

Diabetic Retinopathy Screening

Standards

June 2016

About Healthcare Improvement Scotland

We believe that every person in Scotland should receive the best healthcare possible every time they come into contact with their health service.

We have a key role in supporting healthcare providers to make sure that their services meet these expectations and continually improve the healthcare the people of Scotland receive.

For more information about our role, direction and priorities, please visit:
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We are committed to equality and diversity. We have assessed these standards for likely impact on the nine equality protected characteristics as stated in the Equality Act 2010 and defined by age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, and sexual orientation. A copy of the impact assessment is available upon request from the Healthcare Improvement Scotland Equality and Diversity Advisor.

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Introduction

Background to the diabetic retinopathy screening standards

Diabetic retinopathy is a common complication of diabetes which affects the eyes. It occurs when the small blood vessels in the retina, which is at the back of the eye, become blocked or leak. Untreated diabetic retinopathy is one of the most common causes of visual impairment in Scotland, and the fifth-leading cause of global blindness.²

In its early stages, there are no symptoms so people with diabetes may not realise they have diabetic retinopathy. Screening is important because if the condition is caught early, treatment is effective at reducing the risk of visual impairment and blindness.²

Screening is offered every year to eligible people who have diabetes and are aged 12 and over. A full description of who is eligible is detailed in the terminology section.

In developing these standards we have reviewed the *Clinical Standards for Diabetic Retinopathy Screening*³ document published in 2004 by NHS Quality Improvement Scotland. The 2004 standards document is currently being used by both the Scottish Diabetic Retinopathy Screening Collaborative⁴ and the National Services Division to monitor performance. It is also used to quality assure the Scottish National Diabetic Retinopathy Screening Programme.² This revision will ensure the screening programme remains a high quality, safe, effective and person-centred service.

Scope of the standards

The 2016 Healthcare Improvement Scotland diabetic retinopathy screening standards cover the following areas:

- governance and leadership
- call-recall
- attendance and uptake
- the screening process
- referral, and
- treatment.

Format of the standards

All our standards follow the same format. Each standard includes:

- a statement of the level of performance to be achieved
- a rationale providing reasons why the standard is considered important, and
- a list of criteria describing the required structures, processes and outcomes.

The standards also identify what it means for people receiving diabetic retinopathy screening and for organisations and staff delivering screening.

Within these standards, all criteria are considered ‘essential’ or required in order to demonstrate the standard has been achieved.

Examples of how NHS boards can demonstrate achievement can be found at the end of each standard.

Terminology

Wherever possible, we have incorporated generic terminology which can be applied across all health and social care settings. The term ‘patient’ is used within the criteria to refer to the person receiving diabetic retinopathy screening.

The term ‘eligible people’ is used to describe people who are eligible for screening, that is people aged 12 years and over who have been diagnosed with one of the following types of diabetes:

- type 1 diabetes mellitus
- type 2 diabetes mellitus
- mature onset diabetes of youth (MODY), and
- other diabetes mellitus classified as:
 - latent autoimmune diabetes of adulthood
 - maternally inherited diabetes
 - neonatal diabetes⁵
 - secondary – pancreatic pathology
 - secondary – drug induced
 - secondary – disease
 - diabetes resolved, and
 - diabetes in remission.

Eligible people who did not attend an appointment or take up their invitation can, at any time, contact the DRS Collaborative⁴ for another appointment. Also, eligible people have the right to choose not to participate but to do so they must inform their GP every 3 years.

The Scottish Diabetic Retinopathy Screening Collaborative⁴, known as the ‘DRS Collaborative’, brings together staff from all NHS boards in Scotland to facilitate the delivery of the Scottish National Diabetic Retinopathy Screening Programme.² The DRS Collaborative⁴ provides NHS boards with quarterly national and local key performance indicator data and submits a quality and performance report to the Scottish Standing Committee for screening programmes.

Information for people and their representatives

This document has been developed to support staff and organisations to ensure the highest standards of diabetic retinopathy screening services are achieved. However, each standard also details what people, patients and their representatives, and the public can expect of these services in Scotland.

Summary of standards

- Standard 1:** Scotland has an effective national diabetic retinopathy screening service.
- Standard 2:** All eligible people are invited for diabetic retinopathy screening.
- Standard 3:** The number of people attending diabetic retinopathy screening is maximised within the principles of informed choice.
- Standard 4:** Diabetic retinopathy screening is safe, effective and person-centred.
- Standard 5:** People who require referral and have been screened are referred to ophthalmology services for assessment in line with DRS Collaborative referral protocols.⁴
- Standard 6:** People requiring treatment can access nationally approved treatments¹⁶ in a timely manner.

Diabetic retinopathy screening standards

Standard 1: Governance and leadership

Standard statement

Scotland has an effective national diabetic retinopathy screening service.

Rationale

Population-based screening for eligible people can reduce the risk of visual impairment and blindness caused by diabetic retinopathy.⁶⁻¹¹

Criteria

- 1.1 NHS boards have systems and processes in place to demonstrate the implementation of:
 - (a) diabetic retinopathy screening national guidance⁴
 - (b) multidisciplinary input to diabetic retinopathy screening
 - (c) collection, monitoring, review and action on data relating to diabetic retinopathy screening, and
 - (d) ongoing quality improvement in diabetic retinopathy screening.
- 1.2 NHS boards have a designated public health lead acting as the diabetic retinopathy screening co-ordinator.
- 1.3 NHS boards have a designated lead clinician for diabetic retinopathy screening.
- 1.4 Staff, involved in the ongoing management of diabetic retinopathy, participate in regular audit, which could include the diabetic retinopathy screening external quality assurance scheme.⁴
- 1.5 Staff meet the requirements of the DRS Collaborative⁴ approved training programmes, relevant to their role.
- 1.6 NHS boards have access to a national IT system which enables data collection and supports governance procedures.

What does the standard mean for people participating in diabetic retinopathy screening?

- Wherever you receive diabetic retinopathy screening, you can expect the service to be committed to improving the screening process and management of diabetic retinopathy.

What does the standard mean for NHS boards?

- The NHS board's Executive Team can describe organisational accountability and support for continuous quality improvement, specific to diabetic retinopathy screening.
- NHS boards use quarterly key performance indicator data to review their performance and to foster a culture for continuous improvement.

What does the standard mean for staff?

Staff:

- are aware of their role within the multidisciplinary team
- are supported by a designated lead clinician and a designated co-ordinator
- use data for continuous professional development in line with competency frameworks, and
- have access to a national IT system when recording data.

Practical examples of evidence of achievement (NOTE: this list is not exhaustive.)

- Participation in the diabetic retinopathy screening external quality assurance scheme.
- Executive Team reports or minutes.
- DRS Collaborative quality and performance report.
- DRS Collaborative standard operating procedures.
- Key performance indicators.
- Diabetes improvement plan.
- Assessment of workforce against competency framework.

Standard 2: Call-recall

Standard statement

All eligible people are invited for diabetic retinopathy screening.

Rationale

An effective and systematic call-recall service increases the number of eligible people participating in diabetic retinopathy screening.²

The call-recall service is based on the DRS Collaborative national follow-up protocol⁴, appropriate to the outcome of the screening.

Criteria

- 2.1 NHS boards have a system in place to identify all eligible people for diabetic retinopathy screening.
- 2.2 NHS boards invite all eligible people for diabetic retinopathy screening.
- 2.3 The invitation to attend diabetic retinopathy screening is offered to all newly diagnosed patients within 30 calendar days of the DRS Collaborative⁴ receiving notification.
- 2.4 The date of the appointment offered to all newly diagnosed patients is within 90 calendar days of the DRS Collaborative⁴ receiving notification.
- 2.5 NHS boards recall all eligible people for diabetic retinopathy screening at a frequency appropriate to the:
 - (a) DRS Collaborative national follow-up protocol⁴, and
 - (b) outcome of the diabetic retinopathy screening.
- 2.6 NHS boards recall all eligible people who have not responded to a diabetic retinopathy screening invitation in line with DRS Collaborative protocols.⁴
- 2.7 NHS boards have a system in place to identify all eligible people who choose not to participate in diabetic retinopathy screening, and who have notified their GP of their decision.

What does the standard mean for people participating in diabetic retinopathy screening?

Eligible people:

- are automatically invited for diabetic retinopathy screening, and
- who choose not to participate have the opportunity to inform their GP

What does the standard mean for NHS boards?

- Each NHS board has an effective call-recall system in place which maximises the number of people participating in diabetic retinopathy screening.

What does the standard mean for staff?

Staff are aware, relevant to their role, of:

- the call-recall system
- eligibility criteria
- failsafes
- the patient pathway, and
- the opting-out process for eligible people.

Practical examples of evidence of achievement (NOTE: this list is not exhaustive.)

- Protocol for opting out.
- Protocols for eligibility and invitation.
- Key performance indicator data.
- Evidence of failsafe adherence.

Standard 3: Attendance and uptake

Standard statement

The number of people attending diabetic retinopathy screening is maximised within the principles of informed choice.

Rationale

The risk of visual impairment and blindness rates can be reduced by diabetic retinopathy screening.⁶

Providing accessible and responsive information on diabetic retinopathy screening supports people to make informed choices and helps to maximise attendance.¹²⁻¹³ Informed choice is when an individual receives the right information, at the right time, in the right format for them to decide whether or not to attend their screening appointment.

Engaging with people whose attendance is low is important for maximising attendance.¹⁴⁻¹⁵

The terms ‘attendance’ and ‘uptake’ used here are defined as:

- attendance - the invited person attends their screening appointment, and
- uptake - the invited person completes the screening process, including slit lamp examination, when images are ungradable.

Criteria

- 3.1 NHS boards ensure that they achieve an attendance of 80%.
- 3.2 NHS boards ensure that they achieve an uptake of 80%.
- 3.3 NHS boards maximise attendance by ensuring that eligible people, regardless of their personal circumstances or characteristics:
 - (a) are offered an opportunity to attend, and
 - (b) receive accessible and responsive information to support them make an informed choice.

What does the standard mean for people participating in diabetic retinopathy screening?

- People are invited for diabetic retinopathy screening no matter what their circumstances are or where they live in Scotland.

What does the standard mean for NHS boards?

NHS boards ensure that:

- a minimum of 80% of people attend a screening appointment
- a minimum of 80% of people complete the screening process

What does the standard mean for staff?

Staff:

- are supported to maximise diabetic retinopathy screening attendance, and
- feel confident to support people to make informed decisions when participating in diabetic retinopathy screening.

Practical examples of evidence of achievement (NOTE: this list is not exhaustive.)

- Patient survey.
- Key performance indicator data.
- Complaints against patient charter.
- Copies of documents that detail how the NHS board has worked to maximise attendance, particularly with people whose attendance is low.
- Accessible and responsive information on diabetic retinopathy screening.

Standard 4: The screening process

Standard statement

The diabetic retinopathy screening process is safe, effective and person-centred.

Rationale

To promote safe and effective care, images are obtained by competent staff using equipment and techniques which meet DRS Collaborative protocols.⁴

To ensure accurate results from the images obtained, the images are graded by an approved automated system and/or competent staff.

When people who have participated in the screening process receive accurate and timely results, this supports a person-centred approach to care and reduces unnecessary anxiety.⁶

Criteria

- 4.1 The diabetic retinopathy screening process is carried out in line with DRS Collaborative protocols.⁴
- 4.2 All equipment is procured, maintained and used in line with DRS Collaborative protocols.⁴
- 4.3 DRS Collaborative protocols⁴ are used to internally and externally quality assure the work of graders. A maximum rate of ungradable images is 2.5% for digital imaging and 2% for slit lamp examinations.
- 4.4 A minimum of 95% of people screened are sent the result within 20 working days of being screened.

What does the standard mean for people participating in diabetic retinopathy screening?

People who have been screened:

- experience safe, effective and person-centred diabetic retinopathy screening, and
- receive their results within agreed timelines.

What does the standard mean for NHS boards?

- NHS boards provide safe, effective and person-centred diabetic retinopathy screening.

What does the standard mean for staff?

Staff:

- have clean, safe and effective equipment to use for diabetic retinopathy screening, and
- access approved training programmes to support them when providing diabetic

retinopathy screening.

Practical examples of evidence of achievement (NOTE: this list is not exhaustive.)

- Compliance with DRS Collaborative protocols.
- Key performance indicators.
- Adherence to the maintenance schedules for equipment.

Standard 5: Referral

Standard statement

People who require referral and have been screened are referred to ophthalmology services for assessment in line with DRS Collaborative referral protocols.⁴

Rationale

Timely referral of people with active proliferative retinopathy and symptomatic optical coherence tomography positive diabetic macular oedema reduces the risk of permanent visual impairment.

Criteria

- 5.1** People graded as having previously untreated active proliferative retinopathy (active new vessels at the disc, or active new vessels elsewhere) are referred to ophthalmology services within 5 working days of first grading.
- 5.2** People with symptomatic optical coherence tomography positive diabetic macular oedema are referred to ophthalmology services within 10 working days of first grading.

What does the standard mean for people participating in diabetic retinopathy screening?

- People are referred to ophthalmology services for assessment within agreed timelines.

What does the standard mean for the NHS board?

NHS boards ensure that:

- the management of people referred from diabetic retinopathy screening is safe and effective, and
- people with potentially sight-threatening diabetic retinopathy are identified and referred to appropriately qualified staff.

What does the standard mean for staff?

- Staff involved in the referral process ensure that this is undertaken within agreed timelines.

Practical examples of evidence of achievement (NOTE: this list is not exhaustive.)

- Evidence of meeting local and national protocols.
- Systems data.
- Standard operating procedures.

Standard 6: Treatment

Standard statement

People requiring treatment can access nationally approved treatments¹⁶ in a timely manner.

Rationale

Timely and effective treatment reduces the risk of permanent visual impairment.²

Criteria

- 6.1** People identified as having active, untreated, **high risk** proliferative retinopathy (active new vessels at the disc, or active new vessels elsewhere with vitreous haemorrhage) can access nationally approved treatments within 5 working days of receipt of referral.
- 6.2** People identified as having active, untreated, **early** proliferative retinopathy (active new vessels elsewhere in the absence of vitreous haemorrhage), can access nationally approved treatments within 20 working days of receipt of referral.
- 6.3** People identified as having symptomatic optical coherence tomography positive diabetic macular oedema can access nationally approved treatments^{6, 16-17} within 20 working days of receipt of referral.

What does the standard mean for people participating in diabetic retinopathy screening?

- People identified with specific diagnoses can access treatment within agreed timelines.

What does the standard mean for NHS boards?

- NHS boards ensure that people can access treatment within agreed timelines.

What does the standard mean for staff?

- Staff are aware of, and adhere to, where appropriate, treatment timelines.

Practical examples of evidence of achievement (NOTE: this list is not exhaustive.)

- Key performance indicators.
- Compliance when using nationally approved treatments.

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Appendix 1: Development of the diabetic retinopathy screening standards

A project group, chaired by Dr John Olson, Consultant Ophthalmic Physician and Clinical Director of Retinal Screening, NHS Grampian was convened in August 2015 to consider the evidence and to help identify key themes for standards development.

For information, membership of the project group is set out in Appendix 2.

Consultation

We engaged with service users and the general public, 3rd sector organisations, NHS boards and staff, professional bodies (including Royal Colleges) and private sector organisations using a variety of approaches, including:

- focus groups (with service users, members of the public and NHS staff)
- an online survey, and
- a feedback form.

A full consultation report is available on the Healthcare Improvement Scotland website www.healthcareimprovementscotland.org

Appendix 2: Membership of the diabetic retinopathy screening standards project group

Name	Position	Organisation
John Olson (Chair)	Consultant Ophthalmic Physician and Clinical Director Retinal Screening	NHS Grampian
Michael Black	DRS Collaborative Co-ordinator	NHS Highland
Margaret Bruce	Service Manager, Diabetic Retinopathy Screening Programme	NHS Grampian
Graham Cormack	Consultant Ophthalmologist	NHS Tayside
Emilia Crighton	Interim Director of Public Health	NHS Greater Glasgow and Clyde
Norah Grant	DRS Programme Manager	NHS Lothian
Belinda Henshaw	Senior Programme Manager	Healthcare Improvement Scotland
Scott Horton	Project Officer	Healthcare Improvement Scotland
Bruce Knight	Patient representative	
Paula Leggat	Administration Officer	Healthcare Improvement Scotland
Nicola McElvanney	Chair	Optometry Scotland
Linda McGlynn	Health Engagement Manager	Diabetes Scotland
Jim Smith	Project Officer	Healthcare Improvement Scotland
David Steel	Programme Associate Director, National Specialist and Screening Services Directorate	National Services Division
Caroline Styles	DRS Lead Clinician/Consultant Ophthalmologist	NHS Fife
Ken Swa	Scottish Vision Advisor	RNIB Scotland
Garrick Wagner	Senior Programme Manager, National Specialist and Screening Services Directorate	National Services Division
Fiona Wardell	Team Lead	Healthcare Improvement Scotland

Project group members made a declaration of interest at the beginning stages of the project and further details of these are available on request from hcis.standardsandindicators@nhs.net

Clinical and quality assurance

Clinical members of the project group are responsible for advising on the professional and clinical aspects of the project group's work. The chair was assigned lead responsibility for providing formal clinical assurance and sign-off on the technical and professional validity and acceptability of any reports or recommendations from the group.

As a final quality assurance check, the standards document was reviewed by the representatives of Healthcare Improvement Scotland. This is to ensure that:

- the standards are developed according to agreed Healthcare Improvement Scotland methodologies
- the standards document addresses the areas to be covered within the agreed scope, and
- any risk of bias in the standards development process as a whole has been minimised.

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