# Diabetic retinopathy: Role of the diabetes specialist eye nurse

# Sabera Khan, Sam Wong, Rosi Gorrod, Ismail Gangat, Stephen Hiles, James Deane, Ian Lawrence

#### Article points

- The Diabetes Eye Nurse Project – a joint venture between the ophthalmology and diabetes departments at the University Hospitals of Leicester NHS Trust – was undertaken to optimise the care of people with diabetes and related eye disease.
- 2. An audit was undertaken to evaluate the effectiveness of the service in reducing HbA<sub>1c</sub> and lipid levels over the first 12 months.
- 3. Glycaemic control improved in all cohorts, as did serum lipid levels.
- 4. Diabetes eye care delivered by a diabetes specialist eye nurse is a new, innovative service and is one of the many good examples of the excellent multidisciplinary approach to the care of people with diabetes.

# Key words

- Diabetes specialist eye nurse
- Eye
- Ophthalmology
- Retinopathy

Author details can be found at the end of this article.

Traditionally, there is limited cooperation between ophthalmology and diabetes departments. However, during the implementation phase of the diabetes National Service Framework in Leicestershire, people with diabetes expressed a wish for a "joined-up" diabetes service, giving rise to the Diabetes Eye Nurse Project – a joint venture between the diabetes and ophthalmology departments. The project has improved glycaemic control and reduced lipid levels in a cohort of more than 100 people with diabetic eye disease, thereby reducing the risk of progression of the condition and other microand macrovascular complications. This article reviews this initiative and demonstrates the value of a diabetes specialist eye nurse.

Diabetic retinopathy is a common microvascular complication of diabetes (Donnelly et al, 2000). It is also the leading cause of blindness in people of working age in the UK (Kohner et al, 1996), with an estimated prevalence in people with diabetes of almost 60% (Watkins, 2003). Through optimising some of the risk factors of diabetic retinopathy, the progression of retinopathy can be minimised (Diabetes Control and Complications Trial Research Group, 1993; UK Prospective Diabetes Study Research Group, 1998).

As early as 1997, the worldwide prevalence of diabetes was predicted to increase two- to three-fold by 2010 (Amos et al, 1997). There are now approximately 2.5 million people in the UK with diabetes, and this figure is expected to rise to 4 million by 2025 (Diabetes UK, 2010). With the expected increase in the prevalence of diabetes in the coming years, the burden of diabetic retinopathy workload and the number of people affected by retinopathy is expected to rise accordingly.

In recognition of these factors, the Diabetes Eye Nurse Project – a joint venture between the ophthalmology and diabetes departments at the University Hospitals of Leicester NHS Trust – was undertaken to optimise the care of people with diabetes and related eye disease. This article describes the project and the results of a subsequent audit undertaken to evaluate its effectiveness. *Box 1* outlines the five stages of diabetic retinopathy and *Figure 1* shows a schematic diagram of the eye.

# Retinal screening in Leicestershire

Retinal eye screening is an integral part of diabetes care, and annual screening is recommended for all people with diabetes (NICE, 2004; 2008). In people with type 1 diabetes, retinopathy develops gradually over time and it is unusual for any changes to be seen within the first 5 years. In comparison, one third of people with type 2 diabetes may already have some form of retinopathy at diagnosis. It is therefore important that all people with diabetes have access to retinal screening when diagnosed.

Retinal screening is different from a general eye examination at the opticians, which focuses on the general health of the eye and whether the person can see properly. If spectacles are required, the correct ones are then prescribed. It is therefore important to highlight to people with diabetes that they still need to visit the optician in addition to their annual retinal screening if they wear spectacles.

The English National Screening Committee Programme for Diabetic Retinopathy (ENSPDR, 2006) requires all retinal screeners to have either a Certificate or a Diploma in retinal screening. Locally, the diabetes specialist eye nurse (DSEN) is responsible for the training, assessment and mentoring of the retinal screeners. In addition, the DSEN ensures that the screeners are able to understand the principles and practice of testing the individual's visual acuities and instilling the correct eye drops. Once the competencies are met, the screeners are then registered to undertake the City & Guilds Level 3 Certificate or Diploma in Diabetic Retinopathy Screening.

In Leicestershire, there are approximately 47 000 people with diabetes. To cater for this population there is a systematic diabetic eye screening service delivered in primary care. The University Hospitals of Leicester NHS Trust employs 22 retinal screeners who are placed in GP surgeries to carry out digital retinal imaging, as recommended by the ENSPDR (2006).

Following assessment and documentation of visual acuity, the individual's pupils are then dilated. Images captured are initially graded by the screeners and then by the ophthalmologist. People with

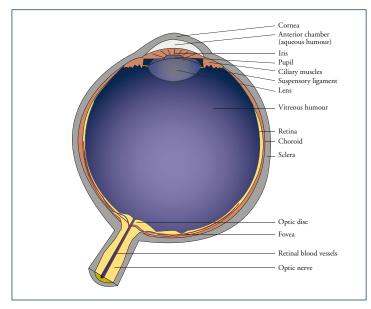


Figure 1. Schematic diagram of the human eye.

#### Page points

- 1. Retinopathy is diagnosed through fundus examination (examining the back of the eyes) by instilling dilating drops (tropicamide 1% and phenylepherine 2.5%).
- 2. It is important to inform people with diabetes that laser treatment is not a cure and cannot restore damaged vision, but can help prevent or delay further damage to the retina in over 90% of cases.

ungradeable images, or images that highlight some indication of retinopathy, are invited to a retinal screening clinic in secondary care for further examination.

Retinopathy is diagnosed through fundus examination (examining the back of the eyes) by instilling dilating drops (tropicamide 1% and phenylepherine 2.5%). The various stages of retinopathy progression (*Box 1*) are then diagnosed and recorded in the individual's case notes. Annual retinal screening is important as this is how retinal changes are picked up.

#### Laser therapy

It is important to inform people with diabetes that laser treatment is not a cure and cannot restore damaged vision, but can help prevent or delay further damage to the retina in over 90% of cases (Diabetic Retinopathy Study Research Group, 1981). In most cases it is possible to preserve the reading and driving vision.

There are three types of laser therapy: panretinal photocoagulation, grid photocoagulation and macula focal photocoagulation.

# Panretinal photocoagulation

Panretinal photocoagulation is usually used for the treatment of proliferative retinopathy. After instilling dilating drops and using a contact lens that enlarges the view of the retina, the ophthalmologist points a tiny laser beam into the abnormal part of the retina. Small bursts of laser dots are applied all over the retina (except for between the optic disc and fovea) to stop the

# Box 1. The five stages of diabetic retinopathy.

#### 1. Background retinopathy

This occurs in most people with diabetes approximately 20 years after the onset of the condition and can therefore affect all age groups from late teens onwards. Usually, no symptoms present until there is macular involvement resulting in impairment of central vision to the eye (*Figures 2a* and *b*). To ensure that the eye in those diagnosed with early changes does not deteriorate further, the person is discharged back to the retinal call and recall services. Such individuals are advised to have annual check-ups to assess the degree of retinopathy (funduscopy – dots, blots and hard, waxy exudates), to control their cholesterol levels, and also given dietary advice and treatment from the diabetes clinic.

#### 2. Preproliferative retinopathy

This may develop in the eyes with background retinopathy only (*Figure 3*). The eye requires close observation but is not usually treated unless regular follow-up is not possible or vision in the fellow eye has been lost to proliferative disease (Scott, 2008).

# 3. Proliferative retinopathy

This is the main cause of visual impairment in people with type 1 diabetes. It occurs sooner following the diagnosis of type 2 diabetes, possibly because the diabetes has gone on for longer undetected. In this form of retinopathy, the blood vessels grow into the vitreous humour and bleed, causing a vitreous haemorrhage (*Figures 4a* and *b*). Laser therapy, if required, can be used to treat proliferative retinopathy and aims to prevent neovascularisation occurring. A laser beam is applied to the retina, as a dead retina will not encourage new vessel growth – scotomas (areas of lost or depressed vision) present cause little visual impairment (Early Treatment Diabetic Retinopathy Study Research Group, 1985). Vitrectomy (surgical intervention) can be used in severe cases to remove the haemorrhage and provide a scaffold into which the new vessels can grow. If performed early in the development of retinopathy, laser therapy can help to improve visual recovery.

#### 4. Advanced retinopathy

This is the end result of uncontrolled proliferative retinopathy (*Figure 5*). The eye can develop retinal tears or a detached retina, which can lead to blindness. Early vitrectomy and also treating neovascular glaucoma (involvement of the iris with major risk of acute glaucoma) improves visual recovery in people with proliferative retinopathy and severe vitreous haemorrhage (Mohamed et al, 2007). The individual also requires management of visual impairment (support from eye clinic liaison officers).

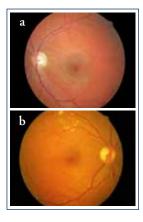
#### 5. Maculopathy

This is the main cause of visual impairment in people with type 2 diabetes (Figure 6), and is classified into four types:

- Focal/exudative.
- Cystoid/diffuse.
- Ischaemic.
- Mixed.

Only the focal/exudative and mixed type of maculopathy can be treated by laser. Cystoid/diffuse maculopathy is difficult to treat by laser and ischaemic maculopathy cannot be treated.

Figure 2. Normal retina with no diabetic retinopathy (a); background diabetic retinopathy with microaneurysms, haemorrhages and exudates (b). Copyright 1st Retinal Screening Ltd.



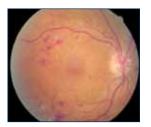


Figure 3. Preproliferative diabetic retinopathy with cotton wool spots, intraretinal microaneurysm and multiple blot haemorrhages. Copyright 1st Retinal Screening Ltd.

growth of new blood vessels (*Figure 7*). This is usually carried out over several appointments within an outpatient eye clinic. Fluorescein angiography is performed in-between sessions to pinpoint remaining affected areas or to establish the need for further laser treatment.

If the vision is stabilised after a few sessions of laser treatment, the possibility of further new vessel formation is relatively unlikely. However, the need for annual screening is still recommended to monitor further changes.

# Grid photocoagulation

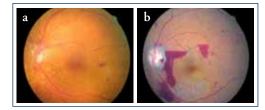
Grid photocoagulation is used for treating exudative maculopathy. Laser spots are applied in a grid pattern lateral to the fovea. In cases of retinal haemorrhage that do not clear using grid photocoagulation, surgical intervention (vitrectomy) may be performed under a general anaesthetic to remove abnormal tissue. Vision can improve significantly but it is a major operation and can be avoided if effective screening and laser treatment is maintained.

# Macular focal photocoagulation

Focal photocoagulation of clinically significant macular oedema substantially reduces the risk of visual loss. Focal treatment also increases the chance of visual improvement, decreases the frequency of persistent macular oedema and causes only minor visual field loss (Early Treatment Diabetic Retinopathy Study Research Group, 1985). Clinically significant macular oedema is defined as retinal thickening that involves or threatens the centre of the macula (even if visual acuity is not yet reduced) and is assessed by stereo contact lens biomicroscopy or stereo photography.

# Role of the DSEN: The Diabetes Eye Nurse Project

Traditionally, there is little or no significant cooperation between ophthalmology and diabetes departments. During the implementation phase of the diabetes National Service Framework (NSF; Department of Health [DH], 2001) in Leicestershire, people with diabetes expressed a wish for a "joined-up" diabetes service. They highlighted a need for Figure 4. Proliferative retinopathy with new vessels at the optic disc (a); proliferative retinopathy with preretinal and vitreous haemorrhages. Copyright 1st Retinal Screening Ltd.



diabetes expertise in the ophthalmology clinics, where many people were attending with diabetic eye disease, including diabetic retinopathy.

Pump-priming funding through a pharmaceutical company led to the appointment of a DSEN working in both the diabetes and ophthalmology clinics in 2004. This new routine service is in line with Standards 10, 11 and 12 of the diabetes NSF (DH, 2001):

- Standard 10: all young people and adults with diabetes will receive regular surveillance for the long-term complications of diabetes.
- Standard 11: the NHS will develop, implement and monitor agreed protocols and systems of care to ensure that all people who develop long-term complications of diabetes receive timely, appropriate and effective investigation and treatment to reduce their risk of disability and premature death.
- Standard 12: all people with diabetes requiring multi-agency support will receive integrated health and social care.

Most people are referred from the district retinal screening service; some from other diabetes retinal clinics. The other ophthalmologists were introduced to the diabetes eye service and the referral protocol via a presentation delivered by the DSEN (*Box 2*). This collaboration has helped raise the profile of the diabetes eye service as the eye department now consists of 14 consultant ophthalmologists, maintaining varied specialist eye clinics, and who have been able to access diabetes expertise as needed.

Following initial assessment of the person by the DSEN, other elements are then reviewed:

• Baseline biomedical parameters (HbA<sub>1c</sub> level, renal function, lipid profile and urine albumin excretion).

Figure 5. Advanced retinopathy – fibrous proliferation. Copyright 1st Retinal Screening Ltd.



Figure 6. Diabetic maculopathy with haemorrhages and circinate exudates and multiple blot haemorrhages. Copyright Ist Retinal Screening Ltd.

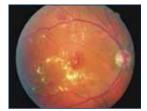
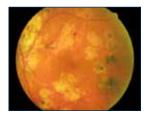


Figure 7. Laser treatment – laser dots around the retina. Copyright 1st Retinal Screening Ltd.



- Blood pressure.
- Lifestyle (including smoking cessation, basic dietary review, physical activities and alcohol consumption).
- Current medications.
- Provision of individual diabetes education, including self-monitoring of blood glucose.

Intervention is provided for any identified diabetes-related problems to delay further progression of eye disease and other diabetesrelated complications. Follow-up care for titration of medication is maintained through telephone contact. The first telephone call is usually within 1–2 weeks of the initial contact and a further DSEN advisory clinic appointment is within 1 month or earlier, depending on the individual's needs. Those with more complex issues are seen in the clinic of the supervising diabetes physician, alongside the DSEN and diabetes dietitian.

# Audit

#### Aim and methods

An audit was undertaken to evaluate the effectiveness of the service in reducing  $HbA_{1c}$  levels over the first 12 months after implementation. The case notes of 181 people seen at least once in the ophthalmology clinic were reviewed. Biomedical parameters, including  $HbA_{1c}$  levels and total cholesterol, were measured at baseline and then monitored every 6 months. The data presented in here are for 6- and 12-month follow-up.

#### **Results and discussion**

Baseline data separated into three cohorts: white European origin (53.6%; n=97); south

# Box 2. Referral protocol.

- People with at least background (or more serious) diabetic retinopathy.
- People with HbA<sub>1c</sub> levels of ≥7.5% (≥58 mmol/mol; changed to ≥9.1% [≥76 mmol/mol] after the service was established).
- Poorly controlled hypertension.
- Raised lipid parameters.
- Microalbuminuria, smoking or obesity.
- Other major concerns regarding the individual's diabetes care that may adversely affect vision.

Asian origin (41.5%, n=75); other (4.9%, n=9). Follow-up data were available for 100 people at 12 months.

Glycaemic control improved in all cohorts (*Figures 8–10*). Mean HbA<sub>1c</sub> levels for the full cohort reduced from 8.67% (71 mmol/mol) at baseline to 8.27% (67 mmol/mol) at 6 months, and at 12 months this had further reduced to 7.64% (60 mmol/mol; *P*<0.001). Prior to the intervention over 30% of individuals had a baseline HbA<sub>1c</sub> of >9% (>75 mmol/mol); following the intervention this number had reduced to 10%. By study end over 50% of individuals had achieved an HbA<sub>1c</sub> level of <7.5% (<58 mmoL/mol).

Compared with baseline, mean total cholesterol levels had reduced at 12 months (4.80 mmol/L vs 4.50 mmol/L, respectively; P=0.001), as had mean LDL-cholesterol levels at both 6 months (3.04 mmol/L vs 2.73 mmol/L, respectively; P<0.05) and at 12 months (3.04 mmol/L vs 2.57 mmol/L, respectively; P=0.001). The improvement in lipid parameters was seen both in the white European and south Asian groups, and the south Asian group also had reduced triglycerides over the 12-month study period (-0.34 mmol/L; P<0.05).

# Conclusion

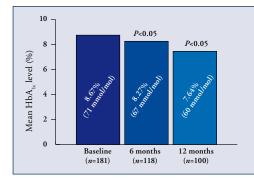
Subsequently, 350 people have been seen as part of the Diabetes Eye Nurse Project, and initial 4-year follow-up data were presented as an abstract at the Diabetes UK Annual Professional Conference in 2010. These data are to be written up for publication later this year.

The Diabetes Eye Nurse Project has helped to identified high-risk individuals with diabetes often with untreated risk factors. Diabetes eye care delivered by a DSEN is a new, innovative service and is one of the many good examples of the excellent multidisciplinary approach to the care of people with diabetes in Leicester.

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# Figure 8. Glycaemic control at baseline, 6 and 12 months for the full cohort.



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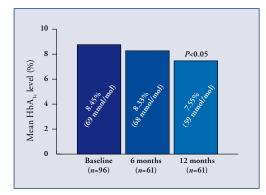


Figure 9. Glycaemic control at baseline, 6 and 12 months for all individuals of white European ethnicity.

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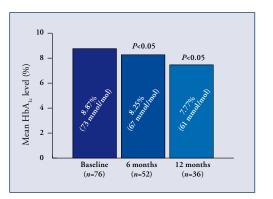


Figure 10. Glycaemic control at baseline, 6 and 12 months for all individuals of south Asian ethnicity.

"Diabetes eye care delivered by a diabetes specialist eye nurse is a new, innovative service and is one of the many good examples of the excellent multidisciplinary approach to the care of people with diabetes in Leicester."