidence)	-	-

All NHS boards had protocols for the acute management of diabetic emergencies, normally contained within the NHS board's diabetes management guidelines. A national protocol for the acute management of diabetic ketoacidosis (DKA), developed by the Scottish Diabetes Group, was being used in a number of NHS boards. An audit of usage of this national protocol was being undertaken across the north of Scotland, as noted in the Scottish Diabetes Framework Action Plan.

Some NHS boards had developed, and were increasingly using, integrated care pathways (ICPs) to track a patient's journey of care from admittance to discharge following a diabetic emergency.

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

Assessment category	NHS boards	
	2004	2007
met	10	14
not met	5	-
not met (insufficient evidence)	-	-

The follow-up reviews confirmed that all patients admitted to hospital with DKA were reviewed by a specialist prior to discharge.

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.

Assessment category	NHS boards	
	2004	2007
met	11	14
not met	4	-
not met (insufficient evidence)	-	-

The follow-up reviews confirmed that patients who experience severe hypoglycaemia were referred, on recovery, to specialist diabetes services for advice on psychological, clinical and lifestyle aspects of their care. Psychological intervention could be provided by members of the diabetes team, when required.

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

Assessment category	NHS boards	
	2004	2007
met	4	5
not met	11	8
not met (insufficient evidence)	-	1

In 2004, the recording of diabetic emergencies was poorly monitored, due in part to the lack of integrated IT systems. There was also a dependence on the national Scottish Morbidity Record (SMR) system; however, this system was deemed unreliable due to problems with inaccurate assigning of codes and issues surrounding identification of the type of emergency presentation.

There remains an inconsistency with SMR clinical coding, although it was noted that this is less of an issue in smaller NHS boards where consultant staff can verify codes. Additionally, issues remain around the linking of clinical management systems in A&E and the sharing of patient information with diabetes services. It is anticipated that the implementation of a new national A&E system should assist in better identifying patients who present with a diabetic emergency.

Outwith the use of SMR data, various individualised audits were being undertaken in some NHS boards. Notably, one NHS board, in liaison with the Scottish Ambulance Service, was undertaking an audit of the number of cases of severe hypoglycaemia treated in the community by ambulance paramedic staff, to ensure diabetes specialist input for every patient, regardless of the point of contact with the health service.

Strengths

- There are protocols for the acute management of diabetic emergencies.
- Patients who experience acute diabetic emergencies receive specialist diabetes review and follow-up.

Challenge

- The consistency and verification of SMR clinical coding.



Recommendations

NHS boards to:

- resolve issues around the linking of clinical management systems in A&E and sharing patient information with diabetes services.
- ensure provision of dedicated inpatient diabetes link specialist nurses to assist with the management of patients who have had an acute diabetic emergency.





Chapter 3

Diabetes UK Scotland summary of findings

3 Diabetes UK Scotland summary of findings

3.1 Living with diabetes: the patient perspective

This summary of findings pulls together feedback from focus groups and questionnaires which offered insights into the experiences of care of people living with diabetes. Inevitably, these are snapshots and vignettes, recording particular people in particular locations at a particular time, and do not represent statistically valid data. This feedback does, however, represent real experiences and, more importantly, experiences from which we can learn.

To involve and assist people in reflecting on their personal experiences, and to elicit views on the care experience of people living with diabetes, the patient focus groups concentrated on three main strands:

- healthcare professionals working together
- information, and
- positive stories and unmet need.

Focus group participants identified four key issues:

- access to support for self-management
- provision of information
- provision of psychological and emotional support, and
- key role of the diabetes specialist nurse in positive care experiences.

Concerns in relation to access to podiatry, dietetic and weight management services, the quality of inpatient care, public and professional awareness of diabetes, and communication between healthcare professionals were also identified.

“It feels like they want to see me in order to meet government criteria and gain funding.”

“I have full confidence in the treatment I have received. It is my impression that the professionals I use are highly capable and are supportive.”

A postal survey was also undertaken to capture the views of children and young people and views from this work are detailed separately within this summary of findings.

Access to support for self-management

Of those who attended the focus groups, it was felt that the commitment to support self-management through patient education and other means has not been matched in terms of service delivery.

Statistics from the focus groups demonstrated that:

- only one in ten patients were aware of a planned programme of diabetes in their area
- fewer than one in ten patients had been offered such a course, and
- one in twenty had completed a patient education course.

Support for self-management is vitally important if the Scottish Government's ambitions for people to take more personal responsibility for their health are to be realised. The majority of patients who attended the focus groups, however, reported that they were either detached from, or unable to, access available opportunities or those opportunities were simply not there.

Evidence from the NHS QIS diabetes follow-up review suggests that patient education (a critical part of self-management support) is being delivered to newly diagnosed patients and continues at annual review and through other mechanisms. However, it should be recognised that patient education covers a very broad spectrum – from one-to-one consultations with a diabetes specialist nurse or other healthcare professional to intensive, structured education courses such as DAFNE or DESMOND. Quantification of actual service delivery in support of self-management for people with diabetes is complex and as yet no in-depth assessment has been carried out to determine the reality of what is being done across the NHS boards. This may explain the disparity between the formal findings of NHS QIS and the focus groups' experience.

Provision of information

Information is a critical part of successful patient care, and areas of good practice in relation to the provision of information were identified both throughout the NHS and the voluntary sector.

“I received most of the information I needed from the diabetes team. Other information I have found in magazines such as Balance and On the Level.”

However, according to participants in the focus groups, information provision remains an issue. Inaccessibility of information or poor management of information were commonly cited.

“I have had to find out myself what complications would be or what to do if and when this happens. I feel that I have been pretty much left to deal with this myself.”

“As a carer I have asked for more information to understand diabetes as I don't have it myself, but as yet I haven't received any.”

Statistics from the focus groups demonstrated that:

- less than half of patients who reported that they had been diagnosed with diabetes in the last 3 years received key information at diagnosis
- less than one in ten received information on key topics at annual review, and
- key information was potentially missing a third of its audience at any given time.

Information is, of course, linked to patient education. From a patient perspective, however, it is clear that strategic delivery of information for people with diabetes often lacks cohesion. It is important, therefore, that the work undertaken on patient information by the Patient Focus and Involvement Group (PFIG), on behalf of the Scottish Diabetes Group, provides a building block for future developments.

Provision of psychological and emotional support

The Scottish Diabetes Framework Action Plan and subsequent work undertaken by the Scottish Diabetes Group and local diabetes MCNs has focused on the need to build service capacity in order to provide emotional and psychological support to people with diabetes. This has included increasing skills in psychological interventions and motivational behavioural techniques. This was highlighted in the Scottish Diabetes Framework Action Plan as a means of improving access to psychological and emotional support for patients with diabetes. However, feedback from the focus group participants identified that there remains a significant gap in service provision.

“The department was unable to help with any psychological support with regards to diabetes care, which was having a significant impact, and still is, upon my blood sugar control.”

The need for improved emotional and psychological support was raised in all of the focus groups and, in seven NHS board areas, this was identified as a key issue. Progress in this area, therefore, needs to be prioritised at a local and national level.

The NHS QIS diabetes follow-up review suggests significant variability across NHS boards in terms of access to psychological support with only two NHS boards providing appropriate access to dedicated diabetes clinical psychological services. However, for patients, there is a need for a spectrum of psychological and/or emotional support and services, ranging from social interaction as offered by Diabetes UK voluntary groups to befriending and advocacy projects to the services of a clinical psychologist. However, the presumption that this is no or low cost and is readily accessible needs to be challenged. The services and support required by people with diabetes will vary dependent on patient need, as diabetes can underpin serious mental health problems and the need to access clinical psychological services will be critical. Serious mental health problems, in particular depression, need to be fully understood in terms of the link with diabetes, diagnosed appropriately and access to clinical psychological services made available.

Counselling helplines, including Diabetes UK’s Careline Scotland service, are mostly voluntary sector based, and local and national voluntary sector organisations often provide the advocacy and mental health projects to which patients are referred or signposted. These structures should continue to be supported and developed to allow access for people with diabetes.

Key role of the diabetes specialist nurse in positive care experiences

In all of the focus groups, the role of the diabetes specialist nurse was highlighted as key in the provision of information and helping to develop patients’ understanding of living with diabetes.



“My diabetes specialist nurse was excellent with transition when I was put on insulin. She was a role model for other healthcare professionals to follow.”

“I love my diabetes specialist nurse and dietitian for the information and help and treatment that they provide.”

It was their view that the diabetes specialist nurse was the most trusted and delivered the most effective support and care.

Although there were significant positive comments on the role of other healthcare professionals including consultant physicians/diabetologists, GPs and practice nurses, these observations were often accompanied by caveats, which focused on attitudes and consistency of access.

The move from caring for patients in secondary to primary care, specifically those patients with uncomplicated Type 2 diabetes, needs to be mindful that access to specialist support is crucial in the future of diabetes care no matter what the care setting. However, it is clear that what patients value most is access to knowledge whether based in primary or secondary care. The process of continuous professional development for staff, particularly non-specialist staff, must deliver sufficient diabetes specialist knowledge in primary care and community settings to meet the needs of a growing diabetes population.

Children and young people

A postal survey of young people (aged 16–25) living with diabetes was undertaken in early 2007. As expected, this raised specific issues in relation to emotional support and the transition from paediatric to adult services, highlighting both positive and negative experiences.

“I have seen a different consultant every clinic visit since moving from the paediatric clinic.”

“The passage from young diabetics care to older, adolescent care went very well. There was no break in records, and a very smooth transition without any concerns.”

Many respondents had recent experiences of the transition from paediatric to adult services. Some young people spoke of the transition being awkward and standards in adult care services being poor in comparison, particularly in terms of waiting times and the loss of the ‘personal touch’.

“I received excellent information at the....Children’s Hospital when diagnosed and at follow-up appointments. Now I attend the adolescent clinic but the ‘personal touch’ is missing. My blood counts are erratic, but the advice on telephoning the clinic is what I know already and not helpful.”

Many responses spoke of a positive relationship with healthcare staff who supported them to live well with their diabetes.

“...the team always know what has been happening with my care. For example, the doctor knows what has been discussed with the nurse, etc. They must communicate effectively.”

“For my last two 6-month reviews, all members of staff were very helpful and were happy to answer questions and give sound advice regarding my diabetic health.”

However, some frustrations were expressed about the need to repeat the same personal information to many healthcare professionals. Co-ordinating information about treatments between healthcare professionals was a common concern, and advice and information received was often repeated. Additionally, there was a sense that care was sometimes being passed between staff and there was inadequate communication with the patient.

“(the) consultant passes you to the nurse who passes you to the dietitian and no-one actually answers your questions. I felt angry and let down due to a lack of support.”

Some young people spoke of an ‘us and them’ attitude, causing frustration, with feelings of anger and extra stress.

In terms of information received at diagnosis, the most common topics among respondents were: insulin, diet, ‘diabetes for beginners’, hypoglycaemia and glucose. Information about eyes, diabetes complications and feet were occasionally available at annual reviews. However, a common theme among respondents was that the information provided, while helpful at the time, was now out of date and no longer relevant to their needs.

“Information given at diagnosis is now 15 years old. Exercise, diet, weight management and sex were not relevant to an 8 year old but are now. Diabetes affects each and every part of living so any new information would help.”

The most relevant information for young people was felt to be on insulin, blood glucose testing and diet. Many respondents also wanted information about issues that affect them as young adults with diabetes. Risk of retinopathy, impact of behavioural difficulties and psychological health were key areas in terms of the experience of living with diabetes as a young adult and the shortfall of information.

Patient education and young people

Many respondents were aware of diabetes education programmes, although only a few had completed courses.

“I was informed of a carbohydrate counting course which I would have liked to attend; however, I was never provided with any further details (dates, times) of the course.”

Of those who had been on courses, the feedback was positive.

“When I started the DAFNE course it explained a lot.”

There is a need to focus on good practice in relation to transitional issues to ensure that healthcare teams are better engaged with young people to lessen the ‘shock’ of entering adult services. More and better targeted information should be made available about diabetes complications and there should be consistent access to patient education.

Conclusion

Reading across these care experiences of people living with diabetes to the data gathered in the NHS QIS diabetes follow-up review provides an opportunity to bring some of that statistical data to life in a challenging way; or, alternatively, to give some context and balance to the views and opinions of individual patients and carers. It is an opportunity to plan for the future: identifying real progress in service delivery across NHS boards while recognising that people’s experiences can vary from measured progress, but are valid in mapping our way forward.





Chapter 4

Appendices

Appendix 1: State Hospital – overview of diabetes service

The State Hospital, Carstairs, was not reviewed as part of the initial 2003 diabetes peer review visits. A meeting was held in May 2007 with representatives from NHS QIS and the State Hospital to gather information on the diabetes service provided to its patients.

Patients are admitted to the State Hospital under the Mental Health (Care and Treatment) (Scotland) Act 2003 and related legislation. The hospital provides assessment, treatment and care in conditions of special security for individuals with mental disorders who cannot be cared for in any other setting.

May 2007:

- 16 patients diagnosed with diabetes, all adult males: one patient with Type 1 diabetes and 15 with Type 2 diabetes.
- Prevalence rate of diabetes higher than in the general population – could be a result of decreased activity levels and medication requirements. Additionally, there is a major obesity problem among the patients with diabetes.
- Diabetic care shared between on-site primary care team and NHS Lanarkshire.
- Diabetes team consists of a practice nurse, dietitian, part-time GP, part-time podiatrist, physical activity facilitator and an on-site pharmacist. A consultant diabetologist from NHS Lanarkshire visits the hospital 4 times per year. As a result, patients are seen by a consultant approximately every 6 months.

Organisation

Due to strict issues of confidentiality at the State Hospital, the health centre uses a stand-alone GPASS system. The consultant diabetologist ensures all information is entered into SCI-DC Clinical for annual review purposes. Relevant information is included as part of the Scottish Diabetes Survey return from NHS Lanarkshire.

There are plans to implement GPASS in the ward areas during 2007. Ward staff are notified of all patients with diabetes, and are provided with paper copies of patients' GPASS and practice nurse records. However, there are recognised issues in terms of ward staff reporting back to the diabetes team.

There is no formal service contract in place for diabetic care with NHS Lanarkshire, although there is good communication between the hospital and Wishaw General Hospital. Additionally, there are no formal strategic or organisational arrangements in place for the State Hospital to link in with NHS Lanarkshire's diabetes MCN.

Detailed written reports relating to the patients with diabetes are prepared quarterly for the physical health steering group. These are then sent to the hospital management team, clinical governance committee and the Board committee.

Patient focus

All patients receive an annual physical health review, which includes screening for diabetes. As a result, there is early identification and diagnosis. Patients are well supported and are provided with personalised, one-to-one education sessions. Patients can also self-refer to Wishaw Health Centre at any time in addition to review appointments. The diabetes team recognises that it has the ability to dedicate time to patients.

Most communication and education provided to the patients is verbal, although a patient diabetic information pack, specific to the State Hospital, has been jointly developed with patients and gives general advice on treatment, complications, exercise etc. This pack is also provided for patients' carers.

The practice nurse is able to attend diabetes study days and national education update sessions in order to keep her knowledge and skills up to date. However, it was noted that there is no cover for the practice nurse. In periods of absence, ward staff contact the GP directly or telephone NHS 24.

Clinical review

Patients are monitored a minimum of every 3 months. Complex care issues are discussed with the consultant diabetologist and managed locally by the health centre staff. Medication is reviewed at least annually by the consultant diabetologist and monitored at every appointment by the GP or practice nurse.

Significant efforts are being made through exercise and diet to tackle the problem of obesity among patients.

The hospital has a successful smoking cessation programme in place, decreasing the number of overall smokers from 84% to 69%.

Clinical management

Eyes

The consultant physician undertakes fundoscopy at the State Hospital as an alternative to retinal screening, due to issues with security. Plans are under way to utilise a mobile screening unit in the future. Patients receive the same service for ophthalmological treatment as patients attending NHS Lanarkshire.

Cardiovascular status

Blood pressure is routinely monitored to achieve optimum levels. The Joint British Coronary Risk Prediction Chart is used to assess coronary heart disease risk.

Feet

Patients receive a 6-weekly foot assessment from the podiatrist as well as an annual diabetic foot assessment. The long-term management of patients with foot problems is undertaken in collaboration with Wishaw General Hospital.

Glycaemia

The diabetes team use blood glucose monitoring guidelines developed by NHS Lanarkshire. The practice nurse undertakes insulin initiation with patients, as required.

Renal

Renal function, particularly creatinine, is closely monitored due to the types of medication used in patients' treatment. Any patient with abnormal renal function would be considered for referral to Wishaw General Hospital. The health centre is implementing an eGFR protocol as part of routine 3-monthly blood testing. Patients are also monitored for microalbuminuria or albuminuria.

Acute management

In the event of an acute diabetic emergency, patients would be treated at Wishaw General Hospital.

Appendix 2: Diabetes steering group members

Chair

Dr Mike Small

Consultant Physician, NHS Greater Glasgow and Clyde

Steering group members

Mr David Cline

Programme Manager – Diabetes, Scottish Government Health Directorate (until July 2007)

Mrs Alison Crooks

MCN Diabetes Project Manager, NHS Dumfries & Galloway

Ms Margaret Doyle

Podiatry Service Lead South Community Health Partnership, NHS Ayrshire & Arran

Dr Malcolm Kerr

General Practitioner, NHS Ayrshire & Arran/Primary Care Advisor, NHS QIS

Dr John McKnight

Consultant Physician, NHS Lothian

Miss Mary Scott

Diabetes Network Manager, NHS Lothian/Project Manager, NHS QIS

Mr Will Scott

Long-Term Conditions Policy Lead, Scottish Government Health Directorate (from June 2007)

Ms Anna Thomson

Public Partner, Forth Valley

Mrs Debbie Voigt

Diabetes Specialist Nurse, NHS Tayside

Support from NHS QIS was provided by **Ms Jan Warner** (Director of Patient Safety and Performance Assessment), **Mr Sean Doherty** (Team Manager), **Mr Steven Wilson** (Team Manager), **Mrs Fiona Russell** (Senior Project Officer), **Miss Jan Nicolson** (Project Officer) and **Mrs Wendy Forbes** (Project Officer).

Appendix 3: Timetable of review visits

Organisation reviewed	Visit date(s)
NHS Ayrshire & Arran	20 December 2006
NHS Borders	24 January 2007
NHS Dumfries & Galloway	8 February 2007
NHS Fife	10 October 2006
NHS Forth Valley	17 April 2007
NHS Grampian	1 March 2007
NHS Greater Glasgow and Clyde*	29 March 2007 23 August 2007
NHS Highland*	13 March 2007 22 August 2007
NHS Lanarkshire	8 March 2007
NHS Lothian	5 April 2007
NHS Orkney	16 November 2006
NHS Shetland	30 November 2006
NHS Tayside	18 January 2007
NHS Western Isles	2 November 2006

* Additional follow-up review visits were undertaken to Argyll & Bute and the Clyde CHP/directorates and the reports subsequently incorporated into the relevant NHS board follow-up report: Argyll & Bute has been incorporated into the NHS Highland follow-up report and Clyde has been incorporated into the NHS Greater Glasgow and Clyde follow-up report.

Appendix 4: Glossary

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.
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.
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.
audit	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.
blood glucose	The main sugar found in the blood and the body's main source of energy. Also called blood sugar.
blood pressure (BP)	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.
body mass index (BMI)	A measurement of weight in relation to height.
call-recall	The process used to invite people for a screening test.
CHD	See coronary heart disease.
CHP	See community health partnership.
chronic	Present over a long period of time. Diabetes is an example of chronic disease.
clinical governance	<p>Ensures that patients receive the highest quality of care possible, putting each patient at the centre of his or her care. This is achieved by making certain that those providing services work in an environment that supports them, and that the organisation places safety and quality of care at the top of its agenda.</p> <p>Clinical risk management at an organisational level is an important aspect of clinical governance. It 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.</p>

clinical management system	A collection of core information from individuals relating to their care which allows ongoing useful clinical information to be recorded for use in direct patient care and service audit.
clinical review	A method of detecting specified disease in a targeted population at a stage where the individuals have no symptoms.
clinical service	Service provided by healthcare professionals.
Clinical Standards Board for Scotland (CSBS)	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.
community health partnership (CHP)	A way of organising non-acute care where NHS boards maximise their ability to support integration across health, and between health and other agencies such as social services. A CHP covers a geographical area and the number within an NHS board depends on the distribution and size of the population. Website address: www.show.scot.nhs.uk/sehd/chp/index.htm
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(singular)/ criteria(plural)	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.
DAFNE	See Dose Adjustment for Normal Eating.
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.
DESMOND	See Diabetes Education and Self-Management for Ongoing and Newly Diagnosed.

Diabetes Control and Complications Trial (DCCT) compatible assay	A standardisation which allows comparison of glycated haemoglobin (HbA1c) results between different laboratories.
Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (DESMOND)	A programme concerned with structured education for people with Type 2 diabetes. The DESMOND website contains information about the current and future research projects and information about how to become involved. Website address: www.desmond-project.org.uk
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 register	A list of people with diabetes and a product of the clinical management system.
Diabetes UK	The principal diabetes organisation in the UK. Previously called the British Diabetic Association or BDA. Website address: www.diabetes.org.uk
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.
DKA	See diabetic ketoacidosis.

Dose Adjustment for Normal Eating (DAFNE)	Where patients are taught to match their insulin dose to food intake on a meal-by-meal basis. The principle is that people adjust their insulin injections to fit their lifestyle rather than adjust their activities and food intake to a pre-set insulin regime, maintaining healthy glycaemic control without an increased risk of severe hypoglycaemia and with minimal support from healthcare professionals.
eGFR	See estimated glomerular filtration rate.
essential (criterion/criteria)	A criterion that should be met wherever a service is provided.
estimated glomerular filtration rate (eGFR)	A test that is used to assess how well your kidneys are working. The test estimates the volume of blood that is filtered by your kidneys over a given period of time. The glomeruli are the tiny filters in the kidneys. If these filters do not do their job properly then the kidney is said to have reduced or impaired kidney function. The eGFR test involves a blood test which measures a chemical called creatinine. Creatinine is a breakdown product of muscle. Creatinine is normally cleared from the blood by the kidneys. If the kidneys are not working properly, the level of creatinine in the blood goes up. The eGFR is then calculated based on age, sex and blood creatinine level.
evidence-based medicine	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.
General Practice Administration System for Scotland (GPASS)	The national primary care system for Scotland and one of Britain's leading general practice computer systems. Website address: www.gpass.scot.nhs.uk
gestational diabetes	A form of diabetes which begins during pregnancy and usually disappears following delivery.
glycated haemoglobin (HbA1c)	A test that sums up how well controlled diabetes has been in the previous 3–4 months.
GP	General practitioner
GPASS	See General Practice Administration System for Scotland.
guidelines	Systematically developed statements which help in deciding how to treat particular conditions.

HbA1c	See glycated haemoglobin.
Health Technology Board for Scotland (HTBS)	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.
healthcare professional	A person qualified in a health discipline.
hormone	A circulating chemical messenger made in one part of the body and acting on other parts.
hyperglycaemia	An excess of glucose in the bloodstream, which if untreated, may progress to diabetic coma.
hyperosmolar non-ketotic state	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"> 1 very high levels of glucose (sugar) in the blood. 2 absence of ketoacidosis. 3 severe dehydration. 4 sleepy, confused, or comatose state.
hypoglycaemia	A condition which occurs when blood glucose levels are low - below 4mmol/l, and which can often cause confusion, light headedness and irritability. Also known as a 'hypo'.
ICP	See integrated care pathway.
IM&T	Information management and technology
incidence	The number of new cases of a disease within a defined group of people over a period of time.
inpatient	A person who is admitted to hospital for observation, examination or treatment.
insulin	A hormone secreted by the pancreas. Insulin regulates the blood glucose level, and is important for growth and tissue repair.
insulin therapy	Treatment using insulin in patients with diabetes following trauma to the body such as a heart attack.

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.
ischaemia	Reduced blood flow, usually because of narrowing or blockage of an artery.
Joint British Societies Coronary Risk Prevention Chart	Validated information produced in the form of a chart which is used by healthcare professionals to predict a person's risk of developing coronary heart disease taking into account several different risk factors.
ketoacidosis	See diabetic ketoacidosis.
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.
LDSAG	See local diabetes service advisory group.
lead clinician	Clinician with administrative responsibilities for a specific service.
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 enhanced service	Essential or additional services delivered to a higher specified standard, for example, extended minor surgery, and services not provided through essential or additional services. The latter might include more specialised services undertaken by GPs or nurses with special interests and allied health professionals and other services at the primary-secondary care interface. The services are tailored to the needs of the area.
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. Each MCN is required to have a quality assurance framework describing the standards the service will meet. The framework has to be accredited by NHS QIS and an annual report on progress is also required.
medication	Drugs prescribed to treat a condition.

microalbuminuria	Leakage of small amounts of protein (albumin) into the urine. An early warning of kidney damage.
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.
morbidity	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.
multidisciplinary	A multidisciplinary team is a group of people from different disciplines (both healthcare and non healthcare) who work together to provide care for patients with a particular condition. The composition of multidisciplinary teams will vary according to many factors. These include: the specific condition, the scale of the service being provided and geographical/socioeconomic factors in the local area.
multidisciplinary system of working	A method of working in a multidisciplinary team with protocols in place for most, if not all, eventualities.
near patient testing	Testing at site of care.
nephropathy	Kidney damage from any cause - quite often diabetes.
neuropathy	Disease of the nervous system and 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.
new General Medical Services (nGMS)	The UK wide contract between general practices and primary care organisations to deliver primary care services to their local communities.
NHS	National Health Service
NHS board	There are 21 NHS boards of two types: 14 territorial boards responsible for healthcare in their areas and seven special health boards which offer supporting services nationally.
NHS Quality Improvement Scotland (NHS QIS)	A special health board established (January 2003) to lead in improving the quality of care and treatment delivered by NHSScotland. To do this it sets national standards and monitors performance, and provides NHSScotland with advice, guidance and support on effective clinical practice and service improvements. Website address: www.nhshealthquality.org

NHSScotland	The National Health Service in Scotland.
obesity	Condition of being grossly overweight, at least 20% heavier than the heaviest weight in the 'ideal' range for that person's height.
ophthalmologist	A medical doctor specially trained to diagnose and treat disorders of the eye. An ophthalmologist is qualified to prescribe medication, prescribe and adjust spectacles and contact lenses, and is usually qualified to perform laser treatment and surgery.
optometrist	Although not a doctor of medicine, an optometrist is specifically trained to diagnose eye abnormalities and prescribe, supply and adjust spectacles and contact lenses.
outcome	The end result of care and treatment 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.
patient	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.
peer review	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.
physician	A specialist in medicine.
plan of care	A written agreement which is developed with the user, and which details the roles and responsibilities of all individuals involved in the person's care and when their care arrangements are to be reviewed.
podiatrist/chiroprapist	Person with expert knowledge in foot care.
prescription	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.
pressure relief	A means of redistributing gravitational force to prevent further tissue damage.
primary care	The conventional first point of contact between a patient and the NHS. This is the care given to patients outside hospitals and is typically, though not always, delivered through general practices. Other providers include dentists, pharmacists, optometrists and ophthalmic medical practitioners. Primary care services are the most frequently used of all services provided by the NHS.

proliferative diabetic retinopathy (PDR)	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.
protein	Proteins are made of amino acids and are the main component of human cells. There are many different proteins in the human body and they all have different functions. Protein is one of the three main food types, found for example in meat, fish, poultry and eggs, and is required to allow the body to grow and to repair its cells.
proteinuria	Too much protein in the urine. This may be a sign of kidney damage.
protocol	Operational instructions which regulate and direct activity. Protocols may be national, or agreed locally to take into account local requirements.
psychological	Relating to human behaviour.
Quality and Outcomes Framework (QOF)	A voluntary incentive programme designed to deliver financial rewards for high-quality care, and part of the arrangements for the new General Medical Services contract. The QOF sets out a range of national standards based on the best available research evidence, divided into four domains: clinical standards linked to the care of patients suffering from chronic diseases; organisational standards relating to records and information, communicating with patients, education and training, medicines management, and clinical and practice management; additional services, covering cervical screening, child health surveillance, maternity services and contraceptive services; and patient experience, based on patient surveys and length of consultations. A set of indicators has been developed for each domain to describe different aspects of performance. Practices are free to choose the domains which they want to focus on and the quality standards to which they aspire.
quality assurance (QA)	Improving performance and preventing problems through planned and systematic activities including documentation, training and review.
rationale	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	Relating to the kidneys.
renal function	A measure of how well a person's kidneys are working to remove waste products from the body.

retinal screening	Diabetes can sometimes lead to disease in the eyes which threatens vision. Retinal screening is aimed at picking up the early stages of diabetes-related eye disease and preventing loss of vision. Patients with diabetes are screened through an assessment of vision and of photographs of the back of the eye (the retina) taken with a digital camera.
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.
Scottish Care Information - Diabetes Collaboration (SCI-DC)	An integrated national programme of information management and technology development. The objective is support of the entire patient journey by making available IT systems and standards for use across Scotland to support clinical communication. These resources are owned collectively, developed and facilitated centrally. SCI-DC aims to deliver effective IT solutions to diabetes services in NHSScotland.
Scottish Diabetes Survey	A Scottish central government initiative to build a national register of people with diabetes and to monitor diabetes care, with the aim of facilitating better healthcare.
Scottish Executive Health Department (SEHD)	A department of Scottish central government whose responsibilities are now undertaken by the Scottish Government Health Directorate.
Scottish Government Health Directorate	Government department responsible both for NHSScotland and for the development and implementation of health and community care policy.
Scottish Intercollegiate Guidelines Network (SIGN)	To help improve the quality of healthcare SIGN develops national clinical guidelines aimed at reducing variations in clinical practice and in outcomes for patients. Founded in 1993 by the Academy of Royal Colleges and Faculties in Scotland, SIGN became part of the national clinical effectiveness body, NHS QIS, on 1 January 2005. The evidence base for many of the clinical standards developed by NHS QIS has been drawn from SIGN guidelines. Website address: www.sign.ac.uk
Scottish Morbidity Record (SMR)	Data for individual patients are collected by the Information Services 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.

screening	Examination of people with no symptoms, to detect unsuspected disease.
secondary care	Care provided in an acute sector setting.
secondary prevention	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.
self-assessment	Assessment of performance against standards by the individual/clinical team/NHS operating division/NHS board providing the service to which the standards relate.
serum creatinine	A biochemical measurement or test of one of the body's waste products which is an indicator of renal function.
SIGN guideline	Scottish Intercollegiate Guidelines Network guideline. See guidelines and Scottish Intercollegiate Guidelines Network.
SMR	See Scottish Morbidity Record.
special health board	Seven health boards focused on specific activities, for example, NHS Education for Scotland, or NHS Quality Improvement Scotland. Special health boards match regional NHS boards in terms of administrative grading. There are also a number of key supporting organisations such as NHS National Services Scotland which are not NHS boards. Website address: www.show.scot.nhs.uk/organisations/special_hbs.html
standard statement	An overall statement of agreed performance.
systolic (blood pressure)	Two levels of blood pressure are measured - the higher, or systolic, pressure, which occurs each time the heart pushes blood into the vessels, and the lower, or diastolic, pressure, which occurs when the heart rests. In a blood pressure reading of 120/80, for example, 120 is the systolic pressure and 80 is the diastolic pressure.
Type 1 (insulin-dependent) diabetes	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.
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.

ulceration	Breaks or deep sores in the skin.
urinary albumin concentration	A measure of how much albumin (protein) leaks from the blood into urine as a result of one or more disease processes in the body.





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NHS Quality Improvement Scotland

Edinburgh Office
Elliott House
8-10 Hillside Crescent
Edinburgh EH7 5EA

Glasgow Office
Delta House
50 West Nile Street
Glasgow G1 2NP

Phone: 0131 623 4300
Textphone: 0131 623 4383

Phone: 0141 225 6999
Textphone: 0141 241 6316

Email: comments@nhshealthquality.org
Website: www.nhshealthquality.org

