Northern Ireland
Diabetic Eye
Screening
Programme

Annual Report

2016-17

HSC Public Health Agency

HSC Belfast Health and Social Care Trust

CONTENTS

Section 1 – Summary

The Diabetic Retinopathy Screening Programme (DRSP) for Northern Ireland was established in 2008. In 2015 the programme name changed to the Diabetic Eye Screening Programme (DESP).

The programme is commissioned and quality assured by the Public Health Agency (PHA) in collaboration with Belfast Health and Social Care Trust (BHSCT) who are responsible for the management and delivery of the programme. The two organisations work closely together to provide an effective, safe and accessible service. Screening is delivered locally in line with national quality standards and protocols. This report summarises the performance of the programme against key standards for the financial year 2016/17.

This report covers a period of considerable change for the Northern Ireland Diabetic Eye Screening Programme. Work continued relating to the programme of modernisation which commenced as a result of RQIA recommendations; some of the major pieces of work which took place in 2016/17 were;

- Training of existing photographers to enable them to not only carry out the digital photography needed for screening but also the initial grading of these images, along with the instilling of eye drops
- Reduction in reliance on general practice with practice nurses no longer required to instil eye drops
- The centralisation of the call/recall function within the screening office, again reducing the burden on general practice
- Upgrade of OptoMize, the screening patient management system to allow for improved call/recall functions and participant management

- Introduction of direct referral to Hospital Eye Services (HES), allowing reduced delays and improve accuracy in the referral process, whilst ensuring the participant's general practitioner (GP) and Diabetologist are kept informed.

Some of the key performance measures in 2016/17;

- 69.2% (45,845/66,271) of all those invited for diabetic eye screening across Northern Ireland attended
- 262 of the 337 GP practices in Northern Ireland (77.8%) had their eligible diabetic participants screened in 2016/17.
- Of the 262 practices screened, 247 were screened in 15 months or less

Further information on screening performance is available in section 6.

Section 2 - Introduction

The Northern Ireland Diabetic Eye Screening Programme (NIDESP) aims to detect diabetic eye disease at an early stage and prevent sight loss in those with diabetes aged 12 years and over in Northern Ireland. The programme is currently undergoing a modernisation project to ensure that it remains a sustainable service and continues to improve in line with national standards.

Diabetic eye disease remains one of the leading causes of blindness in people of working age in the UK.[1] It is a potential complication of diabetes which can cause sight loss. Diabetic retinopathy occurs when the high blood sugar levels associated with diabetes cause damage to the small blood vessels at the back of the eyes called the retina. These vessels can then leak blood into the retina or become blocked. This can affect sight. When changes related to diabetes occur at the centre of the retina (the macula), this can also affect sight, and is known as diabetic maculopathy.

2.1 Rationale for screening

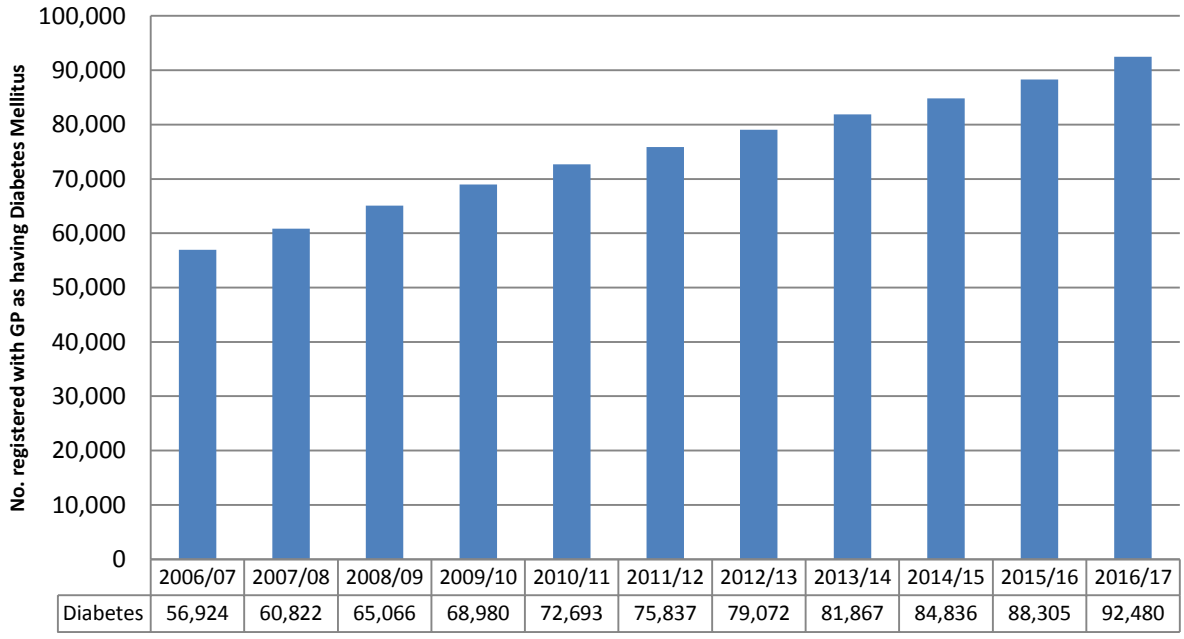
Research has shown that if the changes associated with diabetic eye disease are identified early, for example through screening, and treated appropriately, blindness can be prevented in the majority of people. Screening is important because the early stages of diabetic eye disease usually do not cause any signs or symptoms.

2.2 Public Health Challenge

Reflecting trends worldwide, the number of people living with diabetes continues to grow each year in Northern Ireland, as shown in figure 1.

[1] Diabetes UK https://www.diabetes.org.uk/retinopathy

Figure 1: Number of People, age 17 years and over, registered as having diabetes in Northern Ireland 2006/07 to 2016/17

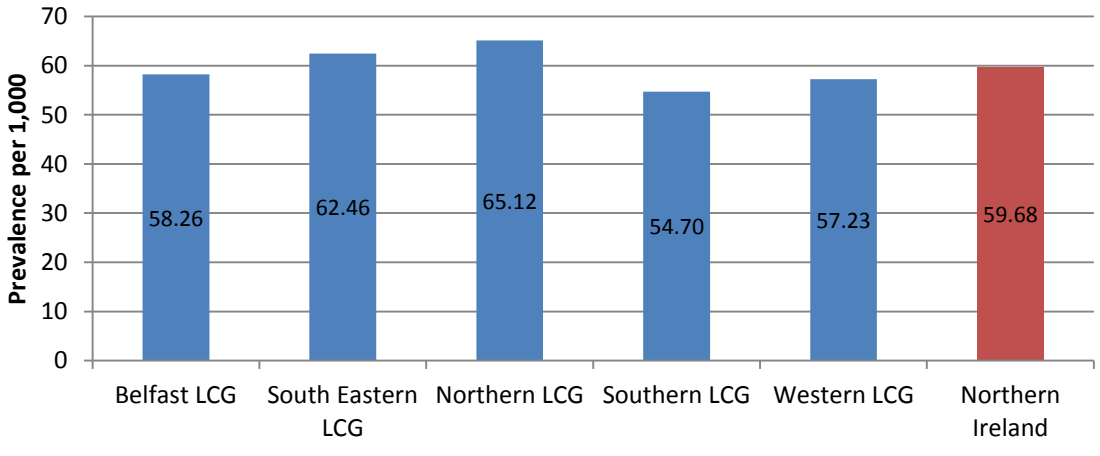


	2006/07	2007/08	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14	2014/15	2015/16	2016/17
Diabetes	56,924	60,822	65,066	68,980	72,693	75,837	79,072	81,867	84,836	88,305	92,480

Source: QOF datasets 'Raw Disease Prevalence Data for Northern Ireland', www.health-ni.gov.uk/publications

According to QOF (Quality Outcome Framework) diabetes mellitus had a prevalence of 40.35 per 1,000 in 2006/07, amongst those aged 17 and older registered with a GP, however by 2016/17 this had increased to 59.68 per 1,000[2]. This prevalence varies across each of the LCG (Local Commissioning Group) areas as shown in Figure 2.

Figure 2: Prevalence of Diabetes in Northern Ireland 2016/17 (per 1,000, 17+ years old)



[2] Based on QOF data accessed at https://www.health-ni.gov.uk/publications/201718-raw-disease-prevalence-trend-data-northern-ireland

Section 3 - Programme Delivery

In most areas of Northern Ireland the diabetic eye screening appointment takes place in the participant's GP surgery. In the Western Health and Social Care Trust (WHSCT) screening occurs in one of six allocated hospitals or health centres. The regional diabetic screening programme team in BHSCT and PHA retain oversight and overall responsibility for the management and quality assurance of the process in all trust areas.

3.1 Who is eligible for diabetic eye screening?

Diabetic eye screening is available to all persons diagnosed with diabetes aged 12 years and over, the only exception is people who have no light perception in either eye. Once a person has been diagnosed with diabetes (excluding gestational diabetes) they should be screened for life. Those already under the care of an ophthalmology specialist for diabetic eye disease are suspended from screening.

3.2 The Invitation Process

The invitation process begins with a list of all those with diabetes within a practice being extracted by Apollo Medical on behalf of the screening programme. The screening team will work with each GP practice to arrange a suitable date, in advance of the time when the practice is due to be screened. The screening team will then issue invitation letters to all eligible participants.

3.3 What happens at diabetic eye screening?

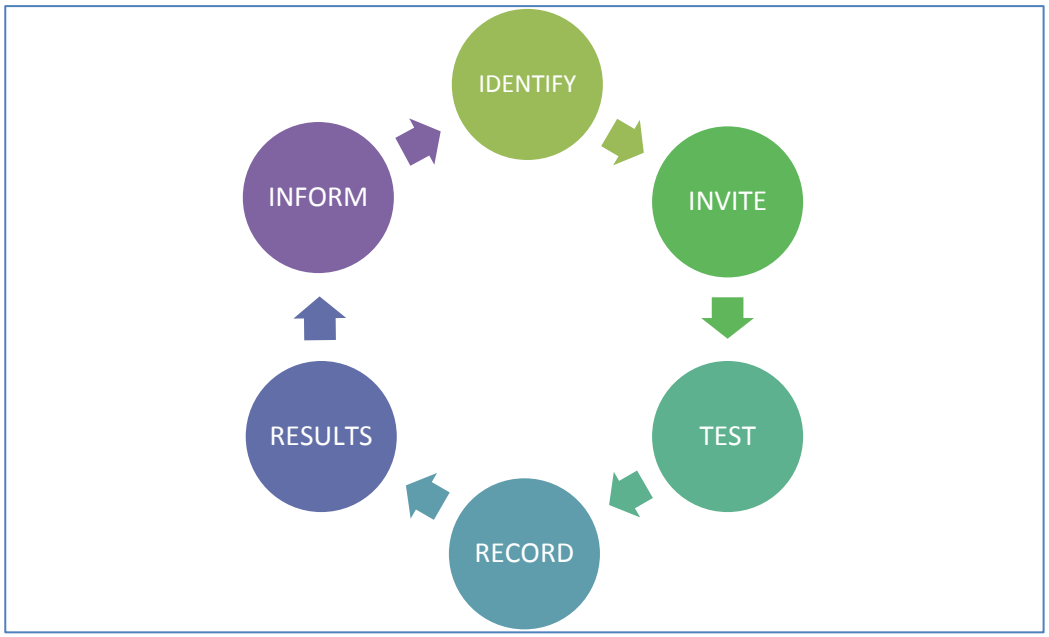
At the screening appointment, two or more photographs are taken of each eye using a special camera. The test is painless and takes about 15 minutes. If a person is over 50 years of age, eye drops are instilled about 15 minutes

before the test, to dilate their pupils. This helps to take a good quality photograph.

3.4 How does the diabetic eye screening programme work?

The retinal imaging is only one part of the screening programme. The programme is a process that consists of a series of key steps summarised in figure 3.

Figure 3: DESP Screening Cycle



The screening process begins by identifying those who are eligible to be screened. These participants are then invited for screening, the screening

test is performed (as outlined above), and the images taken are recorded and then graded giving results. The participant is sent a letter informing them of the results and a copy is sent to their GP. If the test detects an abnormality the participant is referred directly to Hospital Eye Services for further management, which may include treatment. Results requiring prompt referral will be flagged as urgent by DESP staff along the image capture and grading pathways, and are fast tracked through the grading system. Appendix 1 provides further details of the screening process. Monitoring and quality assurance against nationally agreed standards also occurs at each step in the process.

3.5 Mop-Up Clinics

To ensure all those eligible for screening are invited, participants newly diagnosed with diabetes are referred directly to the programme at the time of diagnosis. The aim is to offer these participants an appointment for their first screening encounter, within three months of the referral being received. These appointments are provided at 'mop-up' clinics, which also provide appointments for people with longstanding diabetes who move into Northern Ireland from elsewhere and also, where possible, those who were unable to attend their allocated screening appointment.

Section 4 - Modernisation Project

In 2015 the Northern Ireland Diabetic Retinopathy Screening Programme (DRSP) officially changed its name to the Diabetic Eye Screening Programme (DESP). This was in recognition that the programme is designed to detect a range of diabetic eye conditions, including maculopathy, at an early stage. It was also felt to represent a memorable, self-explanatory brand that is easily recognisable by the lay population.

A modernisation programme is currently underway to ensure that the DESP remains a sustainable service and continues to improve in line with national standards.

4.1 Phase 1

Within 2016/17 the programme focused on Phase 1 of the modernisation project, which included developing the capacity to implement a new bespoke diabetic eye screening IT system, OptoMize, and strengthening the management of the programme and its quality assurance.

The introduction of OptoMize in October 2015 enabled changes to the screening process whereby determining eligibility and generating invitations, communication of results and referrals now occurs centrally. This reduced the total number of steps involved, making the process less labour intensive for general practice. Another change to help alleviate the burden on general practice was the training of the screener/grader to administer eye drops when necessary rather than having to enlist the services of practice nurses.

The type of invitation issued to participants also changed in 2016/17 from an open invitation to a closed invitation. This meant that instead of participants receiving a letter asking them to contact the screening office to make an

appointment, they were issued with a fixed date and time. However if the appointment issued does not suit participants can arrange an alternative appointment through contacting the screening office.

Test and Training was also introduced in 2016/17. This is a grading qualification which the NHS DESP had introduced in the last number of years and which all graders should complete. It enables staff to improve their skills in detecting signs of disease on images.

In October 2016 western area optometrists were able to use the same screening software and complete image grading directly onto the OptoMize system.

4.2 Future Development

Phase 2a of the DESP modernisation programme will concentrate on the introduction of surveillance clinics. These clinics will mean that those who require closer monitoring but not treatment, will receive more frequent eye examinations (every 3, 6 or 9 months) via the screening service, and will not have to be referred to Hospital Eye Services.

Phase 2b will consider changes to the current model of service delivery to ensure sustainability into the future. It will focus on the provision of retinal photography to the eligible population. In 2016/17 preparatory work was carried out in the form of a survey of GP attitudes to the programme and a stakeholder workshop to develop a list of potential model options.

Phase 3 will be the introduction of variable screening intervals as recommended by the National Screening Committee. This would mean that those who are at low risk will be invited for screening every two years, rather than every year, with those at high risk continuing to be screened every year.

Section 5 – Highlights of 2016/17

As previously mentioned 2016/17 was a year of considerable activity and change in the programme.

5.1 New Clinical Lead

One of the key changes was the appointment of a new Clinical Lead, Professor Tunde Peto. She is also the Head of the Belfast Reading Centre, Clinical Professor of Ophthalmology at Queens University Belfast and President of the British Association of Retinal Screeners. Tunde came to Northern Ireland from the DES programme in Tower Hamlets, London. She is highly respected in her field and is heavily involved in working with developing countries to establish eye screening programmes. Since her appointment in the summer of 2016, she has lead a number of significant changes and improvements to the programme.

5.2 NIDESP Stakeholder Workshop, January 2016

The programme held a stakeholder workshop 'Options for Delivering the NI Diabetic Eye Screening Programme', on Wednesday 27th January 2016. The aim of this workshop was to consider and develop a variety of service delivery models to help inform the initial stages of phase 2b of the modernisation project (see section 4.2 for further details). The event was attended by interested individuals from a variety of sectors such as HSC trusts, primary care, HSC Board, the Irish screening programme, PHA, RQIA, voluntary/charitable organisations and users of the service. Feedback from the day was very positive.

5.3 World Sight Day, October 2016

The first World Sight Day Conference to be held in Northern Ireland was on Thursday 13th October 2016 at the Centre for Experimental Medicine, QUB.

This event covered subjects such as current issues and development in screening and treatment pathways, diabetes care provision in Northern Ireland, and current research in diabetic eye disease. It also included an interactive MDT discussion with those in attendance. The day proved very popular, and will now be repeated on an annual basis.

5.4 Patient Survey

A participant survey was completed in June 2016 with randomly selected participants who had not responded to their invitation letter. The purpose of the survey was to get a better understanding of the reasons for non-participation. Over 500 participants were contacted; 100 agreed to participate. One of the key messages from this survey was that 61% indicated they would be more likely to attend for screening if they were provided with a fixed appointment (i.e. specified date and time) rather than the practice at the time of open appointments (i.e. participants were asked to ring to make a suitable appointment).

Section 6 - Programme Performance

The data contained in this report should be considered against a backdrop of significant change, both to the programme as previously discussed, but also to the upgrade of the OptoMize system. In addition, as of the end of 2016/17 Eyecap data, i.e. historical data on existing screening participants had not yet been uploaded onto OptoMize. This meant that all participants were considered as newly diagnosed.

To allow for the significant changes outlined in sections 4 and 5, it should also be noted that there were no screening appointments carried out for three months between December 2016 and February 2017.

6.1 Eligible Population

In 2016/17 the number of people in Northern Ireland aged 12 years and older, living with diabetes was 91,291[3]. Within this population there were 59 people classed as ineligible, i.e. those that have no light perception in both eyes.

A further 1,055 were excluded from screening.

- 788 were informed opt-out
- 267 medically unfit

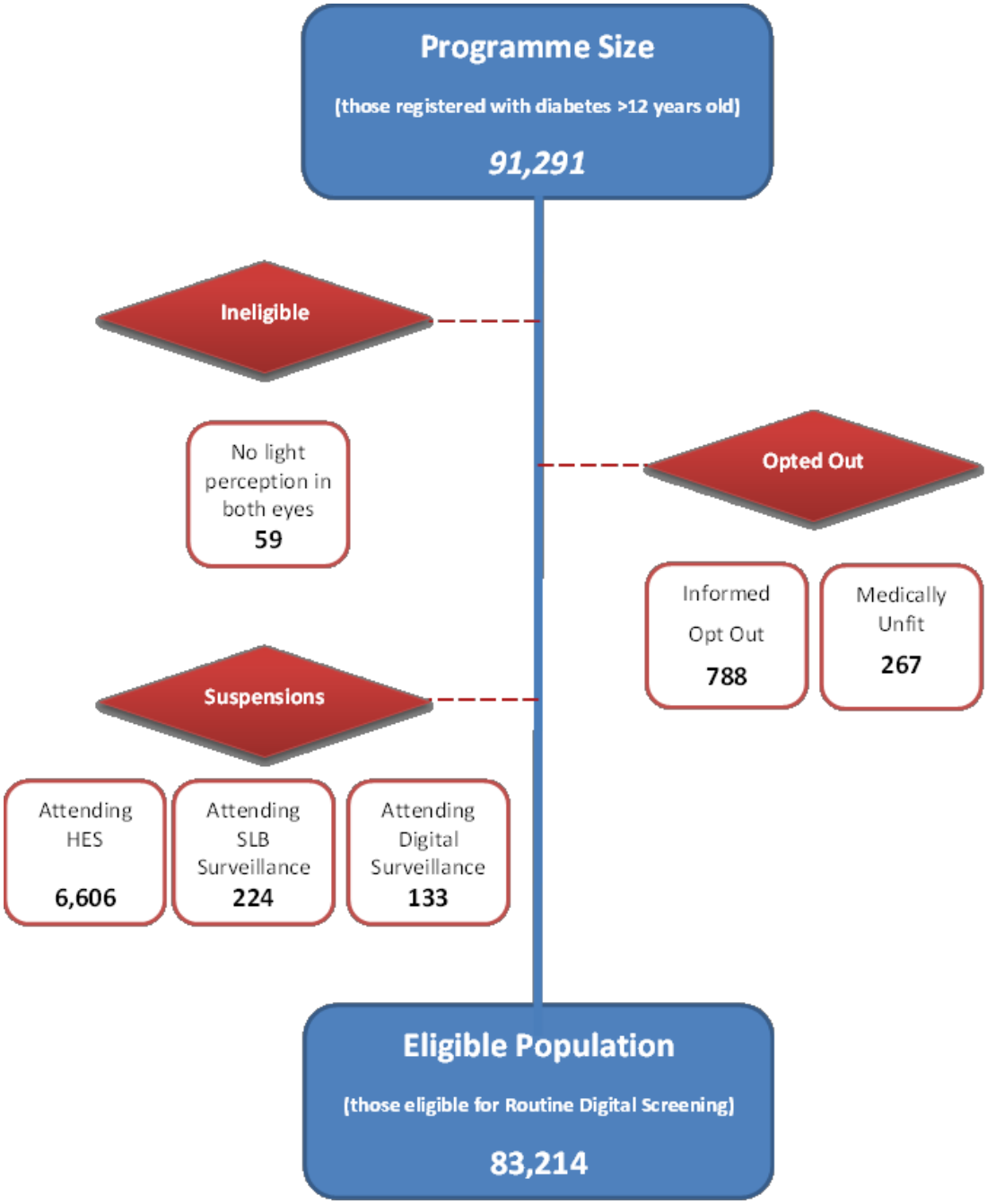
There were 6,963 participants suspended from the programme due to the following reasons

- 6,606 attending Hospital Eye Services (HES)
- 224 attending Slit Lamp Biomicroscopy Surveillance pilots
- 133 attending Digital Photography Surveillance pilots

[3] OptoMize Programme Performance Report

This equates to 83,214 participants eligible for routine digital screening (RDS).

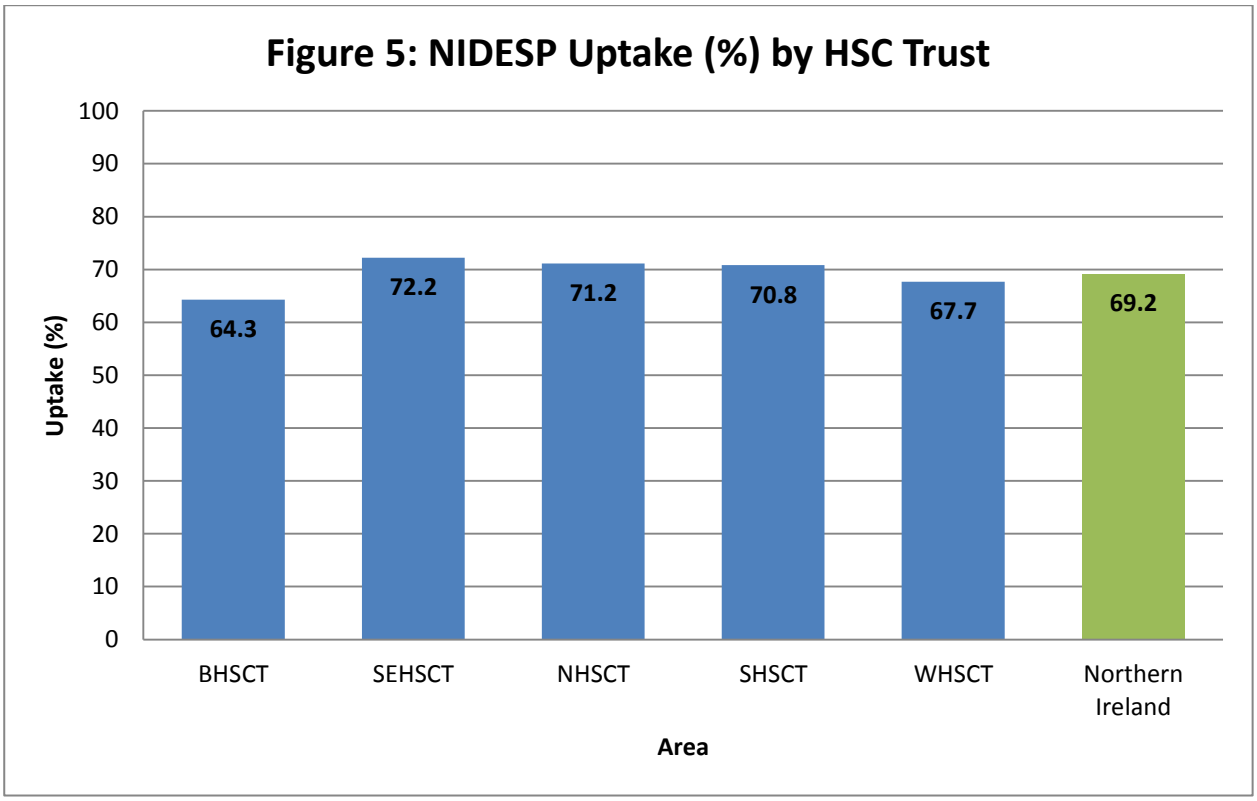
Figure 4: Eligible Population for NIDESP 2016/17



6.2 Invitation and Attendance

In total 66,271 people were invited for RDS, with 45,845 attending for diabetic eye screening across Northern Ireland in 2016/17.

When reviewed by trust area, it can be seen that the South Eastern Trust had the highest uptake with 72.2% and the Belfast Trust the lowest with 64.3% of those invited being screened. The overall Northern Ireland figure is 69.2%.

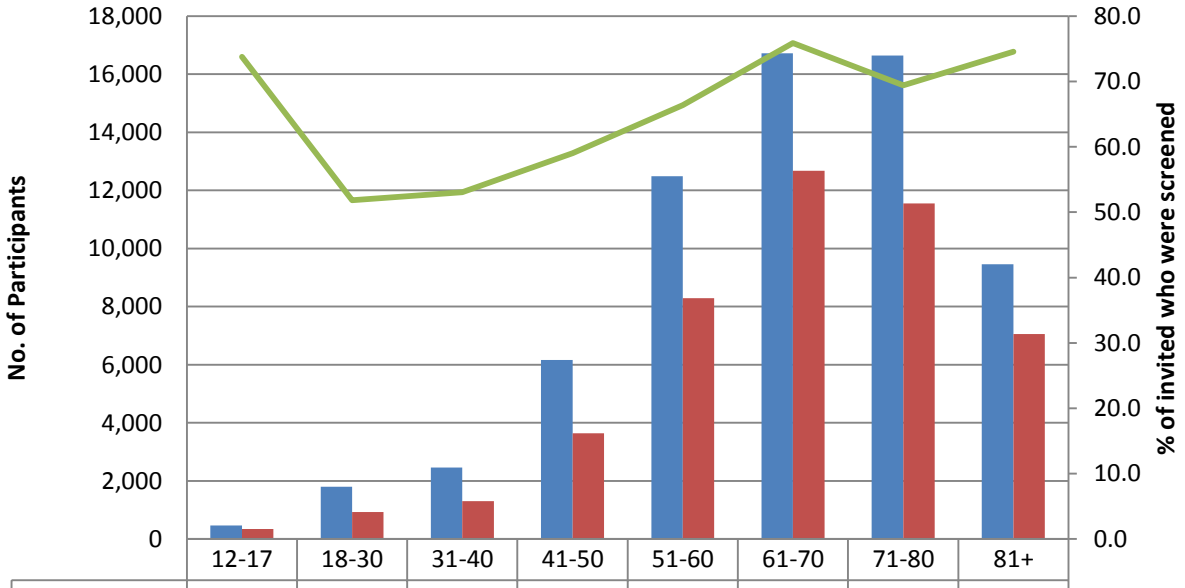


Type 2 diabetes is more likely to affect those over the age of 40 and Type 1 usually starts below the age of 40, however, overall, around 90% have Type 2. The expectation therefore would be that the vast majority of those eligible for diabetic eye screening are over the age of 40. This can be seen in figure 5 below. The age group most likely to attend for screening is those aged 61-70.

The programme will need to explore the variation in uptake amongst the age bands and also the socio-economic gradient. This will help the programme to

understand why some people attend for screening whilst others do not and how ultimately how best to help participants make an informed decision on whether attending for screening is right for them.

Figure 6: NIDESP Uptake 2016/17 by Age Band



	12-17	18-30	31-40	41-50	51-60	61-70	71-80	81+
Invited	473	1,800	2,461	6,166	12,491	16,715	16,640	9,463
Screened	349	933	1,305	3,639	8,292	12,678	11,549	7,056
Uptake %	73.8	51.8	53.0	59.0	66.4	75.8	69.4	74.6

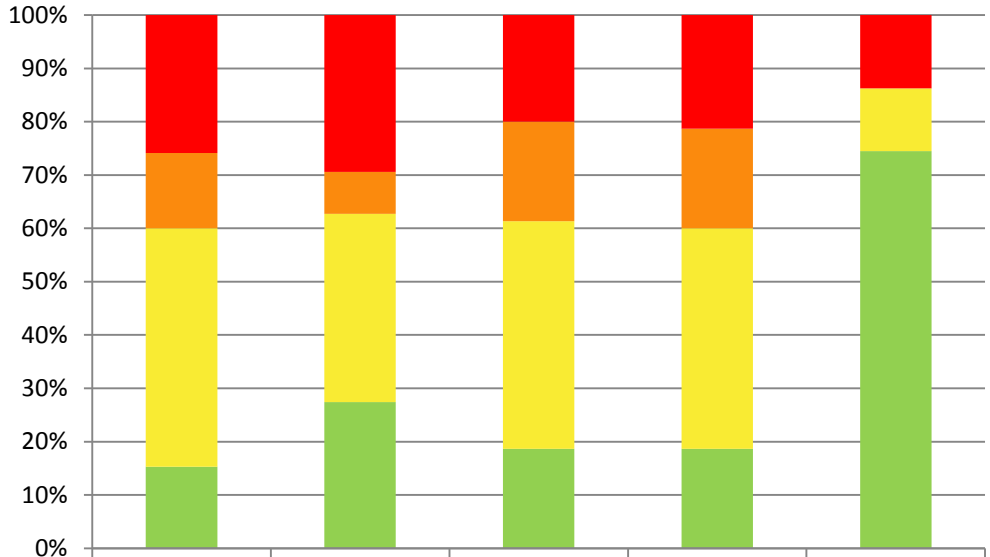
6.3 Practice screening interval

The practice screening interval is the time taken between each screening clinic at a given GP practice. According to national standard this should be within 12 months of the previous visit (+/- 6 weeks). The average interval for Northern Ireland in 2016/17 was 13 months. Of the 262 practices visited by the programme (out of a possible 337) within the period 01/04/2016 to 31/03/2017, 247 were seen within 15 months.

There are many factors which affect the screening programme's ability to meet the 12 months screening interval. However the primary reason for delay is that the NIDESP is not in control of the timely availability of suitable accommodation. The way in which the programme is currently delivered in

the Belfast, South Eastern, Northern and Southern areas means that GP practices are required to provide a room in their premises for a set number of days during a specified period of time. This can prove very challenging for practices, particularly given the increasing size of the eligible screening population, meaning that rooms are required for longer.

Figure 7 - NIDESP 2016/17 Screening Interval by LCG Area (%)



	Belfast	South Eastern	Northern	Southern	Western
Not Screened in 16/17	22	15	15	16	7
≤18mths	12	4	14	14	0
≤14mths	38	18	32	31	6
≤12mths	13	14	14	14	38

In Figure 7 it can been seen that the ability to meet the screening interval standard within the western area is increased compared to the rest of the region. This is primarily due to the way in which the service is delivered, in fixed sites where NIDESP has more control over the availability of accommodation and the scheduling of clinics.

As alluded to on page 11, the work of phase 2b of the modernisation project will help to address this issue. It will review the way in which the programme is currently delivered, assess alternatives and ensure that the service delivery

model chosen will be able to provide a sustainable, safe and high quality service into the future.

Until the Northern Ireland programme is delivered in a way which allows screening to be organised by individual rather than at practice level, it will not be possible to accurately benchmark data against the standards for screening interval.

6.4 Image quality (minimising harm)

Poor image quality in one or both eyes can result in the screening test needing repeated with associated unnecessary delays for participants affected. In 2016/17 5.7% (2,599) of participants screened were affected by poor image quality in one or both eyes. This was within the minimum standard of <7% and within the achievable standard range of 2.5% - 6.3%.

Section 7 – Conclusion and Next Steps

Despite a challenging year with many programme changes, service improvements and initiatives, the NIDESP is committed to continuing to improve the programme, to pursuing the highest quality service for its eligible population.

In 2017/18 the work of the modernisation project will continue;

- Piloting of surveillance clinics prior to full implementation in 2018/19
- Development of digital photography surveillance information leaflet and information on slit lamp biomicroscopy
- Progression of phase 2b with the development of the option appraisal and consultation with stakeholders on the model options available

Work will also begin to look the differences in uptake amongst the different socio-economic and demographic (e.g. age, gender, location) groups and ways to ensure that all participants are able to make an informed decision about whether to attend for screening.

New national quality standards will be adopted by the Northern Ireland programme from 1st April 2017. One of the key changes will be the inclusion of standards on digital surveillance, slit lamp biomicroscopy and screening of pregnant women. Some of the acceptable and achievable standard levels will change along with the revised of standard definitions.

Appendix 1- Diabetic Eye Screening Programme - Screening process

Appendix 2 - Summary of Key Performance Data

Description	Acceptable Threshold	Achievable Threshold	Northern Ireland
Eligible Population *(total programme size minus those with no light perception in both eyes)*			**91,232** *(91,291 - 59)*
No. Excluded *(those who have opted out or been declared medically unfit)*			1,055
No. Suspended *(those attending Hospital Eye Services or Surveillance Pilots)*			6,963
Participants Eligible for Routine Digital Screening (RDS)			**83,214**
Participants Invited *(for RDS during the reported time period)*			**66,271**
Participants Screened			**45,845**
Coverage *Percentage of eligible population invited for screening (including those suspended and excluded)*			**79.6%** *(66,271/83,214) *100*
Uptake *(Proportion of those offered RDS who attend a digital event)*	≥70%	≥80%	**69.2%** *(45,845/66,271) *100*
Ungradables *(Percentage of patients where image has been obtained but final grading outcome is ungradable)*	<7%	2.5% - 6.3%	**5.7%** *(2,598/45,845) *100*
No. GP Practices in NI			337
No. GP Practices Screened within 2016/17[4]			262
% of Practices Screened in 2016/17			**77.8%**

[4] Screening will be provided to the eligible population across all GP practices, however the programme may not be able to provide screening to all practices within the 12 month period e.g. 01/04/2016 to 31/03/17.