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Phoiblí agus Athchóirithe
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Diabetic Retina Screening

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This paper has been prepared by staff in the Department of Public Expenditure & Reform. The views presented in this paper are those of the author alone and do not represent the official views of the Department of Public Expenditure and Reform or the Minister for Public Expenditure and Reform.

Under *A Programme for a Partnership Government*, the Department of Public Expenditure & Reform has established a Prevention and Early Intervention Unit (PEIU). The focus of the PEIU's work is on prevention and early interventions that can improve the life outcomes of children as well as the quality of life of older people dealing with long term conditions such as chronic illness; which the PEIU is locating within the context of population health.

These types of interventions have a strong common-sense appeal; most people are familiar with the idiom that "prevention is better than cure". However, effective prevention and early interventions rely on both knowing what to do (scientific understanding of cause and effect) and being in a position to act (the capacity of the government to intervene).

The PEIU is undertaking a series of Focussed Policy Assessments on key prevention and early interventions supported by public resources. The approach is to describe each intervention by following a common structure:

- Rationale for the intervention;
- Public resources provided to support the delivery of the intervention;
- Outputs and services provided; and
- Achievements of the intervention relative to its stated goal.

As a whole, this series of descriptive reports will provide the evidential base for a thematic consideration of prevention and early interventions in Ireland.

Introduction¹

In 2013, the National Diabetic Retinal Screening Programme, *Diabetic RetinaScreen*, commenced with the aim of offering free annual diabetic retinopathy screening to people with diabetes aged 12 years and older. The programme screens for diabetic retinopathy in order to interrupt the progression of sight threatening diabetic retinopathy and blindness. This morbidity is preventable through screening as early detection and treatment is effective at reducing or preventing damage to sight. The screening programme is part of diabetic care.

The purpose of Early Disease Detection Programmes is to actively search for a disease so as to increase the chances of achieving an early diagnosis, before symptoms appear.² These programmes can involve a mix of screening, diagnostic tests and medical examinations. Screening is a means of detecting disease before symptoms appear. Screening programmes that implement a population-based call and re-call can provide a consistent, high-quality and standardised approach to identifying the population most at risk from a particular disease.

Organised screening programmes have a number of specific advantages. The screening process makes it possible to provide effective early detection which can often increase treatment options and sometimes reduce the invasiveness of that treatment. While screening does not provide a guarantee of diagnosis and cure for all patients, for those people who the screening process has identified as being at risk of a disease, such screening programmes often offer clear referral and treatment pathways and do so within set time limits.

The purpose of this report is to describe the *Diabetic RetinaScreen* programme in terms of rationale, public resources provided, services delivered and results achieved. This is one of a series of descriptive reports that taken together will inform a thematic consideration of prevention and early interventions in Ireland.

Rationale

Diabetic retinopathy is a common complication of diabetes.³ It affects the small blood vessels in the lining at the back of the eye, the retina. Diabetic retinopathy is one of the nine preventable causes of visual impairment that have been prioritised by the World Health Organisation.⁴ As is evident from Figure 1, there is an increasing number of people in Ireland reporting blindness or severe visual impairment and it is especially prevalent amongst older age cohorts.

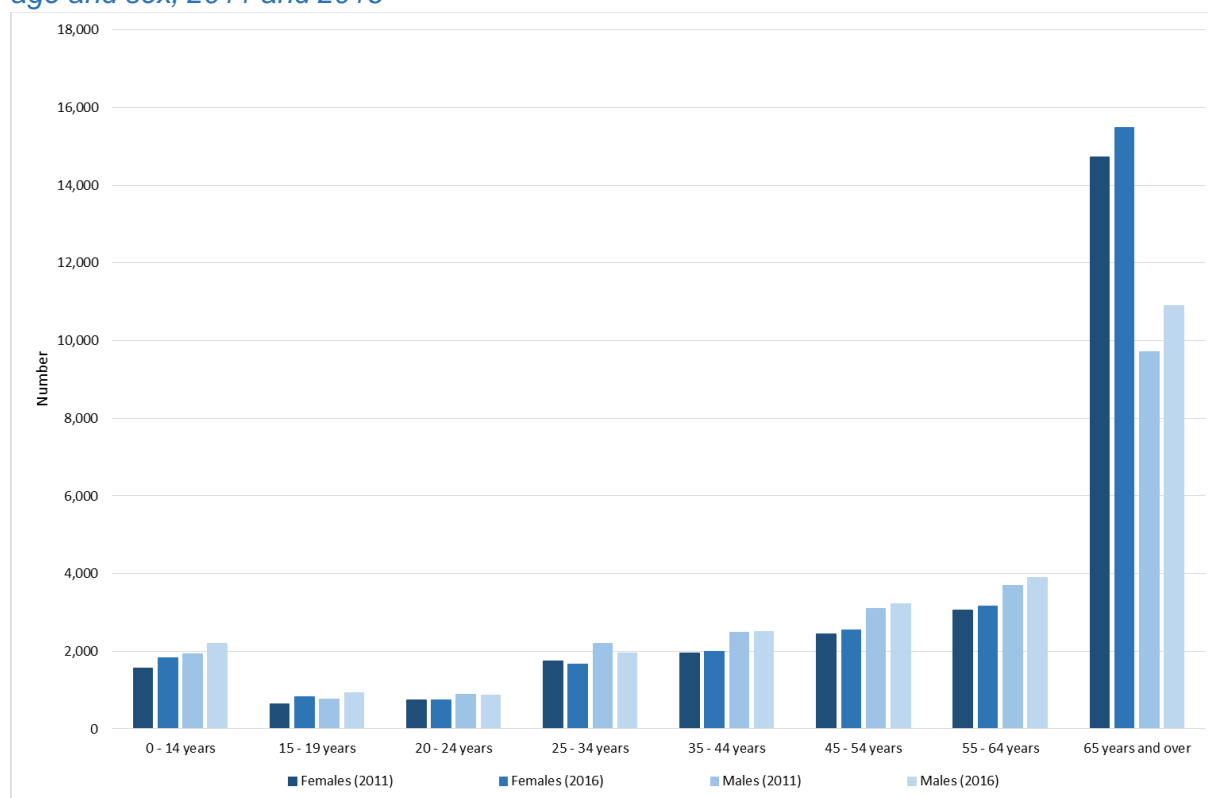
¹ The authors are grateful to their colleagues in the Department of Public Expenditure & Reform for providing comments.

² OECD, Eurostat and World Health Organization. 2017. *A System of Health Accounts 2011: Revised Edition*. Paris: OECD Publishing: 104 and 491.

³ Kelliher, C., D. Kenny and C. O'Brien. 2006. 'Trends in blind registration in the adult population of the Republic of Ireland 1996-2003'. *British Journal of Ophthalmology*. Vol.90: 367-371.

⁴ World Health Organisation. 2010. *Action Plan for the Prevention of Avoidable Blindness and Visual Impairment, 2009-2013*.

Figure 1 – Incidence of Blindness or Serious Visual Impairment in the Irish Population by age and sex, 2011 and 2016



Source: Central Statistics Office, Table E9015 - Population 2011 to 2016 by Disability Type, Sex, Social Class, Age Group and Census Year. CSO StatBank.

When compared with the general population, people with diabetes are at an increased risk of visual impairment and blindness.⁵ The risk of people with type 1 diabetes developing diabetic retinopathy is very high (almost 90%). After 20 years of diabetes, nearly all individuals with type 1 diabetes will develop some degree of retinopathy. Those with type 2 diabetes⁶ are exposed to less risk, due to the later onset of the condition, though they remain at risk of vision impairment due to complications of the disease. After 20 years of diabetes, more than two-thirds of those with type 2 diabetes will develop some degree of retinopathy.⁷

Tracey et al. (2016a) suggest that “it is therefore possible that the full impact of the diabetes epidemic has not yet been realised in Ireland.” For the years 2004-2013, Tracey et al. (2016a) found that the mean annual incidence of blindness due to diabetic retinopathy was 0.9 per 100,000 population and 33.2 per 100,000 population diagnosed with diabetes. They also found that the mean annual incidence of visual impairment due to diabetic retinopathy was 0.3 per 100,000 population and 10.7 per 100,000 population with diagnosed diabetes.⁸

⁵ Tracey, M.L., S.M. McHugh, A.P. Fitzgerald, C.M. Buckley, R.J. Canavan and P.M. Kearney. 2016a. ‘Trends in blindness due to diabetic retinopathy among adults aged 18-69 years over a decade in Ireland.’ *Diabetes Research and Clinical Practice*, No.121: 1-8.

⁶ Type 2 diabetes accounts for about 90% of all cases of diabetes.

⁷ Tracey et al., 2016a; National Screening Service. 2017. *Diabetic Retina Screening Programme Report 2013-2015*: 4.

⁸ Tracey et al., 2016a.

Box 1 – Diabetes

Diabetes is a complex problem and is a serious global health issue. The increasing burden of diabetes is driven primarily by rising levels of obesity and ageing populations. It can have a profound impact on the quality of life of people living with the condition as they run a greater risk of developing one or more severe health complications. In addition to a risk of blindness, people with diabetes may develop other severe complications in addition to the risks associated with conflicting priorities and poly-pharmacy.

There is some uncertainty around the prevalence of diabetes in Ireland as there is no national surveillance programme or national population-based survey of diabetes in Ireland. However, it is clear that diabetes is increasingly prevalent in the population:

- The Central Statistics Office (2001, 2008, 2011) estimates that the percentage of adults with diabetes was 1.5% in 2001, 2% in 2007 and 3% in 2010. While there was little or no difference between males and females, the estimates indicate that prevalence increased with age as the oldest cohort of adults were three times more likely than average to report having diabetes while the youngest age cohorts were one-third as likely to do so.⁹
- The International Diabetes Federation estimated that the prevalence of diabetes was 3.2% in 2000 and that this had increased to 4.3% in 2017.¹⁰
- Tracey et al. (2016b) conducted a systematic review of the available evidence reporting the prevalence of diabetes (both diagnosed and undiagnosed) and related complications (microvascular and macrovascular) among adults in Ireland between 1998 and 2015. Their findings suggest that the prevalence of diagnosed diabetes has increased from 2.2% in 1998 to 5.2% in 2015.¹¹

Systematic screening for diabetic retinopathy has the potential to reduce the incidence of sight threatening visual impairment. Diabetic retinopathy is potentially preventable by adequate risk factor control. Early detection and timely treatment can prevent the onset of sight threatening visual impairment. It is possible to detect pre-symptomatic retinal disease by screening for diabetic retinopathy using digital retinal photography and grading. Once they have been identified, people can be referred to and provided with, in a timely manner, appropriate sight preserving treatments.¹²

In countries that have established population based retinal screening programmes as part of their national diabetes strategy, there is evidence of a reduction in rates of blindness due to diabetic retinopathy.¹³ The first screening programme was established in Iceland in the 1980s.

⁹ Central Statistics Office. 2001. *Quarterly National Household Survey – Module on Health, Quarter 3 2001*. Table 6; Central Statistics Office. 2008. *Quarterly National Household Survey – Health Status and Health Service Utilisation, Quarter 3 2007*. Table 3; and Central Statistics Office. 2011. *Quarterly National Household Survey – Health Status and Health Service Utilisation, Quarter 3 2010*. Table 3.

¹⁰ International Diabetes Federation. 2000 and 2017. *IDF Diabetes Atlas*.

¹¹ Tracey, M.L., M. Gilmartin, K. O'Neill, A.P. Fitzgerald, S.M. McHugh, C.M. Buckley, R.J. Canavan and P.M. Kearney. 2016b. 'Epidemiology of diabetes and complications among adults in the Republic of Ireland 1998-2015: a systematic review and meta-analysis.' *BMC Public Health*, Vol.16 (1).

¹² National Screening Service. 2017: 4-5.

¹³ Kelliher et al., 2006.

Stefánsson et al. (2000) found that the incidence and prevalence of blindness is much lower in populations where screening for diabetic eye disease has been established compared to diabetic populations without screening.¹⁴ A national screening programme in the UK screens about 2 million people a year and in 2014 it was reported that, for the first time since records began, blindness rates in the working age population were no longer primarily due to diabetic retinopathy.¹⁵

Resources

The Department of Health has not yet provided details of expenditure on this programme.

When such details are provided this paper will be updated.

Outputs and Services

The *Diabetic RetinaScreen* register is compiled from national health schemes (e.g., Medical Card Scheme, Drugs Payment Scheme and Long-term Illness Scheme) and is continuously updated by general practitioners who can register people with diabetes with the programme. Over 150,000 people are eligible for screening, and of these about 57% are male and two-thirds are aged 60 years or older.¹⁶

Diabetic RetinaScreen commenced in 2013 with the aim of offering free annual diabetic retinopathy screening to people with diabetes aged 12 years and older. *Diabetic RetinaScreen* uses digital retinal photography to identify specific patients who are at risk of sight loss due to diabetic retinopathy.¹⁷

The first cycle or round of the screening programme was carried out over a two year period (2013 and 2014). Subsequent rounds are carried out on an annual basis.

In 2017, almost 96,240 people were screened with final grading results. This was an eight percent increase on the outturn for the previous year and a 38% increase on the outturn achieved in the programme's first few years of implementation (i.e. 2013/14).¹⁸

¹⁴ Stefánsson, E., T. Bek, M. Porta, N. Larsen, J.K. Kristinsson and E. Agardh. 2000. 'Screening and prevention of diabetic blindness.' *Acta Ophthalmol Scand.* Vol. 78 (4): 374-385.

¹⁵ Liew, G, M. Michaelides and C. Bunce. 2014. 'A comparison of the causes of blindness certifications in England and Wales in working age adults (16–64 years), 1999–2000 with 2009–2010.' *BMJ Open.*

¹⁶ National Screening Service. 2017: 13.

¹⁷ National Screening Service. 2017: 4-5.

¹⁸ HSE. 2017 and 2018. *Management Data Report (March)*. National Screening Service. 2017: 15.

Goals and Achievements

The HSE states that the aim of its *Diabetes Clinical Programme* is to save the lives, eyes and limbs of patients with diabetes. With particular reference to patients' sight, the HSE aims to reduce blindness by 40% (no further details are provided).¹⁹

The overall 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.

One of the objectives of *Diabetic RetinaScreen* is to ensure regular collection of data indicating levels of new blindness due to diabetic retinopathy.²⁰ This data was not yet been published.

The HSE reports that its target uptake rate (clients sent a consent letter who attend a screening appointment) for *Diabetic RetinaScreen* is "greater than 56%". In 2017 and 2018 the programme achieved an uptake rate of 61%.²¹

The available published data suggests that, in Ireland, nine-out-of-ten eligible people who consented to participate in the programme attended a screening. While Tracey et al (2016a) note that evidence from other countries suggests that young adults and those with type 1 diabetes are less likely to attend regular retinal screening examinations (and non-attendance is a risk factor for poor visual outcomes)²², in Ireland, the evidence suggests that, irrespective of a person's age or sex, there is little variation from the overall attendance rate. That said, it is worth noting that attendance by those aged 22-44 years, and in particular amongst females, is between four and five percentage points less than the overall attendance rate.²³

In line with the experience of other countries, Tracey et al. (2016a) expect that as the initial introduction of a screening programme results in the detection of more diabetic retinopathy cases, over time there will be a decline in the frequency and treatment of sight threatening diabetic retinopathy.

In terms of the screening outcomes, no retinopathy is detected in almost two-thirds of those who were screened. (See Figures 2 and 3.) For just over a quarter of those who attend, the screening process has detected background retinopathy. This occurs in the early stages and damage is limited to microaneurysms that do not usually affect vision.

In less than 1-in-20 of screenings, the programme has detected either pre-proliferate retinopathy or proliferate retinopathy. Pre-proliferate retinopathy are changes detected in the retina and while not requiring treatment it needs to be monitored closely as there is a risk that it may progress and affect the eyesight. Proliferate retinopathy are fragile new blood vessels that form on the surface of the retina and these can bleed or develop scar tissue that cause severe loss of sight. Diabetic macular oedema occurs when fluid from leaky blood vessels affect the centre of the macula (part of the retina). If detected early enough, both proliferative diabetic retinopathy and diabetic macular oedema can be treated and managed.²⁴ (While not

¹⁹ HSE. *Clinical Strategy and Programmes Division – Diabetes*.

<https://www.hse.ie/eng/about/who/cspd/ncps/diabetes/> Accessed: 1 October 2018.

²⁰ Objective 13 in *Standards for Quality Assurance in Diabetic Retinopathy Screening*.

<https://www.diabeticretinascreen.ie/fileupload/Documents/DR-PUB-Q-1%20Rev%204%20Standards%20for%20Quality%20Assurance%20in%20Diabetic%20Retinopathy%20Screening.pdf> Accessed: 28 September 2018.

²¹ HSE. 2017 and 2018. *Management Data Report (March)*.

²² Tracey et al., 2016a.

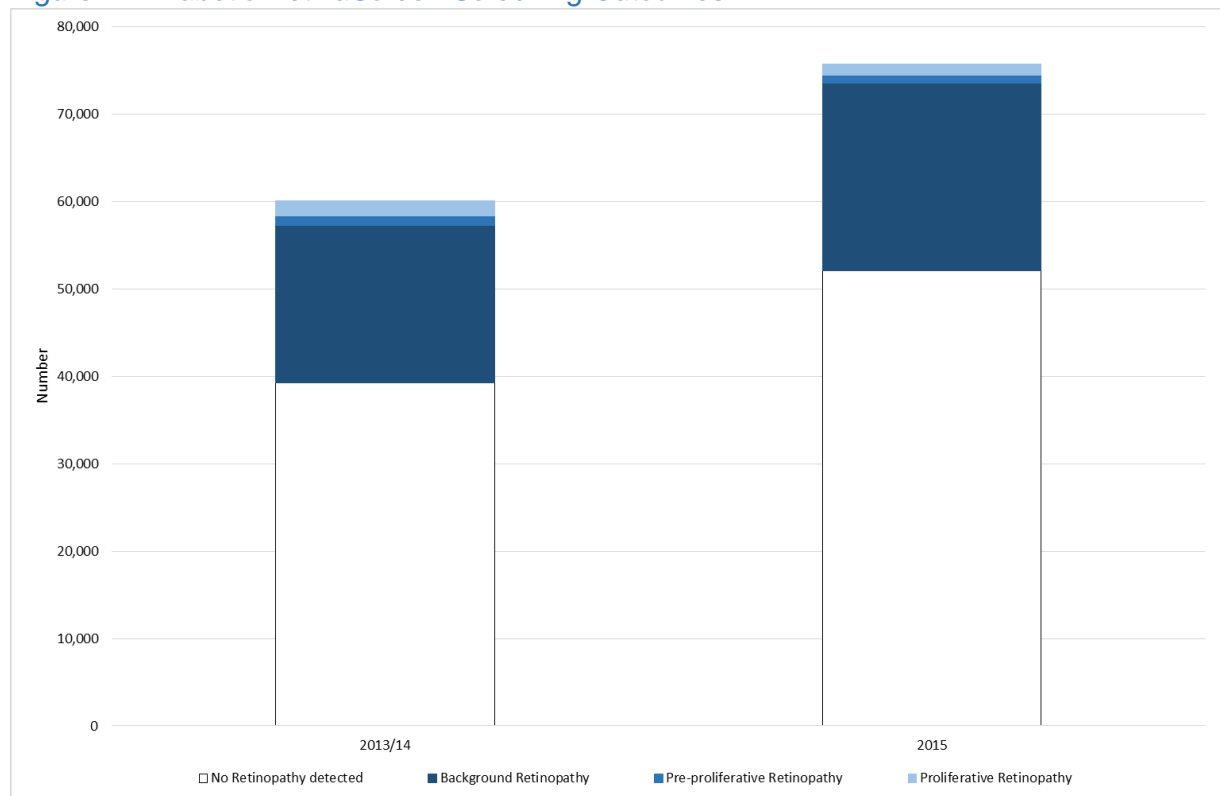
²³ National Screening Service. 2017: 16.

²⁴ See Diabetic RetinaScreen website: <https://www.diabeticretinascreen.ie/diabetic-retinopathy.8.html> Accessed: 24 September 2018.

established as a general eye screening service, this programme has played a role in preventing and treating vision impairment from non-diabetic eye diseases (e.g., cataract, macular degeneration and glaucoma); detected in about 2,500 screening outcomes (3.5%.)

About 11% of those screened are referred to treatment. While most of these are routine referrals for treatment, about a fifth require urgent treatment.²⁵ The urgent referral rate was highest amongst those aged 22-44 years and within this cohort was higher amongst males than females.

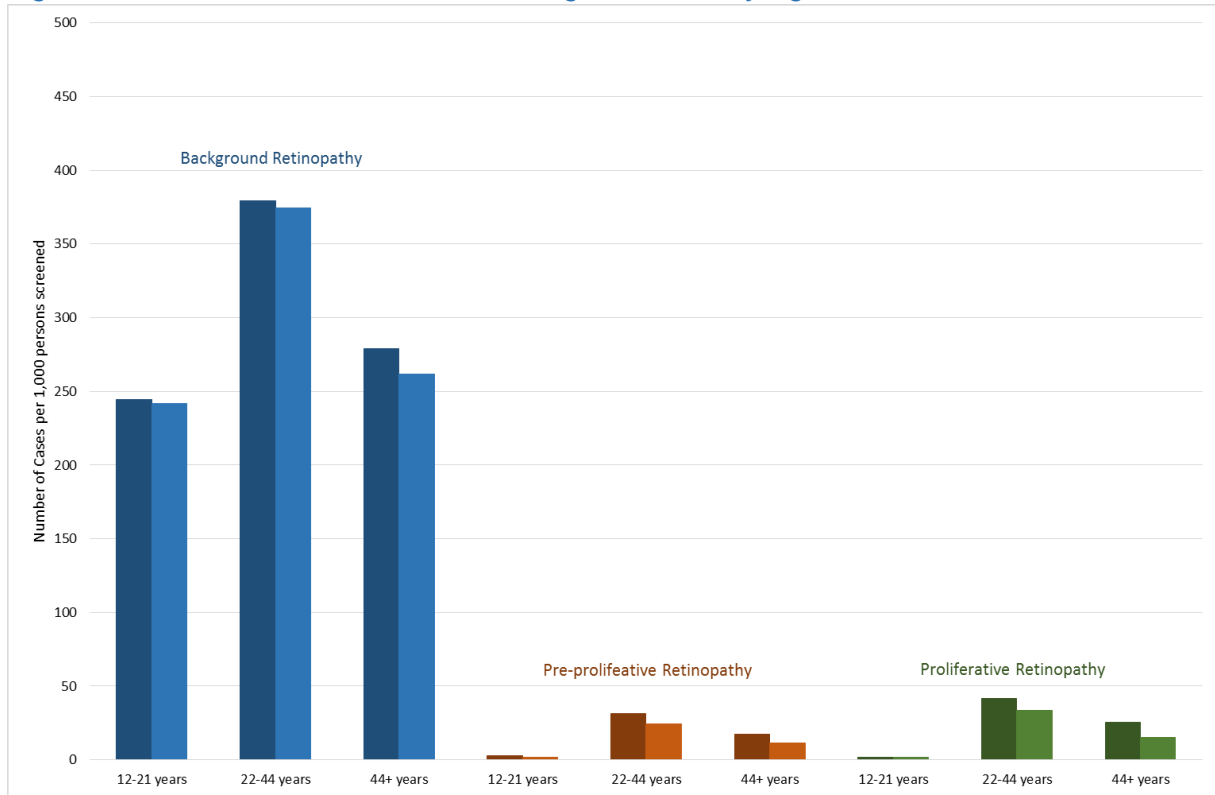
Figure 2 – Diabetic RetinaScreen Screening Outcomes



Source: National Screening Service. 2017. *Diabetic RetinaScreen Programme Report 2013-2015*.

²⁵ National Screening Service. 2017: 18.

Figure 3 – Diabetic RetinaScreen Screening Outcomes by Age



Source: Author calculations based on data provided in National Screening Service. 2017. *Diabetic RetinaScreen Programme Report 2013-2015*.

Quality Assurance Process

To ensure accuracy and methodological rigour, the authors engaged in a quality assurance process within the Department of Public Expenditure & Reform that involved Departmental line management and a Quality Assurance Group.

