Retinal screening is one of the key checks everyone with diabetes needs to have, to avoid complications with the eyes. Yet some patients are still not attending this free and simple test, which might save their vision in the long term. **Iveta Olejkova**, Team Leader, and **Agnes C Bourke**, Administration Manager, from North Central London Diabetic Eye Screening Programme at North Middlesex University Hospitals NHS Trust, discuss the DNA (Did Not Attend) issue and how their team has been addressing it.
FEATURE

DIABETIC EYE SCREENING

Diabetic eye screening (DES) has been around for over 15 years and is one of the NHS national population screening programmes. It involves taking photographs of the retina, which allows practitioners to see the microvasculature in great detail and so pick up any tiny abnormalities. Diabetic retinopathy is the most common of these abnormalities.

An annual DES check is one of Diabetes UK’s 15 Healthcare Essentials. The reason it is included alongside the other checks and processes is that retinopathy can progress without any warning symptoms within a year. Ideally, this would be picked up at the DES appointment, giving enough time to refer and treat in the ophthalmology eye clinic. Left for longer – two, three or four years without any retinal examination and combined with poor diabetes management – diabetic retinopathy can lead to irreversible damage that is very hard to treat and rectify.

Diabetic eye screening – the facts

Between 1 April 2015 and 31 March 2016, more than 2 million of those eligible (82.5 per cent) were screened for diabetic retinopathy and 7,255 were referred by local screening programmes urgently to hospital ophthalmology departments for the highest level of retinopathy (known as proliferative retinopathy) in order to be monitored and treated1. This equates to around one referral per 279 people screened. For pre-proliferative retinopathy, which is the stage leading on to proliferative retinopathy, about 49,658 people were referred, equating to one in 41 people screened.

These figures show that DES is an extremely effective tool in picking up retinopathy. The pathway ensures that patients are referred in a timely manner to ophthalmology depending on the level of disease.

Failing to attend a DES appointment

Unfortunately, not all eligible patients take up the offer of free DES and, for various reasons, do not attend their annual appointments. Eye screening programmes have to come up with ways of engaging with this group of patients and exploring the reasons for non-attendance.

Even though the test is very simple and non-invasive, DNA (Did Not Attend) is a significant issue, causing loss of sight to people with diabetes and putting extra pressure on scarce resources. Non-attendance at DES is costly to the NHS, with one programme estimating that non-attendance costs >£78,000 over a single year2.

Understanding and reducing DNA starts with the following considerations:

• What defines the ‘hard to reach’ patient?
• What DES programme level factors, such as communication, can be addressed?
• What are the next steps we need to take to improve the situation?

We already know that barriers to attendance at DES include lack of time and conflicting priorities, such as having multiple appointments and difficulty taking time off work. This is where a more integrated care approach would work – having a one-stop shop with all the checks taking place during a single visit, and also introducing evening and Saturday clinics.

There is also a need for education, for some patients still believe that other hospital eye appointments or regular optician appointments include a test for diabetic retinopathy. Some will be anxious about their results or possible treatment, while others believe all is fine because their vision is too. Meanwhile, there are patients who simply feel embarrassed about their poor glycaemic control and are failing to engage with all diabetes interventions.

The hard to reach patients include: young adults, rural dwellers, single parents, Black and Minority Ethnic groups, older people (particularly those with mobility issues), deprived inner-city dwellers, young middle class workers, and White British working age men. But hard to reach actually covers anyone who simply doesn’t engage with the DES service. Should we say that they are hard to reach, or are we just not trying hard enough to reach them?

Programme factors influencing DNA rates

The programme level factors we have identified that make a difference to attendance at appointments include:

• clinic locations
• clinic availability
• walk-in slots
• text message reminders
• software restrictions
• mobile screening units
• staff perceptions of non-attenders.

For instance, research suggests that adjusting the wording in the SMS messaging, to one that focuses on the cost involved in a missed appointment, would result in 5,800 fewer missed appointments per year in just one NHS provider – Barts Health NHS Trust – at no additional expense. This study was conducted over five separate specialties, including ophthalmology, which included DES3.

Communication with our patients is of high importance, and even more so...

Diabetes UK says...

Every week, there are 169 amputations and more than 30 people develop sight loss because of diabetes. That’s why Diabetes UK has launched Be in the know to help patients spot the signs of early complications and ultimately, prevent them. Visit www.diabetes.org.uk/up-know to find out more.
Newly diagnosed patients aren’t always given enough information about having diabetes, so phoning them and explaining the reasons for a DES appointment can help them realise that diabetes can cause eye complications.

with the hard to reach groups. Making sure that we have up-to-date phone numbers and that staff can speak to the patient in their own language, if need be, eliminates one obvious barrier. There are other barriers though. Newly diagnosed patients aren’t always given enough information about having diabetes, so phoning them and explaining the reasons for a DES appointment can help them realise that diabetes can cause eye complications and is an opportunity to stress the importance of regular screening. Administration staff who can work outside of normal hours – making evening calls – helps to reach the working population for these discussions.

What can programmes do to support patients further?

What helped to improve our uptake at the North Central London DES Programme, provided by North Middlesex University Hospital NHS Trust, was the fine-tuning of SMS text message Reminders (SMSR) and calling patients a few days prior to their appointments. This was the result of an MSc study in conjunction with Imperial College London with objectives of zero-cost intervention (must prove zero-harm), raising awareness by instilling a little fear (non-conventional behaviour change theory) with the message ‘Diabetes harms eyes before you notice. Screening can save sight’.

This study involved 1,995 patients out of whom 1,011 received intervention SMSR and 984 normal SMSR. The results showed that a patient receiving the intervention SMSR was 0.6 times less likely to DNA (95% CI 0.499-0.799) as a patient who received the normal message. This is a significant result, as p<0.05.

Using the National Audit Office reference cost per DNA of £141 in 2012/2013, this trial saved NCL-DESP £8,460 from the 60 people (6 per cent of 1,011) who would have been expected to DNA, compared with either the predicted DNA baseline or the actual DNA rate of the control group. This saving could effectively be doubled in future now there is no need to maintain a parallel normal SMSR group. This figure is pure saving, because no additional resources were required to conduct this study, nor will any be required for the intervention SMSR to be used in future.

Other factors that have been instrumental at NCL-DESP include, but aren’t limited to:

- detailed capacity planning
- engaging with all DESP staff and getting them involved in increasing uptake, so that everyone feels that they can support patients
- fine-tuning of SMS text message reminders
- sending out two text messages seven days and two days before the appointment day
- reminder calls to newly referred patients, as well as those who had failed to attend their previous appointments, a few days prior to their appointment
- setting up out-of-hours and weekend clinics
- utilising our mobile screening unit to go to over 40 different locations across North Central London to encourage and boost uptake
- working in collaboration with GP practices regarding data cleansing, as well as measures to encourage patients to attend their appointments.

Staff attitudes

There are other aspects to non-attendance that can be addressed. For instance, we need to fine tune staff attitudes. Understanding our patients and using a friendly manner when explaining what can happen if too many appointments are missed, but also being able to advise them about the benefits...
A female patient in her late fifties was diagnosed with Type 2 diabetes in 2001. When we first saw her in our DES clinic, she was on combination treatment of metformin and insulin. Unfortunately, she did not take up the offer of screening until 2014, when she was approached by a retinal screener and offered the test while visiting the podiatry clinic in the same hospital. She agreed and the result showed early stage proliferative diabetic eye disease (2014, above).

At this point, the screener had a discussion with her about what would happen next (referral to ophthalmology clinic) and why it was important to attend. The patient explained that she was suffering from depression and had problems with her feet, so was attending podiatry, as well as various other clinics, to take care of other complications. She did not realise that diabetic eye changes can be asymptomatic. The screener explained that these changes become symptomatic later, as the condition progresses, by which time the window of opportunity for treatment may have been missed. The patient agreed and was very willing to attend her follow-up appointments with the eye clinic.

She had her first appointment in ophthalmology in 2014 and her glucose levels were improving with HbA1c at 64mmol/mol. No laser treatment was necessary at that stage, but the idea of treatment for maculopathy was introduced, to be decided at future appointments, which were unfortunately missed (three in total). This, as she explained, was due to having multiple appointments with other departments. The patient was given another appointment in the eye clinic during 2015, which she attended, with noticeable progression in her diabetic retinopathy. She received laser treatment on the left eye to slow down the progression of proliferative changes and the first Lucentis (anti-VEGF) injection to the right eye to control the macular oedema. Unfortunately, she missed all her follow-up appointments, so was discharged and recalled into the Digital Surveillance clinic for retinal screening in 2016, which referred her back to ophthalmology. This pattern of non-attendance, discharge and re-referral then repeated itself for the following two years.

At her next Digital Surveillance appointment, she explained that her depression was getting on top of her, even though she was on medication. She also developed problems with eating, and was not feeling well enough to engage with all the demands on her health. During the time when she did attend ophthalmology, later in 2016 and early 2017, further laser treatment was administered to her now proliferative right eye and she was given multiple appointments to make sure she could attend. The left eye started to fibrose and after another set of non-attendance, she was recalled for retinal screening this July. She came and the images revealed further deterioration of the left eye due to previous fibrosis, this time with vitreous haemorrhage (2018, above).

The screener explained the urgency of the situation and the patient said she did not realise the condition could be so serious. She still thought her vision was reasonably good, but did complain about its deterioration – this was measured to be at 6/12 for both eyes, which is still considered to be a good vision for that stage of the eye disease. Another referral to the eye clinic was arranged just last month and she was extremely willing to attend ophthalmology. She was prepared to move her other appointments with podiatry to make sure she could attend. But then, through no fault of her own, she could not attend because the transport department refused to provide an ambulance. This was due to stricter criteria on which patients qualified for this service, which had just recently been nationally implemented. The patient’s GP then arranged another appointment with a different hospital, which, in the end, did provide the transport. The patient is due to be seen in ophthalmology within national guidelines this August. We can only hope that she will attend so the diabetic eye disease can be ideally managed on a regular basis. This remains to be seen.

This case history demonstrates that even ophthalmology struggles to keep their patients motivated to attend these important appointments and there is no one solution to all problems. Fortunately, for this lady, she stayed within her pathway due to good communication between the Hospital Eye Service and the DES Programme. As soon as she missed her appointment with the Hospital Eye Service, she was recalled for DES, which makes sure that patients aren’t falling through the gaps in the pathway and are offered timely appointments to reassess their eyes. If the patient does engage with the services and stick with the proposed treatment plan, they can achieve the best possible outcome.
DIABETIC EYE SCREENING

...diabetic retinopathy can lead to irreversible damage that is very hard to treat and rectify.

...of attending (ie peace of mind) and making it easy to attend, (“When can you come?”) saves sight. Showing the patient their retinal images at the screening appointment can also be helpful in demonstrating the importance of regular attendance/the need to attend hospital appointments when referred/the benefits of looking after their health – good glycaemic control, blood pressure cholesterol, not smoking etc.

And patients do need to feel empowered by the healthcare professional in order to take the ownership of their state of health. Then, with constructive and non-judgmental advice and a health management plan, they can cooperate and understand why it is important to comply with screening intervals. We need to talk to patients about the state of their eyes and to understand how that can make them feel – not to frighten them, but to guide them through the process of making it better. The patient will more likely comply with screening or treatment if they are understood, sympathised with and supported.

Working together

All of the above, and more, is possible while we have reliable data to draw from.

For example, patients who have mental health problems won’t always follow up on their appointments, and having established links with support workers helps to manage these appointments. Work with colleagues in Public Health can help to identify patients with mental health issues, including learning difficulties. We also need to engage with local community leaders and faith organisations. We can explore partnerships with local radio stations and represent DESP at cultural and religious events, and at festivals.

For patients, it’s all about – to attend or not to attend! That is the question. Diabetes is a long-term condition and, as such, it is extremely important that patients move towards taking control and managing their condition. Attending DES clinics on a regular basis is a key part of this process.

So, let’s all work together wherever we can – healthcare professionals, people with diabetes and Diabetes UK – to minimise the complications caused by the condition, and create a world where diabetes can do no harm.

British Association of Retinal Screening can be found at www.eyescreening.org.uk

REFERENCES


4 Study not yet published