



**Fiona Riordan** and Sheena McHugh explore ways to increase attendance at diabetic retinopathy screening

iabetes can cause damage to blood vessels at the back of the eye, affecting a person's sight. This complication of diabetes is called retinopathy. Attending regular retinopathy screening increases the chance of damage being picked up early and treated in time.

However, retinopathy screening attendance rates are below the recommended levels in many countries, including Ireland.

There are many reasons why people may not attend retinopathy screening. For example, they:

- May not be aware of the risk of developing diabetic retinopathy
- May not know that regular eye checks with opticians are different to retinopathy screening
- May find it difficult to access screening centres
- May have competing demands on their time.

In an attempt to tackle this issue, researchers in University College Cork (UCC) wanted to develop and test a way to improve screening attendance by working with health professionals in general practice.

People with diabetes visit their GP regularly and the researchers wanted to find out if it was practical for staff in general practices to identify those who had not attended recently and remind them about the national screening service, Diabetic RetinaScreen.

The Improving Diabetes Eye-screening Attendance (IDEAs) study received advice from doctors, nurses and, crucially, people with diabetes. In fact, involving people with diabetes in the design of this new approach was a key part of the

People with diabetes took part in meetings with the research team to

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## **EYE SCREENING**

# What is public and patient involvement (PPI)?

Public and Patient Involvement (PPI) in research is defined as research done 'with' or 'by' members of the public, rather than 'to', 'about' or 'for' them. Traditionally, members of the public take part in research where researchers collect data from participants, analyse that data and publish research results, usually in academic journals. In this type of traditional research, researchers make all the decisions about what and how research is carried out. PPI is a different approach to research where researchers and members of the public work in partnership to plan and conduct research, to interpret research data and to share and publicise the research results.

decide how reminders should be delivered and what information they should contain. The group decided that people would be reminded either in person, over the phone or by letter, and given a short leaflet with key messages about why they should attend retinopathy screening.

After these meetings, some people joined the Public and Patient Involvement (PPI) panel (see box) for the study and continued to advise the research team on different parts of the study.

The PPI panel was made up of five people with diabetes – three women and two men. Three people had Type 2 diabetes and two had Type 1 diabetes. The panel met four times over the course of the study (2018-2021) and was led by Dr Emmy Racine, the study PPI co-ordinator.

Members of the PPI panel advised the research team on the format, content and wording of information materials, and how to let people know about the study results. For example, they advised that the words 'intervention' and 'testimonial' be removed from all patient materials.

Members of the panel also advised the researchers when they were preparing a funding application and took part in a podcast about PPI in research.

One PPI member, Dawn, noted that as the members all had different experiences with their diabetes, "we were able to provide detailed and nuanced feedback on the material that was used in this study".

How did the team test if the reminder would work?

The research team carried out the study in eight general practices across Ireland over a six-month period (July 2019 to January 2020). Four practices were asked to keep doing what they normally do while the other four practices introduced a new system for reminding people about screening.

In both cases, staff searched their practice records to identify patients who had not taken part in screening. The four practices that had introduced the new reminder system then contacted patients to remind them to participate in screening.

In all, the team surveyed 25 staff members to find out what people thought about the new approach. They then interviewed nine of these staff members, as well as 10 people with diabetes who had received the reminders.

### **Findings**

In the four practices that introduced the changes, 31% of people (22 of 71 people) who had not attended RetinaScreen at the start of the study had attended screening by the end of the study. In the four practices that did not introduce the changes, 17% of people (15 of 87) had attended screening by the end of the study.

People with diabetes thought the reminders were acceptable and some felt they influenced their decision to attend screening. They were influenced to take part in the screening programme because the reminder came from their local practice where they trusted their GP and practice nurse.

Some people were motivated to act when they received the reminder because

they were already interested in their health or had concerns about their eyes.

Patient 3: "He [GP] just said 'Look, this is the third letter you've got and for your own sake it's important to get this retinal screening done for your diabetes.' Anything he says I follow, because I have great faith in him. He's a fantastic doctor and he's picked up things in me that no one has ever picked up. He knows me inside out."

Staff thought that the new approach was a good idea and that it would work, but this depended on whether they could manage their time. They found ways to make the changes fit with their usual way of working and their existing skillset.

GP 3: "See, the way we decided to split up the [reminder] phone calls was that I usually come here on a Saturday and Sunday to do these things, so I thought that was the best time to do that [phone calls], because in between surgery is so difficult to do that."

These findings suggest that the new approach could be a practical way of improving attendance. However, it was a very small study. We would need to carry out a much larger study to be certain that this approach improves attendance.

If you would like to know more about the study, visit www.ucc.ie/en/ diabeteseyescreening/

If you are interested in being part of a PPI panel, the research team is currently looking for people to join a panel for a new five-year research project called CUSTOMISE. The aim of this project is to find out how to introduce changes in healthcare in a way that is acceptable and practical for health professionals and service users.

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