



# Diabetic RetinaScreen

Market research 2021

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Diabetic  
**RetinaScreen**

The logo for the Diabetic RetinaScreen programme. It features the word 'Diabetic' in a blue sans-serif font, followed by a circular icon containing a stylized eye with an orange top half and a blue bottom half. Below this, the words 'RetinaScreen' are written in a larger, bold, blue sans-serif font, with 'Retina' in orange and 'Screen' in blue.

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



# Diabetic retina screening

- Diabetic RetinaScreen offers free diabetic retina screening to people with Type 1 and Type 2 diabetes aged 12 years and older
- There are approx. 225,000 people living with Type 1 or Type 2 diabetes in Ireland. 1 in 20 (12,000) of them are at risk of developing vision loss due to retinopathy.
- The longer you have had diabetes, the more likely you are to develop diabetic retinopathy.
- From January 2021, if there is a result of 'no retinopathy' in two previous screenings, the next screening invitation is two years from the time of the last screen. International evidence shows people with this screening history are at very low risk of contracting retinopathy between screenings.



# Research objectives

- Gain insights into awareness, knowledge and understanding of screening in Ireland.
- Understand public sentiment and trust of screening services.
- Explore what drives and inhibits attendance at screening appointments.
- Identify knowledge gaps about screening services, limitations of screening and interval cancers.
- Measure awareness and impact of communications campaigns and explore preferred communications channels for engaging with target audiences.



# Research results

Diabetic   
**Retina**Screen

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# Research aim & objectives

**Research aim:** Identify and explore peoples' perceptions of screening services in Ireland and what drives and inhibits them to attend screening.

- Gain insights into awareness, knowledge and understanding of screening in Ireland.
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# Research approach



## HCW Interviews

8 interviews were conducted with healthcare workers to understand their experience on the ground

July-August



## Online Survey

2,000 nationally representative interviews were completed to effectively measure and quantify findings

Sept-Oct



## Focus Groups

11 focus groups were carried out to delve deeper into findings and to understand the 'why' behind the results

December



# Diabetic RetinaScreen research overview

- National survey was among a total of 764: 178 among those living with diabetes and 598 gatekeepers (parents, carers).
- 3 focus groups, broken down by adults with diabetes, teenagers with diabetes, and parents of children with diabetes.
- There is quite low levels of knowledge and awareness among gatekeepers. The results in this presentation represent those with diabetes, except where gatekeepers are called out.



## High levels of awareness

- 94% are aware of 'Diabetic RetinaScreen'.
- 83% know it's extremely/ very important to attend regular screening.
- 87% are very/ quite likely to attend their next screening appointment.
- 89% feel positive towards Diabetic RetinaScreen.





## Low levels of knowledge

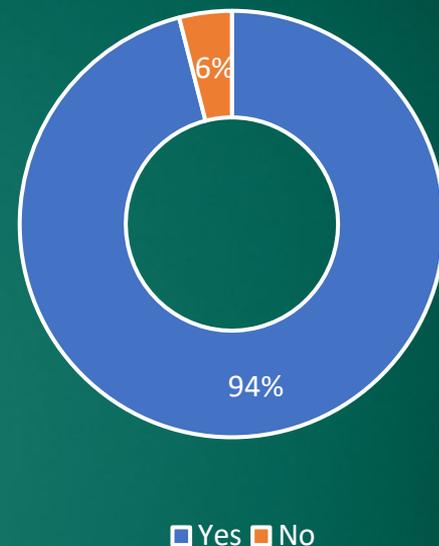
- 20% know little or nothing about diabetic retina screening.
- 28% don't know why it's important to attend diabetic retina screening.
- 27% don't know what they can do to reduce their risk of diabetic retinopathy.
- 78% (of those with diabetes and gatekeepers) don't know the limitations of screening.
- 23% don't think they need to look for symptoms if they attend regular screening.



# Sentiment towards Diabetic RetinaScreen

- 94% are aware of 'Diabetic RetinaScreen'
  - 89% of 18-34 year olds
  - 58% of gatekeepers
- 89% feel positive towards Diabetic RetinaScreen, with this positivity increasing with age (79% in 18-34 up to 95% in 55+). People feel positive because it's a good and important service (46%).
- Providing more information on the service would help people to feel more positively towards Diabetic RetinaScreen.
- There was positive feedback on the test, with one participant describing it as 'seamless'. Once they knew what to expect, and accepted the drops would sting, they were happy with the appointment process.

Awareness of  
Diabetic  
RetinaScreen





## Trust in Diabetic RetinaScreen

There was high trust in the programme, their screener and diabetes nurse.

79%

Puts the interests  
of people first

50%

Admits  
responsibility when  
things go wrong

81%

Provides high  
quality and safe  
health care

77%

Communicates in a  
way that's easy &  
straightforward for  
me to understand



# Diabetic retinopathy

- **Diabetic retinopathy is a complication of diabetes. It's caused by high blood sugar levels damaging the back of the eye (retina).**
- 62% have a good understanding of diabetic retinopathy
  - 68% for 18-34 year olds
  - 56% for 35-54 year olds
  - 17% among gatekeepers
- When asked about how to reduce their risk of diabetic retinopathy:
  - 27% don't know what they can do to reduce their risk
  - 25% know to keep control of blood sugar and/or diabetes while also reducing sugar intake
  - 19% know to lead a healthy lifestyle with a good diet and sufficient amounts of exercise



# Diabetic retinopathy – symptoms

- 76% watch out for symptoms, with only 25% of gatekeepers watching out for symptoms for an immediate family member.
- 42% don't feel confident in spotting symptoms (78% of gatekeepers).
- 23% don't think they need to look for symptoms if they attend regular screening.
- Awareness of what the symptoms are is quite low among those with diabetes and gatekeepers:
  - gradually worsening vision (67%)
  - blurred or patchy vision (59%)
  - shapes floating in your field of vision (48%)
  - sudden vision loss (47%)
  - eye pain or redness (45%)



# Diabetic retina screening

- 54% have a good understanding of diabetic retina screening (only 11% of gatekeepers).
- Focus groups stated that for people with diabetes, screening is just another part of their healthcare routine.
- Some people are not aware that screening is for people without symptoms.
- 40% said screening allows for the detection and diagnosis of sight-related issues.
- 47% are aware that people who have two consecutive results of 'no retinopathy' only need to go for screening every 2 years. There was surprise and disagreement with the 2-yearly screening interval in the focus groups; some thought the delay was COVID-related.

It's not an inconvenience when you have to inject yourself 4 times day.

A blue speech bubble with a white outline, pointing towards the third bullet point in the list. The text inside is white and centered.

# HE Why attend screening

- 83% know it's important to attend regular screening – only 63% of 18-34 year olds.
- Motivations for attending screening include:
  - peace of mind about my health (58%)
  - receiving invitation letter (44%)
  - it is a normal part of my healthcare routine (43%)
  - advice from GP (42%)
  - advice from family/ friends (42%)
- The benefits of Diabetic RetinaScreen are:
  - managing overall health (26%)
  - allows for early detection of sight deterioration and provides advanced warning (25%)
- The benefits (of protecting their sight) far outweigh the inconvenience.

83%

Know it's extremely/ very important to attend regular screening

“I'd rather lose a leg than go blind”

(adult focus group participant)

87%

Plan to attend their next screening appointment



## Misconceptions and knowledge gaps

28%

Don't know why it's important to attend diabetic retina screening.

(62% among gatekeepers)

27%

Disagreed that screening is for people who do not have symptoms.

(People with diabetes and gatekeepers)

22%

Don't know the benefits of diabetic retina screening.

(People with diabetes and gatekeepers)



# Limitations and interval retinopathy

- 78% (of those with diabetes and gatekeepers) don't know the limitations of screening.
- When asked about limitations, some brought up practical limitations regarding location of screening (and follow-up appointments) and difficulty getting to them.
- However, 80% of people with diabetes are aware that diabetic retinopathy can develop between screening tests.
- In the focus groups, some were surprised they have to be aware of symptoms.



## Barriers to attending screening

- The importance of barriers differ by age.

	18-34	35-54	55+
Difficulty travelling to/ from appointment	21%	27%	41%
A fear of finding something wrong	32%	31%	32%
Concerned about COVID	24%	24%	33%
Not knowing whether you are eligible to attend screening	29%	24%	19%
Not knowing how to access diabetic retina screening services	18%	21%	26%
A fear of how the screening process is done	26%	29%	9%

- 52% of gatekeepers are also unsure who is eligible for screening.
- Being unable to get an appointment or no time to attend appointments are also mentioned as barriers.
- Stinging eyes is a barrier for children but they liked getting the day off school.
- Of those who don't attend (or family member doesn't), 13% don't know enough about diabetic retina screening, with other reasons being fear of results, too busy and not having any symptoms.



# What to communicate

- Provide practical information about how to prepare for your appointment.
  - The impact of having blurred vision (not being able to drive or see your phone; limited ability to walk around and buy things).
  - Bring supplies/ distractions for waiting after eye drops put in (, e.g. access to food and drinks for those with type 1 diabetes, and ear phones as you can't see your phone).
  - Bring a hat/ sunglasses to protect dilated eyes afterwards
- Further information is required on the below topics:
  - symptoms to look out for between screenings (49%)
  - when you're most at risk of diabetic retinopathy (34%)
  - where to go if you're concerned about symptoms (34%)
  - the benefits of diabetic retina screening (31%)

Additional specific information is required for some age cohorts:  
**18-34:** how your test is analysed (42%) and why you should avail of diabetic retina screening (32%)  
**55+:** limitations of screening (35%)



# How to communicate – communications channels

- GPs are most cited information source (64%), followed by opticians (41%). 42% mentioned advice from a GP or other healthcare professional as motivation to attend screening.
- 61% like to receive the invitation letter but 61% also said they'd like communication by email. 44% are motivated to attend screening because of the invitation.
- Some teenagers were happy for their parents to take the lead but others said they'd like to be included in communications.
- Contact details for any questions should be provided in the results letter, particularly if retinopathy is detected. Some debate on whether this should be screening services, their specialist or GP or nurse, as important that HCWs are kept in the loop.
- The 2-yearly screening interval should be explained in correspondence (appointment/ results letter) and also perhaps by HCWs.