

Ensuring the effective delivery of diabetic eye screening for children and young people in England

Mike Harris, Lynne Lacey

Diabetic eye screening is a key element of good diabetes care. Screening using digital photography is offered every year to anyone with diabetes aged 12 years and over who has light perception in at least one eye. Attending screening is important because diabetic retinopathy and maculopathy do not cause symptoms until the disease is quite advanced. Children and young people with diabetes are more likely to develop sight-threatening disease later in life because duration of diabetes is one of the main risk factors. The NHS Diabetic Eye Screening Programme has started to work closely with stakeholders to raise awareness of the importance of screening attendance among young people and to emphasise messages around good diabetes control.

Screening for diabetic retinopathy is one of the essential checks that all people with diabetes are entitled to receive (Diabetes UK, 2013). The condition occurs when high blood glucose levels cause the network of tiny blood vessels in the retina to leak or become blocked. Until recently, it was the biggest cause of sight loss among people of working age. Public health interventions, such as screening, have helped to reduce its impact in recent years (Liew et al, 2014), but people with diabetes remain up to 20 times more likely to become blind than the rest of the population (Hamilton et al, 1996).

It is estimated that in England every year 4200 people are at risk of blindness caused by diabetic retinopathy and it results in more than 1500 new cases of preventable sight loss (Scanlon, 2008).

The NHS Diabetic Eye Screening Programme (NDESP) offers annual screening using digital photography to everyone with diabetes aged 12 years and over who has light perception or better in at least one eye (Department of Health, 2013). NDESP aims to reduce the risk of sight loss among people with diabetes through early detection and timely treatment of diabetic eye

disease. It is estimated that screening could save more than 400 people per year from sight loss in England (Scanlon, 2008).

Retinopathy does not cause symptoms in its early stages, so, without screening, people may not realise their retina is damaged until their vision is already affected. Screening is, therefore, the best way to detect disease early so that it can be monitored or treated and sight loss prevented.

NDESP's focus on children and young people

Diabetic retinopathy is a progressive disease and the most important risk factor for developing the condition is the duration of diabetes. Children and young people (CYP) are, therefore, particularly at risk as they live with the disease much longer than people who develop the condition late in life.

Diabetic retinopathy seldom develops within 5 years of the onset of diabetes or before puberty. In people diagnosed with diabetes before 30 years of age, the incidence of diabetic retinopathy is 50% after 10 years and 90% after 30 years (Harney, 2006). Background retinopathy (*Box 1*)

Citation: Harris M, Lacey L (2014) Ensuring the effective delivery of diabetic eye screening for children and young people in England. *Diabetes Care for Children & Young People* 3: 59–63

Article points

1. Ensuring screening is delivered effectively, consistently and equitably to children and young people with diabetes is a priority for the NHS Diabetic Eye Screening Programme (NDESP).
2. Effective communications between local screening programmes, paediatric diabetologists and GPs are vital to ensure that young people do not “fall” through gaps between paediatric and adult services.
3. NDESP's national implementation of a consistent common pathway for diabetic eye screening during 2014 will play a key role in supporting provision for children and young people.

Key words

- Diabetic retinopathy
- Eye screening
- Programme delivery

Authors

Mike Harris is Communications Manager at NHS Screening Programmes, Gloucester and Lynne Lacey is National Programme Manager, NHS Diabetic Eye Screening Programme, Gloucester.

Page points

1. Someone diagnosed with diabetes before 20 years of age is almost certain to develop background retinopathy by the time they are 40.
2. Closing the gaps between paediatric and adult diabetes care to ensure that individuals are not “lost” to diabetic eye screening remains a challenge.
3. The NHS Diabetic Eye Screening Programme recently agreed joint actions with the National Paediatric Diabetes Audit to improve the delivery of diabetic eye screening for young people.

Box 1. Eye conditions that are associated with diabetes.

- **Background retinopathy** is the earliest visible change to the retina. It does not affect eyesight, but needs to be carefully monitored. The capillaries (small blood vessels) in the retina become blocked, may bulge slightly (microaneurysm) and may leak blood (haemorrhages) or fluid (producing exudates). Microaneurysms and dot intraretinal haemorrhages are present in almost all who have had type 1 diabetes for 20 years and nearly 80% of those who have had type 2 diabetes for 20 years (Fong et al, 2004).
- **Proliferative retinopathy** occurs if large areas of the retina are deprived of a proper blood supply because of blocked and damaged blood vessels. This stimulates the growth of new blood vessels to replace the blocked ones. These growing blood vessels grow forwards, are very delicate and bleed easily. The bleeding (haemorrhage) causes a loss of vision that usually clears as the blood gets absorbed. Sometimes the abnormal vessels scar and start to shrink and pull on the retina, leading to it becoming detached. This can cause a permanent vision loss or blindness unless surgical treatment is successful in reattaching the retina.
- **Maculopathy** is when changes occur in the macular area that suggest there may be some threat to vision. The macula is the area of the retina that provides central vision and is essential for clear, detailed vision. If fluid leaks from the enlarged blood vessels it can build up and cause swelling (oedema). This can lead to some loss of vision, particularly for reading and seeing fine details, and everything may appear blurred.

– the earliest signs of changes to the eyes caused by diabetes – is present in nearly all those who have had type 1 diabetes for 20 years (Fong et al, 2004). Someone diagnosed with diabetes before 20 years of age is, therefore, almost certain to

develop background retinopathy by the time they are 40. This is significant because people with background retinopathy are much more likely to go on to develop sight-threatening disease than those found with no retinopathy (Stratton et al, 2013).

In addition to duration of diabetes, other risk factors for developing sight-threatening disease are poor control of diabetes and hypertension, and failure to attend regular diabetic eye screening appointments.

Unfortunately, CYP are often particularly vulnerable to these factors (Orton et al, 2013). Around one in five people with diabetes do not attend their annual screening appointments – with uptake often lower among young adults, particularly males. Experience suggests that those who do not attend eye-screening appointments are also more likely to have poor diabetes control.

Living with diabetes is a challenge for any young person given the peer pressure they often feel to lead a “normal” life and to engage in risky behaviour at odds with good diabetes control. In addition, young people have to make the tricky transition from child to adult healthcare services. Closing gaps between paediatric and adult care to ensure individuals are not “lost” to screening during this transition period remains a challenge that is exacerbated by the fact that many teenagers and young adults frequently change address and healthcare provider.

NDESP is determined to address these issues and recently agreed joint actions with the National Paediatric Diabetes Audit (NPDA) to improve the delivery of diabetic eye screening for young people. These actions include:

- Ensuring paediatricians receive the screening results of all young people with diabetes aged 12 years and over who are under their care.
- Ensuring paediatricians inform the screening service of patients transitioning to adult care in order to close any gaps between paediatric and adult care to minimise the number of people “lost” to screening during that transition.
- Ensuring paediatricians and paediatric diabetologists inform the screening service of young people with diabetes under their care.
- Ensuring local screening services use new fields in nationally mandated software for recording paediatrician details against records of young patients.



Figure 1. Young man with diabetes having retinal images taken with a fundus camera. Digital photographs are taken of the retina in both eyes during the screening test.

Local programmes undertake audits to look at uptake across all people with diabetes. The new standard software includes better reporting facilities to help programmes identify specific age groups that are not attending for screening and look at appropriate local solutions to improve this, such as the use of technology or local community engagement. Some programmes are able to use text and email to remind people about their appointments and to follow up non-attenders by text, email or phone. Future plans for NDESP will include more widespread use of new technology to engage CYP and the evaluation of the production of information leaflets specifically aimed at CYP.

Delivery of diabetic eye screening

Diabetic eye screening has advantages over many of the other essential services for people with diabetes because it should be a seamless service – the same people and same organisations deliver screening whether you are aged 12 or 112.

Screening in England is led and coordinated by NDESP, which is overseen by the UK National Screening Committee (UK NSC). The UK NSC is supported by Public Health England and is

responsible for the NHS Screening Programmes. Diabetic eye screening is delivered by more than 80 local programmes that are commissioned to deliver the service against a single national service specification (Department of Health, 2013) and in line with national quality standards (NDESP, 2012). NDESP holds these local programmes to account through quality assurance visits and the submission of regular reports.

Each local programme coordinates screening, organises invitation letters, screening clinics, result letters and referrals. Screening is provided in a variety of locations, including GP surgeries, hospitals and optician practices. Not all opticians who offer digital retinal photography are part of the screening programme, so patients should always make sure they are screened as part of their local NDESP service.

During the screening appointment, screening staff:

- Explain the screening process and record patient details and level of sight.
- Administer eye drops to make the pupils larger so the retina can be seen more clearly.
- Take digital photographs of the retina in both eyes (Figure 1).

Page points

1. Diabetic eye screening should be a seamless service as the same people and organisations deliver screening regardless of a person's age.
2. Screening in England is led and coordinated by the NHS Diabetic Eye Screening Programme.
3. The screening is delivered by more than 80 local programmes that are commissioned to deliver the service against a single national service specification.

“The new common pathway for diabetic eye screening in England represents a substantial change in operational and reporting requirements for local programmes.”

The photographs are examined by professionals who are trained to detect and grade any diabetic retinopathy according to severity. The graded results are sent to the patient and their GP within 3 weeks. For those individuals for whom a named consultant (e.g. a paediatric diabetologist) has been input into the new database field on the national software, the result will also be sent to that named consultant. Depending on the grade, patients are either recalled for routine screening 1 year later, invited for more frequent monitoring in a surveillance clinic or referred to hospital eye services for assessment and possible treatment (Box 2). Those whose images are ungradable will be referred to a slit lamp surveillance clinic, but CYP rarely have ungradable images (Scanlon et al, 2005).

For individuals with diabetes, the programme’s objectives focus on integrating screening and treatment for diabetic retinopathy with other aspects of diabetes care, such as the management of blood glucose levels and blood pressure. Patients are given information about any changes in their eyes so they can take action to stop more serious changes developing.

Good control is particularly important because the risk of developing sight-threatening disease is greatly reduced by keeping blood glucose, blood pressure and blood fats within agreed targets.

Implementation of NDESP’s new common screening pathway

NDESP is implementing a new common pathway for diabetic eye screening in England and new grading criteria during 2014. These developments will improve the consistency and quality of screening for all people with diabetes, but with particular benefits for children and young people.

Not only will the new pathway and grading criteria ensure a consistent approach to the commissioning and delivery of screening, it will also ensure comparable data are collected so that NDESP can easily identify potential outliers where quality needs to be improved. In addition, fail-safe systems have been developed to help local providers reduce the risk of patients falling through gaps between screening and treatment services.

The new pathway represents a substantial change in operational and reporting requirements for local programmes, and includes significant software

Box 2. Treatments for retinopathy and maculopathy.

If delivered at the right time, treatments for sight-threatening retinopathy and maculopathy are effective:

- **Laser therapy** is the most common treatment for proliferative retinopathy. Beams of bright laser light, administered under local anaesthetic, make tiny burns to treat areas that lack oxygen and stop the growth of new blood vessels. The laser burns allow more oxygen and nutrients to reach the retina, which improves blood circulation.
- Maculopathy can be treated with laser or with an **anti-vascular endothelial growth factor injection**, which can stabilise and help to improve vision. Vascular endothelial growth factor (VEGF) is a protein produced by the retina that stimulates the growth of new blood vessels. It is activated when blood vessels are blocked due to high blood glucose levels. Anti-VEGFs are injected directly into the eye during procedures carried out under local anaesthetic.
- **Vitrectomy** is a major operation that may be performed when a haemorrhage does not clear within several weeks, when someone has advanced proliferative retinopathy or when the retina detaches or peels away from its underlying tissue. During a vitrectomy, the vitreous, which gives shape and support to the back of the eye, is surgically removed and replaced with a clear, synthetic substance. This operation is usually done under local anaesthetic.

amendments. Mandated software changes that will benefit young people with diabetes include:

- A field for recording a patient’s paediatric diabetologist in addition to information about his or her GP.
- Standard letter templates for informing parents/guardians of under-16s of their screening results.

NDESP’s reporting systems are also being reviewed and revised to align with the new pathway.

This should enable the reporting of national screening and outcome data by age for the first time so that resources can be focused on age groups where evidence shows that there is a need.

A major information technology project, GP2DRS, is also under way to enhance the processes of identifying who needs to be invited for diabetic eye screening and of transferring patient information between GP practices and local screening programmes. This will also help to address the issue of patients potentially falling through the gap between paediatric and adult diabetes services, and significantly improve tracking of young people when they change healthcare provider.

Screening data at a glance

There are around 2.7 million people identified with diabetes in England (Diabetes UK, 2014) and that number has been growing steadily by around 5% every year. Providing a consistent, high-quality service to this increasing population is, perhaps, one of NDESP's greatest challenges.

During the first quarter of 2013/14 (1 April to 30 June 2013), 82.8% of people who were offered diabetic eye screening in England attended their appointments (UK National Screening Committee, 2013).

During the 2012/13 screening year (1 April 2012 to 31 March 2013), nearly 1.9 million people were screened for diabetic retinopathy and just over 74 000 of them were referred to hospital eye services for further investigation. Around 4600 underwent treatment to help prevent further sight impairment, underlining the importance of the screening test (NDESP, 2014).

Conclusions

One of the NHS Diabetic Eye Screening Programme's key challenges is to work closely and effectively with local providers, paediatric diabetologists, GPs and other stakeholders to ensure consistent provision of retinal screening for young people through the transition from paediatric to adult diabetes services. The implementation of a new common pathway for diabetic eye screening during 2014 will help to ensure that young people do not fall through gaps between services and that screening is delivered consistently, equitably

and to high standards. At a local level, effective communication between screening and other diabetes services is the most important factor in achieving these aims. ■

“The implementation of a new common pathway for diabetic eye screening during 2014 will help to ensure that young people do not fall through gaps between services.”

Department of Health (2013) *Public health function to be exercised by NHS England. Service specification no.22: NHS Diabetic Eye Screening Programme*. DH, London. Available at: <http://bit.ly/1yddtmv> (accessed 08.08.14)

Diabetes UK (2013) *15 Healthcare Essentials*. DUK, London. Available at: <http://bit.ly/1q0JKZi> (accessed 08.08.14)

Diabetes UK (2014) *Diabetes Prevalence 2013*. DUK, London. Available at: <http://bit.ly/1dR5kdG> (accessed 08.08.14)

Fong DS, Aiello LP, Gardner TW et al (2004) Retinopathy in diabetes. *Diabetes Care* **27**(Suppl 1): s84–s87

Hamilton AMP, Ulbig MW, Polkinghorne P (1996) *Management of Diabetic Retinopathy*. BMJ Publishing, London

Harney F (2006) Diabetic retinopathy. *Medicine* **34**: 95–8

Liew G, Michaelides M, Bunce C (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* **4**: e004015

NHS Diabetic Eye Screening Programme (2012) *NHS Diabetic Eye Screening Programme Quality Assurance Standards*. NDESP, Gloucester. Available at: <http://bit.ly/1r0gJn2> (accessed 08.08.14)

NHS Diabetic Eye Screening Programme (2014) 1.9m screened during year. *NHS Diabetic Eye Screening News*, March. Available at: <http://bit.ly/1qgpibC> (accessed 04.03.14)

Orton E, Forbes-Haley A, Tunbridge L, Cohen S (2013) Equity of uptake of a diabetic retinopathy screening programme in a geographically and socio-economically diverse population. *Public Health* **127**: 814–21

Scanlon PH (2008) The English national screening programme for sight-threatening diabetic retinopathy. *J Med Screen* **15**: 1–4

Scanlon PH, Foy C, Malhotra R, Aldington SJ (2005) The influence of age, duration of diabetes, cataract, and pupil size on image quality in digital photographic retinal screening. *Diabetes Care* **28**: 2448–53

Stratton IM, Aldington SJ, Taylor DJ et al (2013) A simple risk stratification for time to development of sight-threatening diabetic retinopathy. *Diabetes Care* **36**: 580–5

UK National Screening Committee (2013) *Diabetic eye screening key performance indicator report, quarter 1, 2013/14*. Public Health England, London. Available at: <http://bit.ly/1ssmFlh> (accessed 08.08.14)