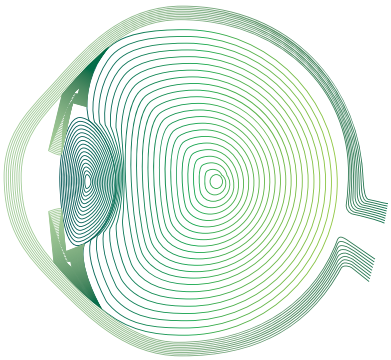
# The success of Diabetic RetinaScreen

Despite the many challenges that Covid-19 has brought, Diabetic RetinaScreen continues to be a hugely successful programme. **Deborah Condon** talks to Clinical Director, Prof David Keegan



The national diabetic retinal screening programme has proven to be a huge success since it commenced in 2012. Now, almost a decade later, it has implemented important changes, which aim "to reduce the burden of appointments on people with diabetes in this country".

Diabetic RetinaScreen is the programme responsible for screening people with diabetes for diabetic retinopathy. This is a complication of diabetes that affects the small blood vessels in the lining at the back of the eye (the retina). It is one of the leading causes of blindness among working-age people in Ireland. However, the condition is largely treatable if caught early enough through regular screening.

Until recently, everyone with diabetes over the age of 12 was invited to attend a yearly screening appointment. However, the programme has now introduced a two-yearly screening pathway for participants who are deemed eligible.

Since mid-February 2021, if a person has received a result of 'no retinopathy' from their previous two screenings, their next screening invitation will be two years from the time of their last screen, instead of one.

This will reduce the number of screening appointments and reduce unnecessary clinic visits and examinations. A number of other countries already offer two-yearly screening intervals, including Scotland, Denmark, Finland and Canada.

"International evidence shows that if a person has two consecutive results of 'no retinopathy', it is safe for them to attend their screening appointment every two years. People who have had two consecutive results of 'no retinopathy' have been found to be at very low risk of progressing to retinopathy between screens," explains the programme's Clinical Director, Prof David Keegan.

Prof Keegan emphasises that the move to two-yearly screening for some patients has nothing to do with Covid-19 and the increased pressure on health services caused by the virus.

"This was on our radar for three years. We simply didn't have enough data in our programme to do it yet, but it was always our intention to launch it in 2021. Covid was immaterial," he notes.

## Reducing burden of appointments

He says that with this condition, there can be "appointment fatigue" and the goal here "is to reduce the burden of appointments on people with diabetes in this country, while keeping them as safe as possible".

Diabetic retinopathy progresses differently depending on the type of retinopathy and the levels of diabetes control a person has. However, according to Prof Keegan, if a person has had a negative screening result, the risk of progressing to sight-threatening retinopathy over the next 12-24 months is extremely low.

"If somebody has no retinopathy, the likelihood of them developing sight-threatening retinopathy within the next year is about 0.02%. So it is not zero, but it is extremely low. The likelihood of them developing sight-threatening retinopathy within two years is 0.1-0.2%, so still very low. That's why we feel as a population measure, we can move to two-yearly screening," he explains.

However, he emphasises that as the risk is not zero, if anyone experiences any changes in their vision, even if they have had a clear screen, they should always have it checked out by a healthcare professional.

## Drivers of retinopathy progression

Prof Keegan notes that there are a number of factors that can drive the progression rate of this eye condition, including poor blood glucose control and poorly controlled blood pressure.

Diabetic retinopathy can also progress

more rapidly during pregnancy, so if a woman with diabetes becomes pregnant in between screening cycles, it is recommended that she is seen by an eye doctor and referred for an eye exam. While Diabetic RetinaScreen does not currently look after pregnant women with diabetes, it hopes to introduce this in the near future.

Meanwhile, the likelihood of developing diabetic retinopathy in gestational diabetes is very low because these women have had no risk prior to the pregnancy. As a result, screening is not recommended for these women. However, some may choose to have their eyes checked for peace of mind. Furthermore, after pregnancy, a number of women with gestational diabetes will go on to develop diabetes and they should then join the screening programme.

### Screening attendance

There are currently around 145,000 people with diabetes on the Diabetic RetinaScreen register and during 2019, which was the last full year of screening, 110,000 of these were screened. However, Prof Keegan points out that worryingly, data suggests that those who do not attend their screening appointments tend to be those most at risk of vision problems.

"This is an area of concern for us. Some of those most at risk haven't engaged with the programme and don't come in to see us. One of the main goals of our programme over the next five years is to convince people to register for the programme once they know they have diabetes and to show up for their screening appointment, so we can pick the condition up earlier," he explains.

Research carried out suggests that peak attendance occurs at the age of 70, but it falls off above and below this.

"Our data shows that for every decade younger than 70 or older than 70, there is a 1.23 times likelihood of people not showing up. The younger somebody is and the older they get – non-attendance goes up and this may be for very different reasons.

*Prof David Keegan, Clinical Director of Diabetic RetinaScreen*

"For example, older people may not have the ability to get to their appointment, but for younger people, they may have multiple appointments and they simply don't get to this one. We have also found that people with Type 2 diabetes are less likely to attend, as are people from more deprived socio-economic groups or areas," he notes.

### Programme success

However, the success of the programme cannot be underestimated. In 2019, 110,000 people were screened and 15,000 people were having their diabetic retinopathy "actively managed" in eight treatment centres nationwide.

"We have picked up most of the disease prevalence and these people are in our treatment centres. The new pick-up of disease among people engaging with our programme for the first time is also very low.

"To put it into context – in our first round of screening, we had a screen positive retinopathy rate of 13.2%. That had reduced to 4.2% by the end of 2018 and by the end of 2019, it was 2.5%. However, that is in the patients that we have screened and have knowledge of," Prof Keegan says.

### Appointment set up

So what is involved with an appointment? Patients must be registered with the programme and they are sent an appointment, which can be changed if it does not suit. During the appointment, their vision is checked and they are given drops in their eyes, which cause the pupils to dilate. This can take about 10 minutes, sometimes longer for darker eyes.

Photos are taken of the eyes – this usually takes about five minutes. Patients are advised not to drive and to wear sunglasses afterwards. The whole appointment takes 20-30 minutes.

The photos are captured on the programme's central system and they are quickly checked for quality by the photographer. If a good-quality image has been taken, the patient can go home.

These pictures are then graded within five to six working days by the grading team, who are experts in looking for patterns of disease.

"They are trained specifically to look for signs of diabetic retinopathy and specific non-diabetic disease. If changes are spotted, it is escalated to a senior grader to confirm, and then that patient receives a referral for one of our treatment centres around the country," Prof Keegan explains.

### Treatment centres

The treatment centres are located in Dublin, Waterford, Cork Limerick, Galway, Sligo and Letterkenny. Patients are referred to their nearest one.

"We try to make it so that the screening location is no more than a

20/30-minute drive and the treatment centre is no more than a 90-minute drive for everybody. There are a few pockets that don't meet this, such as parts of west Mayo and west Kerry, but by and large, we have good coverage," Prof Keegan says.

If you are referred to a treatment centre, you will be deemed either 'routine' or 'urgent'. With a routine appointment, the patient should be seen in 13-18 weeks.

"We are largely meeting that for our diabetic eye disease, however we have struggled to hit those times with our non-diabetic eye disease, but we are working through that," Prof Keegan notes.

With an urgent appointment, the person should be seen within two to four weeks, as they are most at risk of sight loss.

"For somebody who worked in the system before screening and looked after patients with diabetes, this is the key change. We are identifying those most at risk and they are getting the appropriate referral and the appropriate treatment in a timely fashion," he insists.

### Intervention

Ideally, intervention will be based around advice on how to improve blood glucose levels and blood pressure control, as well as perhaps weight loss and other general lifestyle measures.

"I never cease to be amazed about how much is in the control of the patient, where if they do those things, they can reverse and regress these changes with just those measures.

"If they have progressed a little bit more, then they may need injection or laser treatments. In the more extreme cases, they will need surgery," Prof Keegan says.

However, he notes that even among those who need surgery, the profile of patients is changing.

"In 2006/07, I would get patients presenting for surgery with really aggressive end-stage disease with detachments and haemorrhage. I'm still operating on patients with diabetic retinopathy, but it is a much calmer, quieter situation, so the outcomes are a lot better. While I have no hard data on this yet, that is certainly my experience of working on the ground," he points out.

### Impact of Covid-19

But what impact has Covid had? Diabetic RetinaScreen had to stop screening in mid-March, 2020, like all other screening services, as a result of Covid's devastating impact on health services. However, it was able to resume screening in July, 2020.

If Covid had not occurred, the programme would have been aiming to screen around 110,000 people, as it had done in 2019, but despite the difficulties caused by the virus, it still managed to screen 62,000 people last year.

"I am really proud of that figure and we are currently in the process of catching up. However, our issue isn't so much around screening because we know even patients we didn't get to have such a low chance of needing referral for retinopathy. The big issue is the impact of Covid on our treatment centres and getting those patients that we know are most at risk into these centres," he explains.

He notes that at the start of January of this year, the HSE stated that all "urgent, time-sensitive conditions need to be seen". As a result, all urgent diabetic retinopathy patients, for example, those needing urgent laser treatment, are being seen.

## Living with diabetic retinopathy -

The importance of attending diabetic retinopathy screening appointments cannot be overstated. Having recently turned 31, Conor Lennon from Louth is now deemed legally blind as a result of the condition, and he admits that his "one regret" is that he did not attend screening when he was invited to.

Conor was nine years old when he was diagnosed with Type 1 diabetes. He recalls that it was summer time and he had an unquenchable thirst and was going to the toilet a lot.

"During a GAA summer camp, I was literally crawling off the pitch. I had lost a lot of weight and was very dehydrated," he recalls.

His mother, suspecting diabetes, brought Conor to his uncle's house. His uncle had Type 1 diabetes so they checked his blood glucose levels there. The results told them something was wrong and Conor was brought straight to hospital, where the diagnosis was confirmed.

"I spent about two weeks in hospital. It was a really hard time for my parents, but for me it was different. People kept bringing presents into me, so all I had to do was two injections every day and I would get all this stuff! My parents definitely took the brunt of it," he says.

Conor does not recall any major problems with diabetes over the years. He learned to inject straight away so always took responsibility for that.

"I don't remember food being a problem when I was a child. I don't remember thinking I want sweets. It probably wasn't until I was in my 20s that I struggled with that a bit more.

"I think it's because you have your own money then. When you are 14, you ask your parents can you have something, and they say 'no you have diabetes', and you say, 'ok grand'. But when you are 20, you walk into a shop and you realise that it's your money and you can buy what you want," he says.

However, other than this, diabetes never held him back in any way.

"I always did everything – school, sport, college, nights out. It's just diabetes was in the background," he recalls.

Conor was a swimming teacher and one day in August, 2018, when he was going to work, he went to close the car door "and caught myself in the head".

## — interview with Conor Lennon

"I got a load of eye floaters from that, so I started to get checked. I went to the A&E in Drogheda and they sent me straight to the Mater Eye Clinic in Dublin. They were straight on to it and from there, I had surgery and laser treatment a number of times," he explains.

He was diagnosed with diabetic retinopathy, but had never been to a Diabetic RetinaScreen appointment, despite being invited.

"The invite would have gone to my mam's house and she would call me and say that it was there, but I never attended one. I wouldn't take time off work to attend. That is the one thing I regret now," he notes.

Between October 2018 right up to the time of Covid, he had a number of laser treatments to try and stop the progression of the retinopathy.

"Before Covid started, I had a lot of black spots that were taking up a lot of my vision. I was planning to go in and get them checked and then Covid hit. Then at the start of Covid, my vision went perfect. All the black spots cleared up. But then in June, I was putting together a trampoline and I don't know whether it was the lifting or the hot weather, but something blew a load of blood vessels in my eye and it went downhill from there," he explains.

Prior to all of this, Conor wore "just a weak pair of glasses". Now, he is considered legally blind.

"I can make out some things, but I struggle knowing where things begin and end. For example, if I am walking and there is a wall, I struggle to see where the next part of the wall is, they would be blurred together.

"I also have a lot of black spots around my eyes and I wouldn't be able to deal with light changes, so even going from one room into another, it would need to be the same light or I would lose all vision," he explains.

Conor can no longer work as a swimming teacher and he is currently trying to figure out what he would like to do as a job.

"I have lots of working days left. Everybody is pushing me towards computers but I am trying to stay away from them because I hate working on computers! I am taking time to figure it all out," he says.

Despite the major impact diabetic retinopathy has had, he says he is feeling "very good" at the moment.

"I have my up days and down days, but at the start, I knew there was a chance I'd lose my sight. As it progressed, it was getting worse and worse so I kind of came to terms that something serious was going on," he recalls.

However, when asked what advice he would give to others, he does not hesitate.

"I would advise people to attend their screening appointments. Screening is the key," he says.

You can follow Conor on Facebook at **https://www.facebook.com/learningblind**

The next group of concern is time-sensitive patients who are getting intraocular injections and these services are also still running.

According to Prof Keegan, of the 15,000 people being seen in treatment centres, one-third are still undergoing "active treatment", but the rest are at risk of moving into this category

### Future backlog

"Our concern is new referrals or routine follow-ups in treatment centres. We are worried that we can't get all of them in because some aren't coming in and some we can't give appointments to, and they may be progressing to later-stage retinopathy undetected.

"That is our concern, that when we open our health services more fully, we will have a backlog of more severe retinopathy.

"However, that is not just a diabetic retinopathy issue, that is all of ophthalmology, that is all of healthcare in this country as we go back into those less urgent, less time-sensitive groups that we have to manage," he notes.

### Making the programme safe

However Prof Keegan emphasises the huge amount of work that has gone into making the programme, and health services in general, as safe as possible during the pandemic.

"I have to commend our providers and hospital units in how they re-structured to deliver a safe service. Yes, this is sometimes inconvenient – I don't like the idea of service users having to stand outside their screening location waiting for their appointment – but that is just to make it as safe as possible. I can't overstate the monumental effort of everyone working in this programme," he says.

Prof Keegan urges people to register with the programme if they have not yet done so, and to always attend their appointment.

If you are not yet registered with Diabetic RetinaScreen, your GP or healthcare professional can register you, or you can register yourself online at **https://www2.hse.ie/screening-and-vaccinations/diabetic-retina-screening**