



Preventing avoidable sight loss

Developing an evidence base to build better eye care services



supporting blind and partially sighted people

Contents

Making sight loss prevention a priority 3

Sight loss: a public health priority 5

RNIB's Community Engagement Projects 6

- Establishing an evidence base 7
- Building on existing evidence 8
- How you can help overcome eye health challenges 9
- Pilot studies 12

What next? 15

References 16



Making sight loss prevention a priority

Almost two million people are living with significant sight loss in the UK and this figure is predicted to double to four million by 2050 (1). This dramatic increase will needlessly affect the lives of millions and cost billions of pounds in direct and indirect health care costs. Despite the huge impact of sight loss – both financially and emotionally – over 50 per cent of this sight loss could have been avoided (1).

Stopping people losing their sight unnecessarily is a key priority for RNIB. The development of seamless eye care pathways and an evidence base about what works in relation to sight loss prevention lies at the centre of this priority.

To this end, RNIB has developed five Community Engagement Projects (CEPs) across England, Northern Ireland, Scotland and Wales. Each CEP is piloting a range of evidence-based eye health interventions to understand how effective they are at increasing service uptake and treatment concordance.

At the end of these pilot projects RNIB will have developed evidence to help shape future eye care services that the NHS could adopt to better prevent avoidable sight loss in the UK.

This guide introduces RNIB's work to develop these evidence-based eye health interventions. It provides an overview of:

- RNIB's research into the barriers and enablers that affect access to primary and secondary eye care services
- the key recommendations from an evidence review examining the effectiveness of intervention strategies to address inequalities in eye health care
- the five key areas you can address to improve access to, and design of, local eye care services
- the CEP pilot interventions, which seek to improve eye health for groups at an increased risk of sight loss.

RNIB's wider work to prevent avoidable sight loss

Working in parallel with the CEPs are a series of activities that support RNIB's commitment to stopping people losing their sight unnecessarily.

Certificate of Vision Impairment data

RNIB is supporting a project that will collate and examine Certificate of Vision Impairment (CVI) data in England and Wales. The research is being conducted at Moorfields Eye Hospital for the Royal College of Ophthalmologists. It will identify the number of people certified as severely sight impaired (blind) or sight impaired (partially sighted) each year and the eye condition that caused their sight loss. The results are being compared with social services' registration data to understand what proportion of those certified as blind or partially sighted go on to be registered.

The research will help the sector identify how sight loss is changing in England and Wales. This insight will be invaluable now that an indicator based upon the proportion of CVIs attributed to the three main sight loss conditions – age-related macular degeneration (AMD), glaucoma and diabetic retinopathy – will be included as a formal public health indicator in England from April 2014.

Understanding the CVI patient experience

RNIB is working with patients, NHS Trusts and social services departments throughout England to explore patient experiences of the certification and registration process. This insight will help eye health professionals develop patient-centred care pathways.

Additional activities

Other activities that support RNIB's wider commitment to preventing avoidable sight loss include:

- campaigning for access to timely and appropriate eye health treatment
- supporting the development of a Joint Strategic Needs Assessment (JSNA) template, in conjunction with eye-health sector partners, to help commissioners understand the importance of collating eye health data that will inform the design of appropriate eye care service provision
- delivering continuing professional development (CPD) for GPs
- promoting the role of the eye health check, and eye examinations more broadly, in national eye health campaigns.

For more information about RNIB's work to prevent avoidable sight loss visit rnib.org.uk/healthprofessionals or email professionals@rnib.org.uk

Sight loss: a public health priority

Sight loss in the UK is estimated to double over the next 40 years (1), which will have a significant impact on the UK's health and social care system and damage the quality of life for millions of people.

The economic impact of sight loss

A recent report concluded that the annual cost of sight loss in the UK adult population is £22 billion, including direct and indirect health care costs, the loss of disability-free years and the loss of life due to premature death associated with sight loss (1).

The wider impact of sight loss

People with sight loss are three times more likely to suffer depression (2) and are at an increased risk of falls (3). Late diagnosis of eye conditions causes additional health complications that put extra strain on the UK's health and social care system.

Government commitment to tackling avoidable sight loss

There is increasing commitment from governments across the UK to integrate eye health into public health strategies.

In England, the urgent need to tackle avoidable sight loss has been recognised in the Public Health Outcomes Framework, launched in January 2012 (4). This aspirational framework will encourage local authorities, in partnership with Health and Wellbeing Boards, to demonstrate improvements in eye health outcomes. In Northern Ireland the link between smoking and eye disease has been included in the recently published Tobacco Control Strategy (5).

These strategies – and newly emerging public health strategies across the UK – provide eye health professionals with an opportunity to work collaboratively with public health specialists and commissioners to help ensure eye health is given an increased priority.

RNIB's Community Engagement Projects

RNIB's Community Engagement Projects (CEPs) are piloting interventions to understand what models can help increase uptake of eye care services and treatment. The CEP interventions are being hosted in conjunction with local Primary Care Trusts (PCTs) and Health Boards in five different sites across the UK and have been developed in collaboration with commissioners, frontline health professionals, local communities and service users.

Focusing on at-risk communities

Although sight loss can affect anyone at any time, several groups are at an increased risk of losing their sight unnecessarily. South Asian communities have an increased risk of diabetes and consequently diabetic eye conditions, including diabetic retinopathy, and African and African-Caribbean groups have an increased risk of developing glaucoma (1).

In addition, people living in socio-economic deprivation are less likely to access primary eye care services and are therefore at a greater risk of avoidable sight loss (6). To ensure the pilot interventions make a difference where it is most needed, RNIB's CEPs are focused on these at-risk groups.

RNIB's five CEPs are in:

- Bradford, England
- Cwm Taf, Wales
- Glasgow, Scotland
- Hackney, London
- Belfast, Northern Ireland.

The sites are distributed across the UK to ensure the pilot interventions acknowledge the different political, health and regulatory structures that exist across England, Northern Ireland, Scotland and Wales.

Evaluation

The pilot interventions will run for 18–20 months and will be evaluated by the London School of Hygiene and Tropical Medicine to understand their effectiveness (see page 15).

Establishing an evidence base

RNIB commissioned several pieces of research to inform the development of interventions to be piloted in the CEPs:

- **Equity profiles** – local public health specialists conducted a systematic review of data in the five CEP sites to explore the population characteristics, service provision, patterns of use and outcomes among the target populations.
- **Evidence review** – De Montfort University conducted a review examining evidence of the effectiveness of intervention strategies to address inequalities in eye health care, relating particularly to AMD, cataracts, diabetic retinopathy and glaucoma (7) (see page 8 for the key findings).
- **Qualitative research** – conducted with commissioners, frontline eye health professionals, local communities and service users in the five CEP sites to explore awareness, experiences and views on accessing primary and secondary eye care services (8) (see page 9 for the key findings).

The key research findings from the evidence review and qualitative research are summarised on pages 8–11 of this guide. For the full research findings visit rnib.org.uk/healthprofessionals



Building on existing evidence

To ensure the pilot interventions built on the knowledge base established by previous research, RNIB commissioned De Montfort University to undertake a review of the evidence relating to the causes of inequalities in eye health and previous interventions that sought to reduce inequalities, with particular reference to ethnicity, age and socio-economic deprivation (7). The focus was on preventive activity for glaucoma, diabetic retinopathy, AMD and cataract, and interventions designed to improve eye health outcomes.

The review, which looked at all work that might be applicable to the UK practice setting, identified that the majority of studies into inequality in eye health have concentrated on the needs of those found to have sight loss, and the maintenance of their quality of life, or on treatments, rather than on the potential to prevent sight loss through earlier detection. Whilst reports consistently argue for targeted interventions and specific approaches, the research often has differing levels of evaluation and very little research has reported longer-term clinical outcomes.

Despite the limited number of relevant studies to draw upon, the review did identify four key recommendations that could help reduce eye health inequalities:

1. Awareness raising campaigns are most effective in media that is specific to the target at-risk group.
2. “Eye Health Champions” (community-based eye health advocates) can help disseminate eye health messages at a grassroots level.
3. Professional development and training can help service-delivery staff support at-risk groups with access to and concordance with programmes promoting eye health. This may include training to help staff communicate with patients in a sensitive and appropriate way.
4. Structural changes in service delivery, including data recording and monitoring, and tracking patients along care pathways, can help commissioners understand and ultimately address service uptake among at-risk groups.

These recommendations have helped shape the interventions that are being piloted by the five CEPs (see page 12).

To access the full evidence review visit [rnib.org.uk/healthprofessionals](https://www.rnib.org.uk/healthprofessionals)

How you can help overcome eye health challenges

Once sites had been identified for the CEPs, RNIB commissioned an independent research organisation (Shared Intelligence) to conduct qualitative research with commissioners, frontline eye health professionals and service users in each area (8).

This research identified key enablers and barriers that affect access to and uptake of primary and secondary eye care services, from which RNIB developed the following five recommendations. By working with your colleagues at a local level to implement them, you can ensure more customers and service users successfully engage with eye health services and comply with treatment.

1. Explain that eye examination attendance should not be symptom-led

The research found the majority of optometry service users only attend eye examinations in response to deteriorating sight. Symptom-led demand means that eye conditions are not always detected in the early stages, so patients do not access timely treatment.

By explaining to customers that an eye examination is not just about glasses, but is also an important measure in assessing both general health and eye health, and detecting early onset eye disease, you could help change the current culture of symptom-led attendance for eye examinations. This will increase the number of people who attend a routine eye examination and ultimately ensure that more eye conditions are detected in the early stages, where treatment will be most effective.

2. Educate customers about eye “health”

Sight is the sense people fear losing the most (9), yet very few people have an understanding of eye “health”. As a result, people are not aware of the risk factors that contribute to unnecessary sight loss and at-risk groups do not know they are at an increased threat of sight loss.

Educate your customers about the actions they can take to help protect their eye health:

- **Regular eye examinations** – encourage your patients to have their eyes examined at least once every two years, even if there is no change in their vision.
- **Stop smoking** – smoking doubles the risk of developing AMD, the UK’s leading cause of sight loss (10).

- **Healthy diet and weight** – eating a diet low in saturated fats, but rich in green leafy vegetables such as spinach and broccoli may help protect against cataracts and AMD. A balanced diet can also help customers maintain a healthy weight: obesity can increase the risk of developing diabetes, which in turn could lead to sight loss (11).
- **Protection from UV radiation** – wearing sunglasses can protect the eyes from the UVA and UVB rays in sunlight, which can increase the risk of cataracts (12).
- **Protective goggles** – DIY and sport (especially racquet-based sports) cause thousands of eye related injuries each year.

For more information about the key eye health messages, or to order eye health leaflets for your patients, visit [rnib.org.uk/eyehealth](https://www.nib.org.uk/eyehealth)

3. Soften the retail perspective of optometry

The retail setting of many optometry practices can lead people to think eye examinations are part of a commercial process and that optometric practices are driven by sales. The eye health sector needs to address this challenge to increase people's understanding of the importance of the eye health check, which is a vital part of the eye examination. Improving the perception of the eye health check, and optometry in general, may help increase uptake of eye examinations.

Additionally, an individual's previous experience of eye examinations is a key factor in determining their future engagement with optometry. By providing a positive eye examination experience, including a clear explanation of the role of each test, you can help encourage customers to regularly attend an eye examination.

4. Facilitate seamless eye care pathways

Many patients find the eye care system to be fragmented and confusing. This perception can exacerbate an already anxious experience and create a barrier to subsequent engagement with secondary care.

Explain the referral and treatment process

Patients commonly reported that the referral process had never been clearly explained to them. This means that they did not always understand the role of the different clinicians, why it was important to attend different examinations or why appointments were held across different clinics and hospitals.

By explaining the referral process, appointment system and the role of different health professionals and tests, you can help patients understand the benefits of ongoing attendance and concordance with treatment.

Implement a positive non-attendance policy

Many patients find the way non-attendance is managed, including the threat of being discharged, to be demotivating. This can lead to patients disengaging with treatment altogether.

Patients are more likely to successfully manage their treatment and continue attending their appointments if non-attendance for an appointment is managed more positively.

5. Working towards improved data collection

Early detection of sight-threatening conditions and access to appropriate and timely treatment relies on the implementation of seamless care pathways that have been designed to address the specific needs of the local population.

To design a truly needs-based pathway, eye health professionals in primary and secondary care need to effectively monitor the uptake of eye care services, especially among black minority ethnic and deprived communities that are at an increased risk of sight loss.

Important patient outcomes to record across primary and secondary care include:

- referral
- diagnosis
- treatment
- patient discharged
- certification as sight impaired (partially sighted) or severely sight impaired (blind).

Effective recording of such data across primary and secondary care will support commissioners to build up a truly insightful picture of the local population's eye health needs and create services that can ensure no one loses their sight unnecessarily.

More information

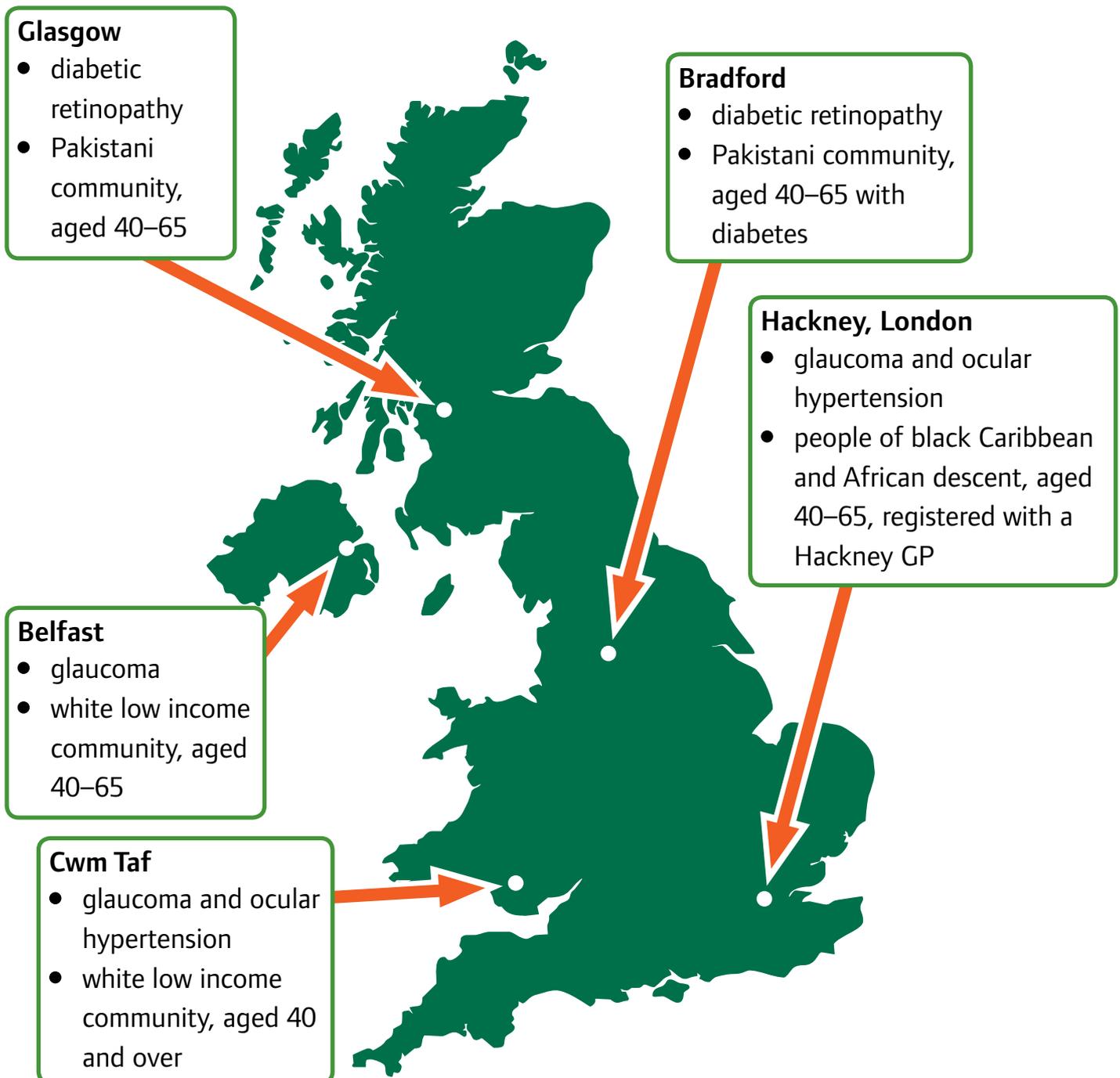
Visit [rnib.org.uk/healthprofessionals](https://www.rnib.org.uk/healthprofessionals) for more information about the research, including the barriers to accessing primary and secondary eye health services. For advice and support in influencing local commissioners and Health and Wellbeing Boards to prioritise eye health please email professionals@rnib.org.uk

Pilot studies

RNIB established Local Advisory Groups (which included commissioners, service providers, service users and community members) to design interventions that could effectively address the barriers that the groups face in the five CEP sites.

Each intervention will be piloted for 18–20 months between 2012 and 2014.

The five CEPs will target the following eye conditions and communities:



Cwm Taf, Wales

Target population: white, low income, aged 40 and over, resident in the Rhondda Valley

Target eye conditions: glaucoma and ocular hypertension

Objectives:

1. Reduce waiting times for the management of patients with stable glaucoma and ocular hypertension.
2. Improve patient satisfaction.
3. Improve service uptake and reduce non-attendance at secondary care clinics.

Pilot intervention:

1. Establishing a nurse-led Ophthalmic Diagnostic and Treatment Centre in the community hospital, to manage patients with stable glaucoma and ocular hypertension.

Belfast, Northern Ireland

Target population: white, low income, aged 40 to 65, resident in the Falls, Clonard, Whiterock and Upper Springfield areas

Target eye condition: glaucoma

Objectives:

1. Increase uptake of eye examinations.
2. Increase knowledge and understanding of eye health and entitlements to care.
3. Improve compliance with glaucoma treatment.

Pilot intervention:

1. Community health campaign about the importance of eye examinations.
2. Community support for people with glaucoma and their families.

Hackney, London

Target population: people of black Caribbean and African descent, aged 40 to 65, registered with a Hackney GP

Target eye conditions: glaucoma and ocular hypertension

Objective:

1. Test the efficacy of a glaucoma case-finding programme in the target population.

Pilot intervention:

1. Targeted case finding inviting people, via their GP, to attend glaucoma screening at a local GP practice.

Glasgow, Scotland

Target population: Pakistani, aged 40 to 65, resident in the Govanhill, East and West Pollokshields areas

Target eye condition: diabetic retinopathy

Objectives:

1. Increase the uptake of eye examinations.
2. Increase the uptake of diabetic retinopathy screening.
3. Increase understanding of the need for eye examinations.
4. Increase understanding of eye health and its relationship to diabetes.

Pilot intervention:

1. Community engagement and awareness raising via eye health champions.
2. Health professionals to deliver consistent eye health messages to the local community about the importance of regular eye examinations and diabetic retinopathy screening.

Bradford, England

Target population: Pakistani, aged 40 to 65 with diabetes, resident in Bradford and Keighley

Target eye condition: diabetic retinopathy

Objectives:

1. Increase uptake of diabetic retinopathy screening.
2. Increase attendance at secondary care (diabetic retinopathy clinic).
3. Increase uptake of eye examinations.
4. Increase understanding of eye health and its relationship to diabetes.

Pilot intervention:

1. Reminder invites, sent via text message, for diabetic retinopathy screenings.
2. Targeted telephone reminders conducted by a bilingual worker for diabetic retinopathy secondary care appointments.
3. Health professionals providing key messages to people with diabetes, supported by a community education campaign.
4. Implementation of a self-care tool for people with diabetes.

What next?

Now that the interventions in the five CEP sites have been designed they will be piloted for 18–20 months between 2012 and 2014.

Evaluation

RNIB has appointed the London School of Hygiene and Tropical Medicine to evaluate the effectiveness of the interventions across the five CEP sites. This will include:

1. **Outcome evaluation** – to examine the impact of the interventions in changing people's knowledge and behaviour with regard to accessing eye care services.
2. **Process evaluation** – to examine if the interventions reached the target population as planned, if they are acceptable and whether they were implemented as planned.
3. **Economic evaluation** – to examine the cost-consequence of the interventions implemented at each site.

For the latest information about RNIB's research and CEPs visit rnib.org.uk/healthprofessionals or email professionals@rnib.org.uk



References

- (1) Access Economics, 2009. **Future sight loss UK: The economic impact of partial sight and blindness in the UK adult population**. UK: RNIB.
- (2) Evans, Fletcher and Wormald, 2007. Depression and anxiety in visually impaired older people. **Ophthalmology**, February 2007, 283–288.
- (3) Campbell, Sanderson and Robertson, 2010. Poor vision and falls. **British Medical Journal**, 340, 1313–1314.
- (4) Department of Health, 2012. **A public health outcomes framework for England 2013-2016**. London: Department of Health.
- (5) Department of Health, Social Services and Public Safety Northern Ireland, 2012. **Ten year tobacco control strategy for Northern Ireland**. Belfast: DHSSPSNI.
- (6) Dickey et al, 2012. **Utilisation of eye-care services: An examination of the effect of Scotland's free eye examination policy**. Scotland: University of Aberdeen.
- (7) Johnson et al, 2011. **A review of evidence to evaluate effectiveness of intervention strategies to address inequalities in eye health care**. UK: RNIB (RNIB/CEP/01, 2011).
- (8) Hayden, 2012. **RNIB Community Engagement Project Insight Research – National report**. UK: RNIB (RNIB/CEP/IR/National/01, 2012).
- (9) nfpSynergy, 2011. **Charity Awareness Monitor, March 2011**. UK: nfpSynergy.
- (10) Evans, Fletcher and Wormald, 2005. 28,000 cases of AMD causing visual loss in people aged 75 years and above in the United Kingdom may be attributable to smoking. **British Journal of Ophthalmology**, 89, 550–553.
- (11) RNIB, 2006. **Feeling great, looking good**. UK: RNIB.
- (12) West et al, 1998. Sunlight exposure and risk of lens opacities in a population based study. **JAMA**, 280 (8), 714–718.

RNIB offers practical support, advice and information to all those with sight loss and those who work with them. For more information about RNIB's prevention programme email professionals@rnib.org.uk