

An Clár Náisiúnta Scagthástála Reitiní do Dhiaibéitigh The National Diabetic Retinal Screening Programme

# Programme Report 2013-2015

#### **Screening charter**

#### About Diabetic RetinaScreen – The National Diabetic Retinal Screening Programme

Diabetic RetinaScreen offers free, regular diabetic retinopathy eye screening to those aged 12 and older, diagnosed with diabetes.

Screening will be carried out using digital photography at either a fixed or mobile unit. The aim of diabetic retinopathy screening is to reduce the risk of sight loss among people with diabetes by the early detection and treatment of sight-threatening retinopathy.

#### Our commitment to you

- We will respect your privacy, dignity, religion, race and cultural beliefs.
- We will arrange services and facilities that are accessible.
- We will keep your screening records safe and confidential.
- We will offer you free, regular screening, once you become known to the programme.
- All aspects of the screening programme will be fully quality assured.
- We will provide clear information to explain each step in the screening process.
- Screening will be carried out using digital retinal photography.
- We will provide a Freephone information and support line during normal working hours.
- We will welcome your views and take them into account.
- If you take part in the screening programme and an abnormality is found, you will be offered timely referral, assessment and quality assured treatment.

Diabetic **RetinaScreen** An Clár Náisiúnta Scagthástála Reitiní do Dhiaibéitigh

The National Diabetic Retinal Screening Programme

#### If you need treatment

- We will explain the treatment available to you.
- We will encourage you to share in decision-making about your treatment.
- We can include your parent, guardian, partner, friend or relative in any discussions if that is what you want.
- You have the right to refuse treatment, to get a second opinion or to choose an alternative treatment.

#### Ways you can help us

- Read any information we send you and if you have any questions you can call the Freephone information line.
- Keep your appointment time or give at least three days notice if you need to change your appointment.
- Tell us if you have special needs.
- Tell us if you change your address.
- Tell us what you think of the service and the care you received. Your views will help us to improve the service for you and for other people.

#### Freephone: 1800 45 45 55 www.diabeticretinascreen.ie

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An Clár Náisiúnta Scagthástála Reitiní do Dhiaibéitigh The National Diabetic Retinal Screening Programme

# Introduction from the Head of Screening, National Screening Service

The National Screening Service (NSS), part of the Health Service Executive, has gained significant expertise, as well as a positive national and international reputation, in the development, implementation and delivery of successful populationbased screening programmes in Ireland.

#### The NSS manages four screening programmes:

**BreastCheck** -The National Breast Screening Programme,

**CervicalCheck** -The National Cervical Screening Programme,

**Diabetic RetinaScreen** -The National Diabetic Retinal Screening Programme and

**BowelScreen** -The National Bowel Screening Programme.

#### **Definition of screening**

Screening is a means of detecting disease before symptoms appear. For population-based screening programmes the usual determinants of effectiveness are reductions in diseasespecific mortality and morbidity and gains in health-related quality of life. Screening for diabetic retinopathy differs somewhat, in that the outcome of interest is interruption of the progression of sight threatening diabetic retinopathy (STDR) and blindness. While there is no impact in terms of mortality reduction from diabetic retinopathy, the morbidity which is preventable through screening, impacts greatly on quality of life. Diabetic retinopathy eye screening is a key part of diabetes care. Early detection and treatment is effective at reducing or preventing damage to sight.

The NSS provides screening for both cancer and non-cancer disease. Although screening does not provide a guarantee of diagnosis and cure for all patients, it provides an opportunity for those who have a positive test to receive confirmatory diagnostic testing, before further definitive diagnoses and treatment stages are put in place.

#### **Population-based screening**

Population-based call, re-call screening programmes provide a consistent, high-quality and standardised approach to identifying the population most at risk from a particular disease, through to diagnosis and referral for treatment. The process begins with developing a register of clients in the identified population, inviting participation in the programme, offering clear referral and treatment pathways within set time limits and developing a mechanism to re-call clients at defined intervals.

Organised screening has many advantages. In particular, it makes it possible to provide effective early detection with a test for which consistent repeat participation is necessary in order to achieve acceptable clinical benefits. This is why adherence to annual screening is an important element of diabetic retinopathy screening.

#### **Diabetic RetinaScreen**

Diabetic RetinaScreen commenced in 2013, with the aim of offering free annual diabetic retinopathy screening to people with diabetes aged 12 years and older.

This report highlights the successes and challenges for the programme and relate to those invited by Diabetic RetinaScreen over the first two screening rounds. The first cycle or 'round' of the programme was carried out over approximately two years, due to the complexity of establishing a programme of its type and ran from 25 February 2013 to 31 December 2014. Since subsequent cycles or 'rounds' are annual, the second round covered the period 1 January 2015 to 31 December 2015. In 2015, the best estimated overall prevalence of diabetes in the population of Ireland was 5.6 to 5.8 per cent.<sup>1</sup> If this estimate is applied to the population, this would mean there would be approximately 200,000 persons with diabetes in Ireland. The programme invited 147,929 people aged 12 years and over with diabetes to participate in the first two screening rounds.

The programme has learned extensively from the experience of the first and second round of implementation. Throughout the third and subsequent rounds, the NSS will continue to work with our photography and grading providers and our acute hospital screening partners to ensure sufficient and high-quality screening and treatment capacity is in place to meet programme needs. In order to achieve 80 per cent uptake, the future focus will be on advertising and promoting the programme and on identifying and removing perceived barriers to screening uptake.

I am delighted that we are now in a position to publish the results for the first two rounds of Diabetic RetinaScreen. The results are very encouraging for the NSS and our partners.

I would like to thank all those involved in the introduction, development and implementation of the Diabetic RetinaScreen programme for their dedication and support. I would also like to thank those who have been part of the ongoing process that oversees the programme's standards for quality assurance and clinical practice guidelines. This ensures we can continue to provide screening services of the highest international standard.

Charles O'Hanlon, Head of Screening, National Screening Service

# Message from the Clinical Director, Diabetic RetinaScreen

It is with great pleasure that we present, on behalf of the whole team, the report for the first two rounds of screening delivered by Diabetic RetinaScreen. Diabetic RetinaScreen was established in 2013, to provide photographic screening and grading to all diabetic patients, who are at risk of development of diabetic retinopathy and potential vision impairment.

#### **Diabetes in Ireland**

It is estimated that between 5.6 and 5.8 per cent of the population of Ireland have diabetes and this would equate to approximately 200,000 patients having the condition across Ireland.<sup>1</sup> It is known that people with type 1 diabetes retain a lifetime risk of approximately 90 per cent of developing diabetic retinopathy and the potential for vision impairment. The risk for people with type 2 diabetes is less, due to the later onset of the condition, however they are still at risk of vision impairment, due to complications of the disease.<sup>2</sup>

Screening for diabetic retinopathy via digital photography and grading, allows for the detection of pre-symptomatic retinal disease and allows the provision of sight preserving treatments such as laser, injections, or indeed surgery in exceptional cases. Our ability to detect and treat pre-symptomatic retinal disease has never been greater and the provision of a gold standard, internationally recognised system of detection and treatment of retinopathy, is critical as part of a patient's overall diabetic management and care. The programme commits to and supports the management of the chronic disease initiative,<sup>3</sup> this is tangible and evident via the programme's clinical information management system.

#### **Diabetic retinopathy screening**

The primary objective of the programme is to use digital retinal photography to identify specific patients (approximately 10%-15%) who are at risk of development of sight loss, due to diabetic retinopathy. Once these patients are identified, they are referred and seen in a timely fashion, to where the appropriate treatment can be delivered.

The development of a register of all diabetic patients was the key first step in the establishment of this programme and the register continues to grow. We work in conjunction with our photography and grading providers (EMIS Care and Global Vision), to deliver this service to patients. All patients on the register receive an invitation to participate in the screening process. Although there was some initial confusion among patients regarding the programme and its linkages to existing ad-hoc screening programmes, improved communications and targeted media campaigns have ensured the public are aware of the benefits of the programme. We continue to work to improve the accuracy of our registration process, increase the completeness of our register and to augment uptake by eligible patients to participate in the programme.

#### The screening tool

The method we employ to deliver the screening programme is digital retinal photography followed by approved grading to well established, best practice standards. In addition, we also identify other potentially blinding conditions and refer for a confirmatory diagnosis, with onward referral to a suitable eye doctor for further management and treatment.

#### **Evidence of efficacy**

Since the establishment of the first screening programme in Iceland in the 1980s, the impact on the prevention of blindness from diabetic retinopathy is markedly notable.<sup>4</sup> Following Iceland, the UK rolled out a national diabetic programme and are currently screening approximately 2 million people with diabetes per annum. Moreover, in 2014 the UK programme published a very significant finding that blindness rates in the working age population were no longer primarily due to diabetic retinopathy for the first time since records began.<sup>5</sup>

#### First screening round results

We screened the first round of patients over 2013 and 2014 to allow for a soft roll out and testing of the systems in place for distribution of invitation letters, receipt of consent forms and scheduling of accurate appointments for screening and treatment. The second screening round conducted in 2015 was our first full screening round in a calendar year.

The results are presented in this report and it is encouraging that we have seen a sustained increase in numbers and accuracy of our register and of the eligible patient cohort. There has been a steady increase in the number of patients undergoing screening and those consenting to the programme who initially chose not to participate. We are not yet at our target of 80 per cent screening of the eligible population, but the upward trend is encouraging and we are ahead of the trends when compared to other similar programmes at early stages of development.<sup>6</sup> It is also encouraging that in the first round of screening, 14 per cent of patients were referred into treatment clinics and this decreased rapidly to 10 per cent in the second round as we had identified incident and prevalent disease. The rates of referral continue to fall; we are now able to direct the patients requiring treatment services in a more efficient and timely manner than prior to the establishment of the programme.

The national diabetic retinopathy screening programme in Ireland is globally unique in having an integrated treatment component and electronic medical records system (Optimize) which allows visibility of the patients through the entirety of their pathway and will allow longitudinal, as well as vertical assessment of the impact of the programme.

This report demonstrates the impact of the programme, with large numbers of patients receiving sight saving pan-retinal laser for proliferative diabetic retinopathy. In addition, the patients have also gained access in a more rapid manner than historically had been the case for injection and focal laser treatment for maculopathy.

We are indebted to the work and support of the staff at the NSS. We have a very productive and collaborative relationship with both screening providers (Global Vision and EMIS Care) which provide coverage at 123 screening locations across the country. The collaboration and cooperation of the general practice community has been invaluable in developing our register. Our screening providers, along with the tireless work of our endocrinology, diabetic practice nurse, and ophthalmology colleagues have all contributed to this success. The treatment clinics have taken on a significant role in the management of diabetics and, under often strained circumstances, have managed the extra clinical burden and delivered quality care for patients in their units. We continue to work through emerging challenges with colleagues across the public hospital system to ensure referred patients receive timely, effective and high quality care.

It is with pride, that the Diabetic RetinaScreen team presents this report for the first two rounds of screening of diabetic retinopathy in Ireland.

#### David Keegan

Clinical Director Diabetic RetinaScreen

> In 2011, the National Cancer Screening Service (NCSS) was commissioned to implement screening for diabetic retinopathy in Ireland.

# Message from the **Programme Manager, Diabetic RetinaScreen**

Since the establishment of Diabetic RetinaScreen, the NSS has made significant progress in developing the programme. Strategic planning for the development and implementation of Diabetic RetinaScreen is provided by the Executive Management Team and the Diabetic RetinaScreen operational committee. These groups incorporate support from all of the NSS, including Programme Evaluation Unit, Information Technology, Finance, Screening Promotion, Communications, Quality Assurance, Facilities, Human Resources and Procurement, as well as Diabetic RetinaScreen staff in Dublin and Limerick. The programme is dependent on maintaining and developing relationships with our Photography and Grading providers, hospital partner sites, nursing teams, managers, photographers, endocrinologists, optometrists, and ophthalmologists. I wish to acknowledge the work and dedication of all of these individuals, which has resulted in the establishment of this invaluable sight saving programme.

Diabetic RetinaScreen invited 147,929 eligible patients to participate in screening. I also wish to recognise the contribution of IPS (postal service provider) and the Call Centre (Freephone) staff. Their dedication and professionalism have ensured that during the first two screening rounds, 147,929 invitation letters were issued promptly, along with many thousands of reminder, recall, results and GP letters. The third round of Diabetic RetinaScreen began in January 2016 and the data collected from round one and two will inform the future direction of the programme. Diabetic RetinaScreen is committed to working in partnership with Global Vision, EMIS Care (photography and grading providers), and hospital partner sites to promote and drive service improvements across all elements of the programme.

This report demonstrates Diabetic RetinaScreen is detecting and treating diabetic retinopathy at an early stage. There are continual improvements to be made, however these should not detract from the fact that the establishment of the programme has been a significant milestone in the improvement of diabetic retinopathy detection and early treatment in Ireland.

Colette Murphy Programme Manager Diabetic RetinaScreen

## **Programme history**

- In 2001 the Irish College of Ophthalmologists prepared a plan for national screening of diabetic eye disease in Ireland, based on the use of digital cameras in fixed locations (hospital-based) and mobile units. This was publicised as part of a national service plan by the Diabetes Federation of Ireland and presented to the Minister for Health in 2002.
- In 2004, planning for systematic screening had begun in the North West counties of Donegal, Sligo, Leitrim and West Cavan, for the first organised population-based regional screening programme for diabetic retinopathy in Ireland.
- In 2007, the Expert Advisory Group on Diabetes highlighted the importance of national screening for diabetic retinopathy. This was followed by the report of the National Diabetic Retinopathy Screening Committee in 2008 and recommendations of the Project Team on the feasibility of a Diabetes Register for Ireland in 2010.
- In 2011, the National Screening Service (NSS)\* was commissioned to implement screening for diabetic retinopathy in Ireland.
- In December 2011, the National Screening Service (NSS) commenced a procurement process seeking expressions of interest from interested parties who wished to be considered as Photography and Grading providers, as part of a national programme. Four companies in total expressed an interest. All four companies were deemed suitably qualified to participate in a competition for services in 2012. Following the competition, two companies (Global Vision and EMIS Care) were successful and were contracted to provide services for an initial period of seven years. The service commenced in 2013.
- In 2012 the NSS were requested to undertake the treatment element of the programme. The NSS commissioned seven public hospitals nationally to carry out the treatment element of the services.

\* The National Cancer Screening Service became the National Screening Service following the introduction of Diabetic RetinaScreen, the first non-cancer screening programme.

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# Developing a high quality and evidence based programme

A significant aspect of the preparations for the introduction of the programme was the establishment of the NSS Quality Assurance (QA) Committee for Diabetic Retinopathy Screening. Its purpose was to review international standards, recommend best practice, monitor and evaluate achievement of the recommended standards and monitor and support adherence by service providers. The Quality Standards are available through our website.<sup>7</sup>

As part of the Diabetic RetinaScreen programme, a Clinical Advisory Group (CAG) was established, which provides support for ongoing clinical development of the programme, specifically to provide medical policy and clinical advice to the Diabetic RetinaScreen Executive Management Team (EMT). The Clinical Treatment Guidelines are available through our website.<sup>8</sup>

In developing the programme, the NSS commissioned extensive research on diabetic retinopathy screening programmes internationally and in addition to a wide ranging review of relevant current literature, a broad consultative process and site visits to key locations in the UK and Ireland were undertaken. This research consisted of three phases: global learnings, including barriers to participation and best practice case studies; branding and messaging of diabetic retinopathy screening programmes; and consumer research, through focus groups, to test and validate the proposals.

This research provided key evidence to inform the branding of Diabetic RetinaScreen and creative material was subsequently developed, including a dedicated website, radio ads, posters, flyers and a suite of information leaflets.

> Quality underpins every aspect of the Diabetic Retinascreen programme.

## **Programme Overview**

#### Background

The National Diabetic Retinopathy Screening Programme - Diabetic RetinaScreen commenced on 25 February 2013 with the aim of offering free screening to people with diabetes aged 12 years and older, on an annual basis.

The primary goal of Diabetic RetinaScreen is to reduce the risk of sight loss among people with diabetes by the early detection and treatment of sight-threatening retinopathy. Over time, Diabetic RetinaScreen should result in a reduction of blindness rates and improve patient care and quality of life for people with diabetes. These benefits are dependent on the highest possible participation in the programme.

The first round was carried out over approximately two years from 25 February 2013 to 31 December 2014 and the second round was completed on 31 December 2015.

#### **Quality assurance**

Quality underpins every aspect of the Diabetic RetinaScreen programme. As a screening service, the NSS is committed to ensure that all screening programmes are quality assured, safety is paramount, there is adequate capacity in place and that there is no impact on the symptomatic service. Accordingly, Diabetic RetinaScreen works in close partnership with the hospital ophthalmology units to deliver services. Prior to the launch of Diabetic RetinaScreen, the programme's Quality Assurance (QA) Committee was formed, consisting of a multidisciplinary team of experts, drawn from the fields of ophthalmology, endocrinology, optometry, general practice, programme operation and administration. The QA Committee is responsible for the continuing oversight of quality within the programme. The committee's purpose is to review international standards, recommend best practice, monitor and evaluate achievement of the recommended standards and monitor and support adherence of the standards by service providers. The QA Committee reports to the Diabetic RetinaScreen Executive Management Team, which in turn reports to the Head of Screening, National Screening Service, who has overall responsibility for quality assurance in all NSS programmes. To ensure continual adherence to quality assurance across every aspect of the Diabetic RetinaScreen programme, the written and auditable QA standards are updated continually to take into account changes in the environment, whether those changes are technological, operational or reflecting advances in clinical excellence.

In addition to the QA Committee's oversight, the programme's quality performance is measured against quality standards as outlined in the Standards for Quality Assurance in Diabetic Retinopathy Screening.<sup>7</sup>

## Communications and screening promotion

Since the programme began in 2013, the NSS Communications Department has advertised Diabetic RetinaScreen widely across targeted press, radio, digital and social media and delivered communications initiatives to increase understanding of and participation in the programme. Consumer research shows that both awareness of and familiarity with Diabetic RetinaScreen are strong, at 90 per cent and 88 per cent respectively, with 77 per cent of respondents rating its advertising as effective.

A Diabetic RetinaScreen website (www. diabeticretinascreen.ie) was also developed to provide information about the programme to the public, stakeholders and other interested parties. The website includes a function where a person with diabetes can self-register to ensure that they are invited to participate in the programme. There is also a dedicated section for health professionals, which includes a function to verify that a client is registered with the programme together with a suite of information leaflets for clients.

The Screening Promotion Team has been actively involved in promoting Diabetic RetinaScreen since the commencement of the programme. For the first screening round, the initial focus was on raising awareness of the programme among healthcare professionals and the screening population. Initial work involved establishing links with health professionals via relevant representative bodies to inform and educate them about the programme. By attending relevant national conferences and other events, engagement with health professionals resulted in practical feedback on how the programme was perceived and what small changes could be made to impact positively on uptake. An information leaflet about the programme was also delivered to all general practitioners.

To promote the programme widely to the screening population, the Screening Promotion Team attended large events, such as the National Ploughing Championships and events hosted by Diabetes Federation Ireland. Particular focus was given to engaging with community groups and special interest groups, such as Traveller representative organisations, HSE Traveller health workers, the deaf population and a number of organisations working with persons with an intellectual disability. Engagement with these stakeholder groups provided important feedback on various issues, which were reported to the Diabetic RetinaScreen Operations Group.

Looking to the future, the Screening Promotion team will continue to educate health professionals, the wider community and members of 'hard to reach' groups given their low level of participation in Diabetic RetinaScreen. Plans are in place to develop links with the Irish Pharmacy Union to promote the Diabetic RetinaScreen programme.

Finally, an important focus going forward will be building close relationships with the new Leads for Health and Wellbeing within the HSE's Community Healthcare Organisations, nationwide. This initiative aims to ensure that key HSE community-based staff will promote Diabetic RetinaScreen through the "Making Every Contact Count" programme. These collaborations provide invaluable platforms for the delivery of focused screening promotion in general.



Client on register invited (via letter) to consent to programme Client consents and receives (via letter) screening appointment Client attends screening location and consents to dilating drops and use of images for grading Client's grading outcome; return to annual screening or referral to treatment clinic

#### **Treatment Pathway**

 Treatment Clinics: Dublin (2), Waterford, Cork, Limerick, Galway and Sligo

 Urgent Referrals
 Appointment must be within 2-4 weeks

 Routine Referral
 Appointment must be within 13-18 weeks

 Each patient will be reviewed, investigated as required and treated in line with the Clinical Practice Guidelines for Treatment Clinics8

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# **Programme Statistics**

#### Eligible population by gender and age group

Table 1 outlines the population eligible for screening on the Diabetic RetinaScreen register, and is comprised of men, women and children aged 12 years and older with type 1 or 2 diabetes. The register was compiled from national health schemes, such as the Medical Card Scheme, Drugs Payment Scheme and Long-term Illness Scheme. The register is continuously updated by GPs who can register people with diabetes with the programme.

During the first two screening rounds, Diabetic RetinaScreen invited 147,929 eligible people to participate in the programme. Of the 147,929 eligible people, it is noted that 84,816 (57 per cent) were males compared to 63,113 (43 per cent) females. This is in line with international experience.<sup>6</sup> Table 1: Eligible population by gender andage group on Diabetic RetinaScreen register\*

Age	Male	Female	Totals
12-19	777	804	1,581
20-24	820	799	1,619
25-29	932	1,122	2,054
30-34	1,255	1,863	3,118
35-39	1,947	2,739	4,686
40-44	3,018	2,990	6,008
45-49	4,590	3,278	7,868
50-54	6,332	3,995	10,327
55-59	8,377	5,216	13,593
60-64	10,756	6,463	17,219
65-69	12,235	7,546	19,781
70-74	12,381	7,851	20,232
75-79	9,643	7,077	16,720
80-84	7,106	5,846	12,952
85+	4,647	5,524	10,171
Total	84,816	63,113	147,929

\* Eligible population as of 31 December 2015



Figure 1: Eligible population pyramid\*

\* Eligible population as of 31 December 2015

#### **Eligible population pyramid**

The population pyramid in Figure 1 shows the age distribution of known eligible clients on the Diabetic RetinaScreen register. The highest eligible population (97,075; 66 per cent) is in the 60 plus age group. It also highlights the greater number of males compared to females in the eligible population.

A higher percentage of males attended for screening.

#### Table 2: Overall screening activity\*

	Round One	Round Two
Client Cohort	134,513	147,929
Clients sent consent letter	134,513	69,802*
Clients consenting to take part in the programme	76,798	22,234
% Consenting	57.1%	31.9%
Eligible clients invited for screening	69,906	88,678
Clients attended for screening	62,951	79,184
Uptake% ^	46.8%	53.5%
Overall acceptance rate (%) †	90.1%	89.3%
Clients who opted out of the programme	746	1,030

\* Includes clients re-invited if no response in round one and new registrants

^ Based on clients sent a consent letter and attended screening appointment

† Based on attendance at a screening location

#### **Screening activity**

During the first two screening rounds, the total number of people on the register who received a consent letter to participate was 147,929. During the first screening round 134,513 people were sent a consent letter and 69,802\* were sent a letter in round two (Table 2). The programme issues a minimum of up to two letters in each screening round upon registration which include the consent letter and invite letter (appointment letter). Repeat letter(s) to nonresponders are sent in the following round.

In round one, 76,798 (57 per cent) eligible people consented to take part and 22,234 (31.9 per cent) eligible people consented to take part in round two.

Following consent, clients are invited to a screening location. There was a large increase in the numbers invited for screening between round one and two, rising from 69,906 to 88,678. A similar increase was seen in the numbers who attended screening in the two rounds, rising from 62,951 in round one to 79,184 in round two. Overall, 46.8 per cent of the eligible cohort had a screen and final grade in Round 1. This increased to 53.5 per cent in Round 2 (Figure 2).



#### Figure 2: Uptake of screening by round

## Acceptance of screening by consented clients

Acceptance of screening relates to those who have provided consent to participate and have attended a screening appointment. Acceptance of screening in the first two screening rounds was slightly higher for males than for females (round one; 90.11 per cent compared to 89.19 per cent), (round two; 89.75 per cent compared to 88.82 per cent) (Table 3). Acceptance was higher among males in the 22 to 44 and 45+ age groups. Acceptance of screening by consented eligible clients (Figure 3) in the second round was slightly higher for the 12 to 21 age group (round two 92.7% compared to 91.8% in round one) however uptake in the 45+ age group was slightly higher in the first round (round one 90.0% compared to 89.4% in round two).

#### Table 3: Acceptance of eligible clients by age group and gender

	Roun	d One	Roun	d Two	Roun	d One	Roun	d Two	Roun	d One	Roun	d Two
Age	12	-21	12·	·21	22-	44	22-	-44	45	5+	45	<b>i</b> +
Sex	м	F	М	F	М	F	М	F	м	F	М	F
Eligible invited	650	638	822	856	2,952	2,751	4,067	3,773	37,976	24,927	47,344	31,806
Screened	592	590	761	794	2,599	2,373	3,516	3,212	34,643	22,145	42,716	28,177
Acceptance (%)	91.1%	92.5%	92.6%	92.8%	88.1%	86.3%	86.6%	85.1%	91.2%	88.8%	90.2%	88.6%



#### Figure 3: Acceptance of consented clients by age group and round

## Screening outcomes final grade by round

The proportion of clients screened with an ungradable image was very low at 0.7 per cent, well within the QA standard of 7 per cent (Table 4). Over the two rounds 62 per cent and 66 per cent respectively had no retinopathy detected. Over one quarter had background retinopathy and smaller numbers had preproliferative and proliferative retinopathy. A considerable amount of non-diabetic eye disease (NDED) was detected and referred appropriately.

While not established to act as a general eye screening service, detection of incidental eye disease has played a role in preventing and treating vision impairment by non-diabetic causes including cataract, macular degeneration and glaucoma. During the first two screening rounds, in excess of 62% of clients had no retinopathy detected.

#### Table 4: Screening outcomes; final grade by round

	Round One	Round Two	QA standard
Number of clients attending for screening	62,951	79,184	
Number of clients screened with an ungradable image	443	564	
Clients screened with an ungradable image (%)	0.7%	0.7%	< 7%
No Retinopathy detected	39,267	52,086	
No Retinopathy detected (%)	62.4%	65.8%	
Background Retinopathy	18,011	21,448	
Background Retinopathy (%)	28.6%	27.1%	
Pre-proliferative Retinopathy	1,128	968	
Pre-proliferative Retinopathy (%)	1.8%	1.2%	
Proliferative Retinopathy	1,663	1,298	
Proliferative Retinopathy (%)	2.6%	1.6%	
Non diabetic eye disease	2,272	2,629	
Non diabetic eye disease (%)	3.6%	3.3%	
ARMD*	167	191	
ARMD (%)	0.3%	0.2%	

\* Age-related macular degeneration (ARMD)

#### Referral rates to treatment based on outcomes from screening by round

In round one and two; 86.2 per cent and 89.2 per cent respectively of screened clients were returned for routine annual recall with 13.6 per cent and 10.5 per cent of clients being referred to treatment (Table 5). Routine referrals to treatment were 8.7 per cent which include NDED with 1.9 per cent of clients requiring urgent referral to treatment. While the uptake of the programme has increased over the first two screening rounds, the referral rate to our treatment clinics is reducing. This indicates the higher impact of detected retinopathy in the first and second round, with patients now receiving appropriate treatment in a timely manner. The programme expects an ongoing reduction in these rates over the coming rounds, as the incidence of eye disease is identified.

We identify potential non diabetic disease ocular conditions as part of the programme and these are referred to our treatment clinics for confirmatory diagnosis and onward referral to ophthalmologists. Urgent NDED referral is reserved for obvious active age related macular degeneration (ARMD).

The low rates of ungradable images, at 0.7 per cent of clients screened, indicate a robust process of image acquisition and grading. In the event of grading not being possible at the initial screening event, a referral is made for a slit lamp appointment in a hospital outpatient clinic to check for diabetic retinopathy. If a grade is not possible using slit lamp, then a clinical examination is performed to attempt to give a screening grade prior to the decision to refer for treatment. The percentage of those screened with an ungradable image was very low at 0.7%, well within the QA Standard of 7%.

Diabetic 🗿 RetinaScreen

Standards for Quality Assurance in Diabetic Retinopathy Screening

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	Round one	Round two
Attending for screening	62,951	79,184
Annual recall	54,287	70,663
Annual recall (%)	86.3%	89.2%
Early recall	52	27
Early recall (%)	0.1%	0.03%
Routine referral to Ophthalmology	6,504	5,524
Routine referral rate (%)	10.3%	7.0%
Urgent referral to Ophthalmology	1,824	1,422
Urgent referral rate (%)	2.9%	1.8%
NDED* urgent referral to Ophthalmology	14	89
NDED urgent referral to Ophthalmology (%)	0.02%	0.1%
NDED routine referral to Ophthalmology	235	1,350
NDED routine referral to Ophthalmology (%)	0.4%	1.7%

#### Table 5: Referral rates to treatment based on outcomes from screening by round

\* Non diabetic eye disease (NDED)

## Screening outcomes on final grade by round, age and gender

In screened clients above the age of 22 years, background retinopathy was higher among males than females across both screening rounds (Table 6). For both males and females, the rate of background retinopathy was highest among 22 to 44 year age groups. Likewise pre-proliferative and proliferative retinopathy was highest in this age group, with males having higher detection rates than females. The youngest age group (12 to 21 years) has the highest rate of no retinopathy across both screening rounds. Rates of ARMD were low and ARMD was only detected among older clients.

All grades of retinopathy may include patients with maculopathy. These can be referable or non-referable.

The rate of urgent diabetic eye disease referral to ophthalmology was highest among screened clients aged 22 to 44 years, with males having higher referral rates than females (Table 7). Patients with sight-threatening proliferative retinopathy were referred in each round (round one; 1,663, round two; 1,298).

The same pattern of age and gender was found for routine referral to ophthalmology; the prevalence of diabetic retinopathy increases as a patient gets older and the longer the client has diabetes. The younger patient cohort has lower levels of diabetic retinopathy. Rates of NDED requiring urgent referral to ophthalmology were highest among older clients with active macular degeneration. While some of these clients were under an existing care plan, a significant number were able to enter an appropriate care pathway following referral, which is a significant additional benefit of the programme.

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Round	Round	One	Round	l Two	Round	d One	Round	d Two	Round	d One	Round	l Two
Age	12-3	21	12-	21	22	44	22-	44	45	+	45	.+
Sex	¥	Ľ	W	Ľ	W	ш	M	Ľ	W	ш	W	Ľ
Number of clients attending for screening	592	590	761	794	2,599	2,373	3,516	3,212	34,643	22,145	42,716	28,177
Screened with an ungradable image	m	2	9	-	ω	11	13	10	243	176	283	251
Screened with an ungradable image (%)	0.5	0.3	0.8	0.1	0.3	0.5	0.4	0.3	0.7	0.8	0.7	0.9
No retinopathy detected	449	430	579	582	1,290	1,371	1,844	1,894	21,104	14,618	27,694	19,485
No retinopathy detected (%)	75.8	72.9	76.1	73.3	49.6	57.8	52.5	59.0	60.9	66.0	64.8	69.2
Background retinopathy	136	153	172	204	1,067	818	1,384	1,136	10,148	5,688	11,799	6,753
Background retinopathy (%)	23.0	25.9	22.6	25.7	41.1	34.5	39.4	35.4	29.3	25.7	27.6	24.0
Pre-proliferative retinopathy	-	2	2	~	06	65	104	90	696	274	573	228
Pre-proliferative retinopathy (%)	0.2	0.3	0.3	0.1	3.5	2.7	3.0	1.9	2.0	1.2	1.3	0.8
Proliferative retinopathy	-	~	0	с С	117	89	132	94	1,001	454	727	342
Proliferative retinopathy (%)	0.17	0.17	0.00	0.38	4.50	3.75	3.75	2.93	2.89	2.05	1.70	1.21
Non diabetic eye disease	2	2	2	m	27	19	39	18	1,360	860	1,530	1,037
Non diabetic eye disease (%)	0.3	0.3	0.3	0.4	1.0	0.8	1.1	0.6	3.9	3.9	3.6	3.7
ARMD*	0	0	0	0	0	0	0	0	91	75	110	81
ARMD (%)	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.3	0.3	0.3	0.3

\*Age-related macular degeneration (ARMD)

	2020					- <b>C</b> 2		200	2010			
Round	Round	l One	Round	Two	Roun	d One	Round	d Two	Roun	d One	Roune	d Two
Age	12-	21	12-:	21	22	-44	22-	44	45	+2	45	±.
Sex	Σ	u.	Σ	ш	Z	u.	¥	u.	M	u.	R	u.
Attending for screening	592	590	761	794	2,599	2,373	3,516	3,212	34,643	22,145	42,716	28,177
Annual recall	576	574	740	769	2,108	2,036	2,989	2,849	29,576	19,410	37,942	25,366
Annual recall (%)	97.3	97.3	97.2	96.9	81.1	85.8	85.0	88.7	85.4	87.7	88.8	90.0
Early recall	0	2	0	-		4	0	0	20	26	17	6
Early recall (%)	0.0	0.3	0.0	0.1	0.0	0.2	0.0	0.0	0.1	0.1	0.0	0.0
Urgent referral to Ophthalmology	2	-	0	m	115	06	133	67	1,081	535	791	398
Urgent referral rate (%)	0.3	0.2	0.0	0.4	4.4	3.8	3.8	3.0	3.1	2.4	1.9	1.4
Routine referral to Ophthalmology	13	13	16	18	373	242	371	255	3,801	2,060	3,091	1,773
Routine referral rate (%)	2.2	2.2	2.1	2.3	14.4	10.2	10.6	7.9	11.0	9.3	7.2	6.3
NDED* urgent referral to Ophthalmology	0	0	0	0	0	0	0	0	5	6	49	40
NDED urgent referral to Ophthalmology (%)	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.1	0.1
NDED routine referral to Ophthalmology	0	0	m	-	0	0	20	6	141	94	768	549
NDED routine referral to Ophthalmology (%)	0.0	0.0	0.4	0.1	0.0	0.0	0.6	0.23	0.4	0.4	1.8	2.0

Table 7: Referral rates to treatment based on outcomes from screening by round, age and gender

\*Non-diabetic eye disease (NDED)

## Conclusion

The publication of this report formally concludes the first two rounds of the Diabetic RetinaScreen programme. There is much to celebrate with several key important outcomes delivered.

In summary, from 25 February 2013 to 31 December 2015:

- Diabetic RetinaScreen invited 147,929 eligible clients to participate in screening.
- In round one 62,951 and in round two 79,184 attended and received a satisfactory outcome (final grade), which resulted in a screening uptake rate of 47 per cent in round one and in excess of 53 per cent in round two.
- The uptake of the programme has increased over the first two screening rounds although the referral rate to our treatment clinics is reducing. This indicates the impact of detected retinopathy in the first and second round.
- Acceptance of screening for consented males was slightly higher than in consented females in both round one (90.1 per cent compared to 89.2 per cent) and round two (89.8 per cent compared to 88.8 per cent).
- In round one 86.2 per cent and in round two 89.2 per cent of screened clients were returned for routine annual recall with 13.6 per cent and 10.5 per cent of clients being referred to treatment respectively.
- The rate of urgent referral to ophthalmology was highest among screened clients aged 22 to 44 years, with males having higher referral rates than females.
- The percentage of clients screened with an ungradable image was significantly below the acceptable threshold outlined in the programme quality assurance standards.

The programme team remains focused on making continual improvements in both the quality of the programme and in other key areas of success, such as client uptake.

Over time, based on a target uptake of 80 per cent, a successful national, quality assured diabetic retinopathy screening programme has the potential to significantly reduce sight threatening diabetic retinopathy and blindness rates in the screened population.

## **Useful Terms**

Terms	Criteria
Eligible cohort	The number of clients on the register that are within the age range and who have type 1 or type 2 diabetes.
Clients consenting	The individual client who indicates they wish to be part of the programme and be invited to a screening appointment.
Eligible clients invited for screening	Following verification of consent from the client an invitation letter is sent to attend a screening appointment at a screening location.
Clients attending for screening	Clients accept the invitation, attend screening appointment, complete screening and have a final grade assigned.

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An tSeirbhís Náisiúnta Scagthástála National Screening Service







Feidhmeannacht na Seirbhíse Sláinte Health Service Executive



Cuid d'Fheidhmeannacht na Seirbhíse Sláinte. Part of the Health Service Executive.

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