NHS
Quality Improvement Scotland

Clinical Standards ~ *March 2004*

Diabetic Retinopathy Screening

ISBN 1-84404-258-8

First published May 2003. Revised March 2004.

www.nhshealthquality.org

Contents

1. Introduction

This document introduces the NHS Quality Improvement Scotland (NHS QIS) *Clinical Standards for Diabetic Retinopathy Screening*. The standards focus on specific elements of screening for diabetic retinopathy and are set in the context of the *Clinical Standards for Diabetes* (2nd ed.) The standards cover:

- Organisation;
- Call-Recall and Failsafe;
- Screening Process;
- Proficiency Testing; and
- Referral.

The standards will be used by NHS QIS to assess performance in these areas in NHS Boards throughout Scotland where diabetic retinopathy screening services are provided.

The initial sections of this document provide background information on NHS QIS and on the process used to develop the standards (Sections 2 and 3 respectively).

The development of the *Clinical Standards for Diabetic Retinopathy Screening* is outlined in Section 4, and the membership of the Project Group undertaking this work is given in Section 5. The overarching principles guiding development of the standards are provided in Section 6.

Section 7 provides basic information about diabetic retinopathy screening, and the evidence underpinning the standards is presented in Section 8.

Section 9 contains the *Clinical Standards for Diabetic Retinopathy Screening.*

Finally, Section 10 provides a glossary of terms used in the standards.

2. Background on NHS Quality Improvement Scotland

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

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

A part of this remit is to develop and run a national system of quality assurance of clinical services. Working in partnership with healthcare professionals and members of the public, NHS QIS sets standards for clinical services, assesses performance throughout NHSScotland against these standards, and publishes the findings. The standards are based on the patient's journey as he or she moves through different parts of the health service. A wide range of diseases and services are at present being addressed, including infection control, anaesthesia services and maternity services.

Project Groups

For each service in the work programme, NHS QIS appoints a project group comprising appropriate healthcare professionals and members of the public to:

- oversee the development of, and consultation on, the standards;
- recommend an external peer review process; and
- report on its findings to the NHS QIS Board.

As part of their rolling programme, individual project groups ensure that the standards are regularly evaluated and revised so that they remain relevant and up to date (reflecting new procedures and treatments). They also ensure that targets of achievement are raised as performance improves.

Development of Standards

The way in which standards are developed is a key element of the quality assurance process. Groups working on behalf of NHS QIS are expected to:

- adopt an open and inclusive process involving a wide range of both members of the public and professional people through a variety of mechanisms;
- work within NHS QIS policies and procedures; and
- test standards through undertaking pilot reviews to ensure that they meet the principles of NHS QIS.

In addition to standards for specific services or conditions, generic clinical governance standards have been set which apply to all clinical services.

Review

The framework for the NHS QIS review process is as follows:

- once the standards have been finalised, each relevant NHS Board is asked to undertake a self-assessment of its service against the standards;
- a review team visits the NHS Board on behalf of NHS QIS to follow up this self-assessment exercise with an external peer review of performance in relation to the standards; and
- NHS QIS reports the findings for the NHS Board, based on the self-assessment exercise and on the external peer review.

Peer review teams are multidisciplinary, including both healthcare professionals and members of the public. All teams are led by an experienced clinician and are supported by staff from NHS QIS.

All the processes being developed are subject to review and evaluation, and this will help NHS QIS improve its quality assurance system.

Further Information

For further information about NHS QIS, or to obtain additional copies of these standards, please contact:

NHS Quality Improvement Scotland
Edinburgh Office
Elliott House
8-10 Hillside Crescent
Edinburgh
EH7 5EA

Tel: 0131 623 4300
Fax: 0131 623 4299

comments@nhshealthquality.org
publications@nhshealthquality.org

Copies of all NHS QIS publications can also be downloaded from the website (www.nhshealthquality.org).

3. Background on Clinical Standards – Basic Principles

The standards set by NHS Quality Improvement Scotland (NHS QIS) are:

- focused on clinical issues and include non-clinical factors that impact on the quality of care;
- written in simple language;
- based on evidence (recognising that levels and types of evidence will vary);
- written to take into account other recognised standards and clinical guidelines;
- clear and measurable;
- achievable but stretching;
- developed by healthcare professionals and members of the public;
- consulted on widely;
- published on paper and electronically (on the Internet); and
- regularly reviewed and revised to make sure they remain relevant and up to date.

Some standards are common to all clinical services, others specific to particular conditions.

Format of Standards and Definition of Terminology

All standards set by NHS QIS follow the same format:

- each standard has a **title**, which summarises the area on which that standard focuses;
- this is followed by the **standard statement**, which explains the level of performance to be achieved;
- the **rationale** section provides the reasons why the standard is considered to be important; and
- the standard statement is expanded in the section headed **criteria**, which states exactly what must be achieved for the standard to be reached.

As already mentioned, NHS QIS aims to set standards that are **achievable but stretching**. This is reflected in the criteria. Most criteria are **essential**, in that it is expected that they will be met wherever a service is provided. Other criteria are **desirable**, in that they are being met in some parts of the service and demonstrate levels of

quality which other providers of a similar service should strive to achieve. Each project group is responsible for determining which criteria are essential and which are desirable.

The criteria are numbered for the sole reason of making the document easier to work with, particularly for the assessment process. The numbering of the criteria is not a reflection of priority. The distinction between 'essential' and 'desirable' is the only way in which criteria have been prioritised.

Generic Clinical Governance Standards

As mentioned earlier in this document, generic clinical governance standards have been developed which apply to clinical services generally. A second edition (Healthcare Governance Standards) will be published in August 2004.

Copies of the generic clinical governance standards are available on request from NHS QIS or can be downloaded from the website (www.nhshealthquality.org).

4. Development of the Clinical Standards for Diabetic Retinopathy Screening

This document contains the *Clinical Standards for Diabetic Retinopathy Screening* in Scotland. The standards are based on the clinical standards for cervical and breast screening and aim to complement the clinical standards for general diabetes care.

Background

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

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

The Scottish Diabetes Framework Working Group was established in April 2001 to draw together existing guidance and best practice to address provision of diabetes care throughout the patient journey. The Group was multidisciplinary, and included lay representatives. Information on key milestones was published in November 2001, followed by the full *Scottish Diabetes Framework* document in April 2002. The *Framework* sets out a proposed programme of diabetes care to be delivered over the next 5-10 years.

Working in partnership with the Diabetic Retinopathy Screening Implementation Group, a Diabetic Retinopathy Screening Standards Project Group was set up, in 2002, to identify clinical standards for this screening process. The remit of this Group was to direct the development of a core set of clinical standards for diabetic retinopathy screening using the NHS Quality Improvement Scotland (NHS QIS) quality assurance template. Healthcare professionals and members of the public are represented, and the Group drew on work already undertaken such as the Health Technology Board for Scotland (HTBS) assessment report, SIGN Guideline 55 and the *St Vincent Declaration*.

The Diabetic Retinopathy Screening Standards Project Group identified several key standards relevant to diabetic retinopathy screening, and also incorporated applicable generic clinical standards. These clinical standards both complement and reach beyond the priorities identified in the *Scottish Diabetes Framework*.

Whilst it is acknowledged that a national programme for diabetic retinopathy screening does not yet exist in Scotland, the programme, once implemented, will be structured in line with the timescales and recommendations contained in the Diabetic Retinopathy Screening Implementation Group report, *Diabetic Retinopathy Screening Services in Scotland: Recommendations for Implementation.* Naturally, the associated quality assurance standards and framework will also reflect these guidelines. Further, it is important to recognise that development of an effective national diabetic retinopathy screening programme, and the associated national quality assurance framework and standards, is an 'evolutionary' rather than a 'revolutionary' process. Further research, complemented by initial experiences, audit, and issues raised in the course of NHS QIS reviews will drive the inevitable revision and modification of the standards, and the programme, as it is rolled out to all NHS Board areas.

Consultation

A consultation period was successfully completed with valuable feedback received at an open meeting and through a wide range of written comments. The responses and comments were then considered by the Project Group and many of the points raised were incorporated into the standards.

5. Membership of the Diabetic Retinopathy Screening Standards Project Group

The membership of the Diabetic Retinopathy Screening Standards Project Group, chaired by Dr John Olson, Consultant in Medical Ophthalmology, Grampian University Hospitals NHS Trust; Lead Clinician, Diabetic Retinopathy Screening Collaborative Network, National Services Division, is presented below:

Name	Title	NHS Board Area/Organisation
Dr David Cromie	Consultant in Public Health Medicine	Lanarkshire
Ms Karen Hunter	Clinical Network Manager	Tayside
Mr Ross Kerr	Lay Representative	Fife
Dr Graham Leese	Consultant Physician	Tayside
Dr Fraser MacLeod	General Practitioner	Greater Glasgow
Ms Susan Pellegrom	Diabetes Managed Clinical Network Manager	Grampian
Mr Jim Slattery	Principal Statistical Epidemiologist	NHS Quality Improvement Scotland
Mr Steve Whittaker	Optometrist Adviser	Scottish Executive Health Department

The NHS Quality Improvement Scotland (NHS QIS) Board member specifically working with the Diabetic Retinopathy Screening Standards Project Group is Professor John Cromarty, Trust Chief Pharmacist, Highland Acute Hospitals NHS Trust.

Support from NHS QIS was provided by Ms Jan Warner (Director of Performance Assessment and Practice Development), Mr Steven Wilson (Review Team Manager), Mrs Sarah Brown (Senior Project Officer), Ms Clare Echlin (Senior Project Officer), Miss Jane Allen (Project Officer), Miss Jan Nicolson (Project Officer) and Miss Josephine O'Sullivan (Project Administrator).

6. Overarching Principles

As mentioned in Section 2, NHS Quality Improvement Scotland (NHS QIS) has developed generic clinical governance standards of care that underpin all clinical services provided by NHSScotland. They provide a broad context for all NHS QIS condition-specific standards. They are also applicable to the patient journey through the diabetic retinopathy screening programme, which involves several groups of healthcare professionals, to ensure a seamless process.

The following key points underpin the *Clinical Standards for Diabetic Retinopathy Screening*:

- Screening is a non-diagnostic test; the primary aim is to identify those individuals who may be at risk of developing a certain condition from those who may not. In cases where the screening result suggests presence of disease, the patient is referred to a specialist for further investigation and diagnosis.

- A screening programme offers a test, at a regular interval, to a defined population known to be at risk from the disease. The frequency of the test depends on the natural progression of the disease. The aim is to offer treatment at an early stage when it is likely to be more effective and less invasive.

- People with diabetes are at high risk of developing diabetic retinopathy, a sight-threatening disease. Screening for this condition can pick up the disease at an early stage when it can be treated.

- For a screening programme to be effective, robust systems must be in place at every stage. This ensures that screening is offered on a regular basis (annually for diabetic retinopathy), integrated care is provided where necessary, false positive and negative results are within reasonable limits, and the potential for participants to be lost to the programme is minimised.

- Diabetic retinopathy screening involves taking a photograph of the retina, the nerve fibre layer at the back of the eye, and examining this image for signs of retinopathy. The emphasis should be on highly effective photography, and have grading and reporting as key components of the programme. This ensures that users of the service have confidence in the value of the process.

- Relevant information and the opportunity to participate should be provided in a user-friendly manner so that potential participants are encouraged to attend for screening and recognise the benefits it imparts. Information should be available at all stages and must be developed via consultation with all of the groups of healthcare professionals involved in screening.

- Public participation in development of the information is essential.

- Staff at all stages and levels in the programme should be trained not only within their own setting, but also have an understanding of the wider aspects of the programme.

- A multidisciplinary team working across all the components of the programme provided in NHS Board areas, co-ordinated and monitored by the NHS Boards, is the basis for a seamless patient journey through the screening process.

- The Scottish Diabetic Retinopathy Screening Programme must reach all eligible people with diabetes irrespective of their status, race or any special needs requirements.

Those involved in providing diabetic retinopathy screening are keen to find ways of raising awareness about personal responsibility for attending for screening, as well as professional responsibility for providing screening services. The importance of presenting information in a way that allows people to make choices is recognised, and more training and health promotion 'tools' are needed if this is to be effective. It is particularly important that those providing the screening programme are not penalised for respecting choices.

The *Clinical Standards for Diabetic Retinopathy Screening* are evidence-based and have been developed in conjunction with many people across Scotland. They represent what are considered to be the key elements that comprise an effective screening programme, and will have a direct impact on the quality of care a person with diabetes receives on his or her journey through the screening process.

7. An Introduction to Diabetic Retinopathy Screening

Basic Facts about Diabetes

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

Normally, a hormone called insulin carefully controls the amount of glucose in our blood. Insulin is made by a gland called the pancreas, which lies just behind the stomach. It helps the glucose to enter the cells of the body where it is used as fuel. 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, the level of insulin falls. Insulin, therefore, plays a vital role in regulating the level of blood glucose and, especially, 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 it can occur in younger people.

What is Diabetic Retinopathy?

People with diabetes have a higher chance of developing certain serious health problems, including damage to the eyes. A well-recognised and common complication of diabetes is damage to the blood vessels in the retina, the nerve fibre layer at the back of the eye. This is known as retinopathy and is the largest single cause of blindness amongst adults of a working age in the UK (*Scottish Diabetes Framework,* April 2002). In its early stages, diabetic retinopathy is symptom-free and progression of disease can be prevented by laser treatment or by improved metabolic and/or blood pressure control.

Background (Non-Proliferative) Diabetic Retinopathy (BDR)

Diabetes can cause the small blood vessels in the retina to become blocked and damaged. This can result in the damaged vessels leaking small amounts of blood and the retina being starved of oxygen. This is known as background non-proliferative diabetic retinopathy.

Proliferative Diabetic Retinopathy (PDR)

If enough small blood vessels become blocked, new blood vessels start to grow within the eye in an attempt to provide oxygen to the damaged retina. This is known as proliferative retinopathy and initially has no effect on vision. However, the new blood vessels created within the eye are generally weak and grow into the vitreous, the jelly-like substance inside the eyeball. The weak vessels can bleed (vitreous haemorrhage) and/or pull the retina off the back of the eye (retinal detachment) resulting in loss of vision. New vessel growth can be stopped by laser treatment. Bleeding and pulling on the retina, from new vessels, can be treated by surgery.

Maculopathy

Loss of vision may occur if the centre of the retina, known as the macula, is affected by diabetic retinopathy. Damaged blood vessels at the centre of the retina may leak fluid causing the macula to swell (macular oedema). If these blood vessels become blocked, the macula may become starved of oxygen, resulting in sick and dying cells 'ballooning up', another cause of macular oedema. Either problem can affect central vision. Swelling from leakage may be amenable to laser treatment, but not if caused by blocked blood vessels.

Diabetic Retinopathy Screening

People with diabetes are unlikely to notice the early stages of diabetic retinopathy as it does not cause any symptoms. To ensure that early, potentially damaging changes to the retina are identified and treated, people with diabetes require regular eye checks.

A Scottish Executive Health Department survey of NHS Boards in Scotland found that while many people with diabetes already received regular screening for diabetic retinopathy, there was variation in services across Scotland. To ensure equitable access to an effective screening programme for all eligible people with diabetes throughout Scotland, a national screening programme is being established, based on recommendations made by the Health Technology Board for Scotland (HTBS).

Effective 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, and applies equally to the screening for diabetic retinopathy as it does to all other aspects of effective care provision.

8. Evidence Base for the Clinical Standards for Diabetic Retinopathy Screening

The evidence base for the *Clinical Standards for Diabetic Retinopathy Screening* is principally drawn from documents produced by the National Health Service Diabetic Retinopathy Screening Programme Working Groups, at Scottish and UK level.

Key References

The standards follow the patient journey and the following references apply to the main stages of the process.

Standard 1: Organisation

Diabetic retinopathy screening services are provided across both primary and secondary care settings. Effective service delivery is dependent on co-operative working between these, which is co-ordinated and monitored at NHS Board level.

Standard 2: Call-Recall and Failsafe

An essential component of the programme is the entering of information onto the diabetes register. This triggers the screening process by issuing invitations and reminders to people diagnosed with diabetes. It depends on interaction with a comprehensive and accurate clinical management system, as detailed in the *Clinical Standards for Diabetes* (2nd ed.), and robust criteria of eligibility.

Standard 3: Screening Process

The photographer is the main point of contact for people with diabetes participating in the programme, and must be suitably trained and effective in carrying out this procedure. This will encourage people with diabetes to continue to participate in the programme. The photographic image itself must be of a high quality.

Standard 4: Proficiency Testing

Proficiency testing is a core element of quality assurance, and incorporates regular assessment to maintain skill levels and identify any areas requiring improvement at an early stage. Accurate grading of photographs is an essential component of the screening test. This requires the appropriate facilities and equipment, trained staff, quality assurance, and performance management and monitoring.

Standard 5: Referral

When screening identifies a person with diabetes as having a possible problem, picked up from a digital photograph, he or she must receive appropriate, effective and timeous referral to a qualified specialist health professional.

Reference List

1. Clinical Standards Board for Scotland (CSBS). Clinical Standards: Breast Screening. Edinburgh: CSBS (2002). www.clinicalstandards.org/finalstand.html [full document] url cited 01/03/04.

2. Clinical Standards Board for Scotland (CSBS). Clinical Standards: Cervical Screening. Edinburgh: CSBS (2002). www.clinicalstandards.org/finalstand.html [full document] url cited 01/03/04.

3. Clinical Standards Board for Scotland (CSBS). Clinical Standards: Diabetes. 2nd ed. Edinburgh: CSBS (2002). www.clinicalstandards.org/finalstand.html [full document] url cited 01/03/04.

4. Clinical Standards Board for Scotland (CSBS). Clinical Standards: Generic. Edinburgh: CSBS (2002). www.clinicalstandards.org/finalstand.html [full document] url cited 01/03/04.

5. Clinical Standards Board for Scotland (CSBS). Quality Assurance and Accreditation Manual. Edinburgh: CSBS (2000).

6. Diabetic Retinopathy Screening Implementation Group. Diabetic Retinopathy Screening Services in Scotland: Recommendations for Implementation. A Report by the Diabetic Retinopathy Screening Implementation Group. Edinburgh: Scottish Executive Health Department (2003).

7. Health Technology Board for Scotland (HTBS). Health Technology Assessment. Report 1: Organisation of Services for Diabetic Retinopathy Screening. Glasgow: HTBS (2002). http://docs.scottishmedicines.org/docs/pdf/ASSESSMENT%20REPORT.pdf [full document] url cited 01/03/04.

8. National Services Division (NSD). Diabetic Retinopathy Screening Training Manual for Screeners and Graders. Edinburgh: NSD (2003).

9. Royal College of Ophthalmologists of London (RCOphth). Guidelines for Diabetic Retinopathy. London: RCOphth (1997).

10. Royal National Institute for the Blind (RNIB). See It Right [Pack of 12 A5 Booklets]. London: RNIB (2002). www.rnib.org.uk/seeitright/#order [content and order information] url cited 01/03/04.

11. Scottish Executive. Diabetic Retinopathy Screening Services. NHS HDL(2003)33. Edinburgh: Scottish Executive.

12. Scottish Executive. Our National Health: A Plan for Action, a Plan for Change. Edinburgh: Scottish Executive (2000). www.scotland.gov.uk/library3/health/onh-00.asp [full document] url cited 01/03/04.

13. Scottish Executive. Scottish Diabetes Survey. NHS HDL(2000)12. Edinburgh: Scottish Executive.

14. Scottish Executive. Scottish Diabetes Framework. Edinburgh: SEHD (2002). www.scotland.gov.uk/library5/health/sdf-00.asp [full document] url cited 01/03/04.

15. Scottish Intercollegiate Guidelines Network (SIGN). SIGN Guideline 55: Management of Diabetes. Edinburgh: SIGN (2001). www.sign.ac.uk/guidelines/index.html [access to full document]. url cited 01/03/04.

16. UK National Screening Committee (UK NSC). Preservation of Sight in Diabetes: A Risk Reduction Programme. (2000). www.diabetic-retinopathy.screening.nhs.uk/index.html [dedicated website with electronic documents] url cited 01/03/04.

17. World Health Organisation (WHO). Diabetes Care and Research in Europe - The St Vincent Declaration (1989). www.show.scot.nhs.uk/crag/topics/diabetes/vincent.htm url cited 01/03/04.

.

9. Clinical Standards for Diabetic Retinopathy Screening

STANDARD 1 - Organisation

STANDARD 2 - Call-Recall and Failsafe

STANDARD 3 - Screening Process

STANDARD 4 - Proficiency Testing

STANDARD 5 - Referral

STANDARD 1 ~ Organisation

Standard Statement	Rationale
1(a)There is an agreed area-wide structured diabetic retinopathy screening programme, in line with national recommendations which clearly defines: - reporting arrangements and accountability; - the processes of care that people with diabetes should expect to receive within the programme; - the protocols and guidelines that determine which clinician is responsible for the delivery of specific aspects of care; - criteria for referral.	There is clear evidence that early detection of diabetic eye conditions (retinopathy) using regular screening is important to improve outcomes, particularly as sight-threatening retinopathy can be symptomless. Effective care involves partnerships between patients and all healthcare professionals who contribute to diabetic retinopathy care in the NHS Board area. Multi-professional access to agreed individualised plans of care facilitates greater team involvement in the provision of ongoing care and consistent advice. References: (11), (17)

Criteria
Essential 1(a)1 There is an effective, well-organised strategic planning group including stakeholders: eg a Local Diabetes Service Advisory Group (LDSAG), or equivalent, which is accountable to the NHS Board. 1(a)2 There is a local strategy and implementation plan for diabetic retinopathy screening services that covers assessment, diagnosis and referral. 1(a)3 There are agreed guidelines for effective communication between the screening programme and ophthalmology services, GP and hospital care, which are jointly reviewed. 1(a)4 There is an identified individual with delegated responsibility and authority for co-ordinating and monitoring the diabetic retinopathy screening programme.

STANDARD 1 ~ Organisation (continued)

Standard Statement	Rationale
1(b) There is a national service specification in place for those involved in providing and monitoring diabetic retinopathy screening services in NHS Boards.	A well-defined service specification facilitates organised population-based screening.
1(c) All communication with the users of the screening programme, including prompts to attend for screening, is clear, informative, relevant and timeous, and utilises nationally agreed guidelines for communications.	The current recommended format has been developed with input from health professionals and service users. There is evidence that providing screening information to people with diabetes in this format encourages compliance and reduces anxiety. References: (4), (17)

Criteria

Essential

1(b)1 The service specification includes the following:

1. audit
2. training
3. quality assurance
4. information for people with diabetes
5. call-recall
6. photography
7. grading
8. reporting
9. follow-up
10. treatment

1(b)2 NHS Boards have arrangements in place to ensure that the specification is monitored and met.

Essential

1(c)1 Up-to-date National Services Division (NSD) information is used.

1(c)2 Supplementary information pertinent to local service provision conforms to national guidelines for communications and is developed in conjunction with service users.

1(c)3 Mechanisms are in place to monitor and evaluate the effectiveness of communication between health professionals, and service users.

STANDARD 2 ~ Call-Recall and Failsafe

Standard Statement	Rationale
2(a) Effective call-recall arrangements, utilising the national diabetic retinopathy screening support software or its equivalent, are in place to ensure all eligible people with diabetes are invited for screening at least once every year.	There is good evidence that effective call-recall, which allows tracking of people with diabetes within an NHS Board area and beyond, improves uptake and coverage.
2(b) A national follow-up protocol is in place, appropriate to the outcome of the screening episode.	A national follow-up protocol is important to ensure that all people with diabetes with referable grades of retinopathy are referred as appropriate.

Criteria

Essential

2(a)1 All eligible people have a written prompt to attend for screening at least once every year, unless a current screening result is already on the call-recall module.

2(a)2 Arrangements are in place to reach people not on the diabetes register or accessible via their GP (eg long-stay institutions).

2(a)3 A minimum of 80% of eligible people with diabetes are screened within the last year.

2(a)4 Screening uptake is monitored at NHS Board level and action taken where targets are not achieved.

2(a)5 The NSD protocol is followed for the management of non-attenders, both those who fail to attend appointments and those who actively optout of the screening programme, taking into account patient choice and responsibility for their care.

2(a)6 All staff involved in call-recall receive training in using the call-recall IT system before undertaking unsupervised work.

Essential

2(b)1 A national protocol defining failsafe procedures for follow-up of eligible people with diabetes with referable grades of retinopathy is in use.

STANDARD 3 ~ Screening Process

Standard Statement	Rationale
3(a) By March 2006, all retinal screening photographs are taken using equipment which meets NSD guidance.	There is evidence that digital photography is the most suitable method for diabetic retinopathy screening. References: (6), (7), (16)
3(b) Personnel performing retinal screening are appropriately trained and qualified (or under supervision) in accordance with an approved national training programme covering all aspects of diabetic retinopathy screening.	Trained/experienced photographers obtain a higher rate of satisfactory photographs.
3(c) All eligible people with diabetes receive their diabetic retinopathy screening result timeously and in a recommended format in line with national recommendations.	Delayed reporting increases anxiety. To further reduce anxiety, it is important that people with diabetes receive information regarding their results in a format that they can easily understand.

Criteria
Essential 3(a)1 Photographs are taken using equipment and techniques in accordance with national guidelines.
Essential 3(b)1 All staff have full training in retinal screening before working unsupervised, and all staff receive training in new techniques. 3(b)2 Staff undertake continuing professional development (CPD) as per professional and/or national guidelines.
Essential 3(c)1 A minimum of 80% of people screened are sent the result in writing within 4 weeks (20 working days) of the photograph being taken.

STANDARD 4 ~ Proficiency Testing

Standard Statement	Rationale
4(a) All grading staff have successfully completed a recognised training programme.	Grading digital photographs for diabetic retinopathy is complex and skilled. Experience is the core of basic training and the national training programme is being developed to reflect this.
4(b) Diabetic retinopathy screening programmes have a system in place to ensure that the competency of individual graders is assessed by ongoing quality assurance.	Clinically important grading errors include: 1. failure to notice unequivocal signs of referable retinopathy; 2. failure to note that an image is of such low quality that no screening decision is feasible. Sampling from cases who are not referred for quality assurance purposes can detect errors of this kind.
4(c) Case review and audit is undertaken by the local screening programme to facilitate continuing improvement.	Audit is an important process that helps identify variations in practice, encourages examination of the reasons for these, and helps to identify the changes that are required to effect improvements.
4(d) There is evidence of external quality assurance (EQA).	Participation in external quality assurance schemes such as NSD proficiency testing, and technical external quality assurance schemes, provides a useful means of independently monitoring performance.

Criteria
Essential 4(a)1 Only staff trained and accredited according to national guidelines sign-off reports.
Essential 4(b)1 The images from a minimum of 500 randomly selected patients (or all images graded if less than 500 patients) per grader per annum, not otherwise referred to a third level grader, are reviewed by a third level grader. 4(b)2 If clinically important grading errors are found, further investigation and/or additional training of the grader is carried out.
Essential 4(c)1 Screening histories of eligible people with diabetes developing referable retinopathy are reviewed, and any areas in the programme which require improvement are identified and addressed. 4(c)2 All services must submit national minimum dataset returns.
Essential 4(d)1 All staff in the screening programme participate in NSD proficiency testing as part of revalidation training.

STANDARD 5 ~ Referral

Standard Statement	Rationale
5(a) All eligible people with diabetes who have identified signs of referable retinopathy, according to national grading recommendations, are referred to an ophthalmologist for assessment, and, if necessary, treatment.	Diabetic eye disease is the commonest cause of visual loss in adults of a working age in the UK. Progression is reduced by good glycaemic and blood pressure control. Laser photocoagulation is effective in saving vision. References: (3), (7), (15), (17)

Criteria
Essential
5(a)1 There is a referral process to a consultant ophthalmologist-led service for people with diabetes, with identified signs of developing diabetes-related retinopathy, in accordance with national grading recommendations.
5(a)2 The diabetes care provider should be notified of all people whose eye examination has revealed retinopathy.

10. Glossary of Terms

accreditation	A process, based on a system of external peer review using written standards, designed to assess the quality of an activity, service or organisation.
acute sector	Hospital-based health services which are provided on an in-patient or out-patient basis.
AHPs	See allied health professions.
allied health professions (AHPs)	Healthcare professionals directly involved in the provision of primary and secondary healthcare. Includes several groups such as physiotherapists, occupational therapists, dietitians, etc. Formerly known as professions allied to medicine (PAMs).
arteries	Blood vessels which carry blood away from the heart to supply the tissues.
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.
background (non-proliferative) diabetic retinopathy (BDR)	Diabetes can cause blocking and subsequent damage to the small blood vessels in the retina. This can result in damaged vessels leaking small amounts of blood and the retina being starved of oxygen.
BDR	See background diabetic retinopathy.
blood glucose	A measurement of the amount of sugar in the blood.
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.
call-recall	The process used to invite people for a screening test.
carer	A person who looks after family, partners or friends in need of help because they are ill, frail or have a disability. The care they provide is unpaid.
clinical governance	A framework through which NHS organisations are accountable for both continuously improving the quality of their services, and safeguarding high standards of care, by creating an environment in which excellence in clinical care will flourish. Management of clinical risk at an organisational level is an important aspect of clinical governance. Clinical risk management recognises that risk can arise at many points in a patient's journey, and that aspects of how organisations are managed can systematically influence the degree of risk.

.

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 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.
clinician	A healthcare practitioner who specialises in seeing, diagnosing and/or treating patients.
college	In the UK, the term 'college', when used relating to healthcare, as for example in 'The Royal College of...', refers to organisations which usually combine an education role with promotion of professional standards.
compliance	A measure of how conscientiously a person carries out advice tailored for that individual's benefit. For example, a situation where clinician and patient are in agreement about the best course of action and the patient carries out the plan by taking tablets or injections.
consultant endocrinologist	A senior physician trained to diagnose and treat complex hormonal disorders and metabolic conditions.
consultant in medical ophthalmology	A senior physician trained to diagnose and treat the medical and ophthalmic aspects of systematic (whole body) disorders affecting vision.
consultant in public health medicine (CPHM)	A senior doctor who specialises in the health of populations.
consultation	The process of obtaining feedback on the content of proposals or a document. For example, draft clinical standards go out to consultation.
continuing professional development (CPD)	An ongoing commitment to learning in various forms, which maintains and enhances professional standards of work, and develops the ability to recognise good practice.
CPD	See continuing professional development.
criterion(sing)/ criteria(pl)	Provide the more detailed and practical information on how to achieve the standard, and relate to structure, process or outcome factors.
CSBS	See Clinical Standards Board for Scotland.
data source	The source of evidence to demonstrate whether a standard or criterion is being met.

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 should strive.
diabetes mellitus	A condition in which the amount of glucose (sugar) in the blood is too high because the body cannot use it properly.
diabetes register	A list of people with diabetes, and a product of the clinical management system.
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.
digital camera	A camera which captures images which can be digitised, stored and transmitted using microprocessor technology.
eligible people with diabetes	All people diagnosed with either Type 1 or Type 2 diabetes mellitus and aged over 12 years, or post-puberty, are eligible for screening for diabetic retinopathy.
EQA	External quality assurance.
essential (criterion/criteria)	A criterion that should be met wherever a service is provided.
evidence-based medicine	Evidence-based clinical practice is an approach to decision making in which the clinician uses the best evidence available, in consultation with the patient, to decide upon the option which suits that patient best.
failsafe	Reliable back-up
generic standards	Standards that apply to most, if not all, clinical services.
GP	General Practitioner.
grader	The member of staff who interprets and records the appearance of a retinal photograph.
grading	The process of interpreting and recording the appearance of a photograph.
guidelines	Systematically developed statements which help in deciding how to treat particular conditions.
HDL	See Health Department Letter.
Health Board	See NHS Board.
Health Council	Each NHS Board area has a Health Council, an organisation whose aim is to promote public consultation and participation in health-related matters. Sometimes referred to as a Local Health Council.

Health Department Letter (HDL)	Health Department Letter (formerly known as Management Executive Letter - MEL), formal communications from the Scottish Executive Health Department to NHSScotland.
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.
HTBS	See Health Technology Board for Scotland.
Information and Statistics Division (ISD)	The Information and Statistics Division is part of the Common Services Agency, NHSScotland. Health service activity, manpower and finance data are collected, validated, interpreted and disseminated by the division. This data is received from NHS Boards, NHS Trusts and general practices. Website: www.isdscotland.org
insulin	A hormone secreted by the pancreas. Insulin regulates the blood glucose level, and is important for growth and tissue repair.
ISD	See Information and Statistics Division.
Island NHS Board	There are three Island NHS Boards (Orkney, Shetland and the Western Isles). They have always had a combined strategic and operational role. See NHS Board.
laser photocoagulation	Use of a highly focused light beam to treat diseased body tissue. In the eye this is used to treat damaged small blood vessels to stop them leaking or to treat an undernourished retina to stop the release of 'chemicals' that make the new vessels grow.
laser treatment	See laser photocoagulation.
lay representation	The inclusion of a member(s) of the general public in a professional group.
LDSAG	See Local Diabetes Service Advisory Group.
lead clinician	Clinician with administrative responsibilities for a specific service.
LHCC	See Local Health Care Co-operative.
Local Diabetes Service Advisory Group (LDSAG)	A strategic planning group of local diabetes service users, carers and providers who advise NHS Boards in matters relating to services for individuals with diabetes.

Local Health Care Co-operative (LHCC)	In Scotland, Local Health Care Co-operatives (LHCCs) are voluntary groupings of GPs and other local healthcare professionals intended to strengthen and support the primary healthcare team in delivering local care.
macula	The area of the retina that is the centre of sight.
macular oedema	Fluid in the part of the retina that is at the centre of sight. It may be a result of leaking small vessels causing fluid to accumulate around the cells of the retina or may be a result of sick and dying cells 'ballooning up' because they are starved of oxygen and food.
maculopathy	Retinopathy affecting the centre of the retina (the macula).
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.
Management Executive Letter (MEL)	Formal communications from the Scottish Executive Health Department to NHSScotland, now known as Health Department Letters (HDLs).
MEL	See Management Executive Letter.
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.
multidisciplinary	A multidisciplinary team is a group of people from different disciplines (both healthcare and non-healthcare) who work together to provide care for patients with a particular condition. The composition of multidisciplinary teams will vary according to many factors. These include: the specific condition, the scale of the service being provided, and geographical/socio-economic factors in the local area.
multidisciplinary system of working	A method of working in a multidisciplinary team with protocols in place for most, if not all, eventualities.
multi-professional	Consisting of members of more than one profession.
national guidelines	Guidelines defined at national level. See guidelines.
National Services Division (NSD)	The division of the Scottish Common Services Agency with responsibility for ensuring the provision of national screening programmes and specialist services on behalf of NHSScotland. Website: www.show.scot.nhs.uk/nsd/

national standards	Standards defined at a national level.
NHS	National Health Service.
NHS Board	NHS Boards are responsible for strategic planning, performance management and governance of each of Scotland's 15 local health systems. Most NHS Board areas (excluding Island NHS Boards) contain one Acute and one Primary Care Trust, with operational and employment responsibilities, but since 2001 they have operated within a strategic framework drawn up by the NHS Board. By 2004, Trusts will have been abolished and replaced by operating divisions of the NHS Board (see also NHS Trust).
NHS priorities	The three national clinical priorities are mental health; coronary heart disease and stroke; and cancer.
NHS QIS	See NHS Quality Improvement Scotland.
NHS Quality Improvement Scotland (NHS QIS)	NHS Quality Improvement Scotland is a statutory body, established as a Special Health Board in January 2003. Its role is to focus on improving the quality of patient care and the health of patients. It will have a particular emphasis on the quality of care and the patient journey for vulnerable groups. NHS Quality Improvement Scotland has been created by the merger of five organisations: Clinical Standards Board for Scotland (CSBS); Health Technology Board for Scotland (HTBS); the Scottish Health Advisory Service (SHAS); Nursing and Midwifery Practice Development Unit (NMPDU), and the Clinical Resources and Audit Group (CRAG). Website: www.nhshealthquality.org
NHS Trust	A Trust is an NHS organisation responsible for providing a group of healthcare services for the local population. An Acute Trust provides hospital services. A Primary Care Trust provides primary care/community health services. Mental health services (both hospital and community based) are usually provided by Primary Care Trusts. Since 2001 Trusts have operated within an overall framework drawn up by their NHS Board. Subject to legislation, Trusts will be dissolved by April 2004, becoming operating divisions of the NHS Board. The NHS Board will be the single employer for the local system. In two areas – Borders and Dumfries & Galloway – since April 2003 there have been no Trusts or operating divisions with the NHS Board fulfilling a dual strategic and operational role (like the three Island NHS Boards). The term 'Trust' is retained in NHS QIS publications during the period of Trust abolition. Where unification has occurred, the term 'Trust' should be taken to signify an operating division of the local NHS Board. See also NHS Board.

NHSScotland	The National Health Service in Scotland.
non-attenders	Eligible people who do not attend following an invitation for screening.
non-eligible	People with diabetes undergoing regular reviews by an ophthalmologist, those who are medically unfit to receive laser treatment (as determined by their GP), or who are completely blind, are not included in the diabetic retinopathy screening programme.
NSD	See National Services Division.
oedema	An abnormal collection of fluid in the tissues.
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.
ophthalmology	The study, diagnosis and treatment of diseases and defects of the eye.
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.
patient journey	The pathway through the health services taken by the patient (the person who is receiving treatment), and as viewed by the patient.
PDR	See proliferative diabetic retinopathy.
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.
photograph	A permanent record of an image produced on photosensitive film or paper by the process of photography.
physician	A specialist in medicine.
primary care	The conventional first point of contact between a patient and the NHS. This is the component of care delivered to patients outside hospitals and is typically, though by no means exclusively, delivered through general practices. Primary care services are the most frequently used of all services provided by the NHS. Primary care encompasses a range of family health services provided by family doctors, dentists, pharmacists, optometrists and ophthalmic medical practitioners.

proficiency testing	Regular testing to maintain skill levels and identify any areas requiring improvement at an early stage.
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.
protocol	A policy or strategy which defines appropriate action in specific circumstances. Protocols may be national, or agreed locally to take into account local requirements.
public consultation	The process of formal consultation and feedback on NHS Quality Improvement Scotland standards with healthcare professionals and members of the public.
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.
retina	The light-sensitive tissue that lines much of the back of the eyeball, in which nerve impulses are generated. From the retina these impulses are relayed to the brain, where they are interpreted as vision.
retinal photograph	A picture of the surface of the retina.
retinopathy	Damage to the retina at the back of the eye. Retinopathy is one of the possible long-term complications of diabetes. The retina contains many small blood vessels that can be injured by high blood glucose and high blood pressure.
RNIB	Royal National Institute for the Blind. Website address: www.rnib.org.uk
satisfactory photograph	A photograph that visualises the retina with enough detail to ensure that referable retinopathy will not be missed.
Scottish Diabetes Survey	A Scottish Executive initiative designed to develop an understanding of the national prevalence of diabetes and the provision of care for those who have diabetes with the aim of facilitating better healthcare.
Scottish Executive Health Department (SEHD)	The Scottish Executive Health Department is responsible for health policy and the administration of NHSScotland. Website: www.show.scot.nhs.uk/sehd

Scottish Intercollegiate Guidelines Network (SIGN)	SIGN was established in 1993 by the Academy of Royal Colleges and Faculties in Scotland, to sponsor and support the development of evidence-based clinical guidelines for NHSScotland. Where a SIGN guideline exists for a specialty or service for which NHS Quality Improvement Scotland is setting standards, it will be referenced. For further information relating to SIGN guidelines or the methodology by which SIGN guidelines are developed, contact: SIGN Secretariat, Royal College of Physicians, 9 Queen Street, Edinburgh, EH2 1JQ. Website: www.sign.ac.uk
screening	Examination of people with no symptoms, to detect unsuspected disease.
screening episode	A cycle of a person's screening events.
screening histories	An historical record of a person's screening events.
screening programme	The systematic and co-ordinated offer of an examination to a defined population known to be at risk from a particular disease.
secondary care	Care provided in an acute sector setting. See acute sector.
SEHD	See Scottish Executive Health Department.
self-assessment	Assessment of performance against standards by individual/clinical team/Trust/NHS Board providing the service to which the standards are related.
SIGN	See Scottish Intercollegiate Guidelines Network.
SIGN guideline	Scottish Intercollegiate Guidelines Network guideline. See guidelines and Scottish Intercollegiate Guidelines Network.
slit lamp	A method of examining the structures of the eye using a special microscope.
St Vincent Declaration	The main aim of the St Vincent Declaration is to reduce the serious health problems linked to diabetes, such as blindness, renal failure, amputation and coronary heart disease, through governmental and healthcare team initiatives.
standard statement	An overall statement of agreed performance.
statistical epidemiologist	Provides predictions on frequency, distribution, effects and causes of diseases within populations based on epidemiological data and statistical models. Predictions can cover not only infectious diseases, but conditions such as heart disease, cancer, and diabetes.
statutory	Enacted by statute; depending on statute for its authority as a statutory provision. Required by law.
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.
unified Board	See NHS Board.
Unified Health Board	See NHS Board.
user	A user (or service user) is a person who uses services, eg a person with a diagnosis of schizophrenia who uses health services. Some people do not identify with the term 'user' and may instead prefer terms such as 'patient' or 'client'.
vision	The ability to see images with the eye.

Our Commitment

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

- **patient and public focus**
  - promoting a patient-focused NHS that is responsive to the views of the public

- **independence**
  - reaching our own conclusions and communicating what we find

- **partnership**
  - involving patients, carers and the public in all parts of our work
  - working with and supporting NHS staff in improving quality
  - collaborating with other organisations such as public bodies, voluntary organisations and manufacturers to avoid duplication of effort

- **evidence-based**
  - basing conclusions and recommendations on the best evidence available

- **openness and transparency**
  - promoting understanding of our work
  - explaining the rationale for our recommendations and conclusions
  - communicating in language and formats that are easily accessible

- **quality assurance**
  - aiming to focus our work on areas where significant improvements can be made
  - ensuring that our work is subject to internal and external quality assurance and evaluation

- **professionalism**
  - promoting excellence individually and as teams and ensuring value for money in the use of public resources (human and financial)

- **sensitivity**
  - recognising the needs, opinions and beliefs of individuals and organisations and respecting and encouraging diversity

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

- Electronic
- Audio cassette
- Large print

NHS Quality Improvement Scotland

Edinburgh Office **~ Elliott House 8-10 Hillside Crescent Edinburgh EH7 5EA Tel 0131 623 4300**

Glasgow Office ~ Delta House 50 West Nile Street Glasgow G1 2NP Tel 0141 225 6999

comments@nhshealthquality.org www.nhshealthquality.org

This document is produced from elemental chlorine-free material and is sourced from sustainable forests