



# The cost of sight loss Scotland: 2010–2020

**RNIB**  
Scotland

supporting blind and  
partially sighted people



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# Foreword

In 2008, RNIB Scotland, Optometry Scotland and Eyecare Scotland (representing professional ophthalmologists, orthoptists and optometrists working in acute care) launched the “Scottish Vision Strategy” document with wide-ranging support from across the statutory and voluntary sector. The strategy signalled a step change aimed at making a real and lasting difference to the eyecare of the people of Scotland and to improving the lives of those who have lost some or all of their sight. This document makes the case for strategic investment in eyecare across Scotland over the next decade to secure that level of change.

In a context of unprecedented public spending pressures, a 62 per cent rise in Scotland’s elderly population by 2031 and poor public awareness of the impact that lifestyle choices have on sight, Scotland is facing a considerable challenge.

It is therefore critical that our resources are used to best effect. Scotland has had notable success in developing eyecare services over the last decade and it is now uniquely placed to maximise the potential opportunities that exist. Through a clear focus on prevention, integration and support services, alongside innovation and quality, the strategic investment of resources can meet these challenges.

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# Executive summary

Recent attention and resources have focused on H1N1 influenza (swine flu). Imagine we currently had no eye disease at all in Scotland but an infection threatened to spread that experts predicted would lead to sight loss in 3,000 people a year, leaving 40,000 people blind or partially sighted and a further 140,000 with significant sight loss. Tackling this would receive the highest of priorities, yet because the problem of sight loss has been with us since the birth of the NHS, it can be overlooked.

This report makes the case that:

- sight loss is set to double by 2031
- when sight loss occurs it has a major impact on people's lives
- this impact is underestimated by the public and by clinicians
- the cost of sight loss to society is equivalent to each patient requiring ten hospital admissions a year.

Scotland has made good progress in developing services recently, and Scottish Government Health Directorates (SGHD) and the NHS deserve credit. However, we now need to ensure that good practice is universally available so that we can support patients, integrate services and embrace effective prevention strategies. National targets are needed so we can demonstrate this is happening alongside a strategic investment plan for the next decade.

## Sight loss is set to double

In 2009, 35,588 Scots were registered as blind or partially sighted with their local authority, with 2,934 new registrations a year. Research suggests that around 10 per cent of eligible people do not register, suggesting the true figure is around 40,000. A further 148,000 people in Scotland are estimated to have significant sight loss (Scottish Executive 2006, Access Economics 2009). By 2031, with no intervention beyond the current provision, this is expected to double to almost 400,000 due to increases in the elderly population and a variety of health factors.

## **Sight loss has a severe impact on patients' lives**

The consequences of sight loss are serious. Data used by the National Institute for Health and Clinical Excellence (NICE) in 2006 to evaluate treatments for age-related macular degeneration (AMD) showed that, compared to full health, which was rated at 100 per cent, mild disease equated to 83 per cent, moderate disease to 73 per cent and severe disease to 57 per cent of full health. This emphasises the very serious impact of sight loss on a person's quality of life.

## **The impact of sight loss is underestimated**

The NICE data showed that the public and even clinicians involved in caring for eye disease underestimate the impact it has on patients' quality of life. When asked to read a description of what it was like to have the different severities of AMD, the public rated them at 96 per cent, 92 per cent and 86 per cent for mild, moderate and severe respectively. Clinicians' ratings were 93 per cent, 88 per cent and 82 per cent.

## **Sight loss is expensive, costing as many as ten admissions per patient each year**

These diseases cost the NHS and the public sector in Scotland a minimum estimated cost of £194 million a year, plus £434 million more in terms of broader costs to the economy and to society. It should be noted that this figure does not include the recent additional cost of new wet AMD treatments. Given there are 35,588 people registered with blindness and partial sight, this means that the cost per person affected is, at minimum, £17,646 a year. Of this, £5,451 are costs to the public sector. With a general medical admission costing £1,790 in Scotland in 2008/09, the cost is roughly equivalent to ten hospital admissions per year.

## **Good progress has been made**

Scotland has had notable success in developing eyecare services over the last decade and received international acclaim for innovations in optometry, ophthalmology and community eyecare practice – in particular for its integrated service delivery.

The "Review of community eyecare services" (Scottish Executive) was published in December 2006 and included a number of detailed recommendations, with the emphasis on the delivery of integrated services, provided locally.

In December 2007, the Scottish Government committed to the implementation of the Community Eyecare Review through the investment of £2.6 million “pump prime” funding to be allocated to pilot projects across Scotland. In addition to this, it provided significant investment in optometry services, to ensure access to free eye tests for all.

**“Through the pilot projects, NHS boards and their partners have evidenced their commitment to improving services and outcomes for visually impaired people and identified significant progress across an array of services and issues.”**

(RNIB Scotland 2010)

The Scottish Eyecare Group is a national alliance between Eyecare Scotland, covering hospital-based services, Optometry Scotland and RNIB Scotland. In support of the Scottish Vision Strategy, the Scottish Eyecare Group has made notable progress in promoting and supporting integrated services, improving service delivery and developing joint care pathways.

A commitment to further strengthen the development, authority and influence of Managed Clinical Networks (MCNs) was given in “Better health, better care action plan” (Scottish Government 2007). There are at present two MCNs relating to eye health: the National Uveitis MCN and an eyecare MCN covering Edinburgh and the Lothians.

In 2005, the Government funded a pilot project in Fife to evaluate the feasibility, safety, clinical effectiveness and cost of the electronic referral of patients directly from optometrists to the hospital eye service (HES). In summary, the pilot highlighted that electronic optometrist referrals with images are “safe, speedy, efficient and clinically accurate” (Cameron et al 2009). It noted that DNA rates dramatically improved, avoiding unnecessary HES consultations. An outline business case is currently underway with a view to rolling out the electronic transfer of digital images over the next three years. This roll out would radically advance the integration agenda, improve patient service and positively impact on waiting times and resource pressure.

## **More is needed**

In Scotland during 2008/09, over 1.6 million people took the opportunity to have a free eye examination. Over the same period, Scotland’s eye clinics dealt with over 400,000 appointments with an almost 15 per cent increase in the number of new patients (NHS Scotland 2009).

On average 16–17 per cent of all outpatient appointments at Scotland’s hospitals are for eyecare. This report identifies some of the major pressures facing eyecare in Scotland. It argues for the need to continue integration and improvement of service provision, to implement effective prevention measures and to provide additional support to those with significant sight loss specifically at the point of diagnosis. In particular it makes the case for strategic investment in eyecare services over the next decade.

## Integration

The integration of eyecare services was initiated through the Government’s “Review of community eyecare services in Scotland” (Scottish Executive 2006). Stemming directly from the review, pilot projects were established across Scotland to drive forward the integration agenda. The “Pilot project evaluation report” (RNIB Scotland 2010) identified the substantial progress that has been made through integrating service planning, care pathways, training opportunities and referral procedures.

Major opportunities now exist to build on this success through implementing a national electronic referral system and further developing care pathways and managed clinical and care networks (MCNs). These areas, alongside others mentioned below, are detailed later in the report.

The Scottish Government’s Health Department (SGHD) should also consider the establishment of a standing committee, with the aim of driving forward the integration of services, promoting best practice and designing and monitoring the implementation of a national prevention strategy for eyecare.

## Prevention

The World Health Assembly 2003 has estimated that 50 per cent of sight loss could be avoided through effective prevention measures including public awareness campaigns, screening, treatment pathways, and stop smoking initiatives among others. A number of countries, notably Australia, have already invested heavily in systematic prevention strategies with considerable success. Hurley and Matthews (2008) identified that for every 1,000 smokers who quit, there would be 48 fewer cases of age-related macular degeneration and 12 fewer cases of blindness. This would be equitable to a gain of 1,600 quality adjusted life years (QALYS) or a saving of \$1.1 million Australian dollars to the health services for eyecare alone. This reinforces the strong link between preventative strategies and efficiency savings.

This report argues that prevention should become a cornerstone of Scotland's investment strategy, that it is an essential component in ensuring the best use of limited resources and in addressing what has been described as the "demographic tsunami" facing Scotland.

## Support

People who lose their sight are much more likely to develop mental health problems, notably depression and anxiety. People can very quickly lose their confidence and become isolated. RNIB (2009) has found that over 80 per cent of patients are offered no support at all, and even the fortunate 20 per cent rarely access support at the point of diagnosis, when their need is greatest. While there are examples of excellent vision support services in several areas, a network approach covering all Scottish NHS boards and available to all new patients is urgently required.

Given the strong correlation, consideration should be given to screening existing patients for mental health problems. This could be done initially as a pilot study.

Optometry Scotland and RNIB Scotland have developed a unique proposal for a national community support referral system for people with sight loss. Such a service would ensure that those in most need of support would be quickly and easily referred to existing community support services across Scotland, improving both the access and uptake of services.

SGHD and health boards should consider estimates for 2011 which specify the proportion of people who are diagnosed with sight loss and offered support. Research conducted by RNIB in Northern Ireland has indicated that around 12 per cent of all new patients at eye clinics require some level of emotional support and practical advice (RNIB Northern Ireland 2008). We propose a target of 8 per cent of new patients by 2012, rising to 12 per cent of new patients by 2014.

## National priorities... but where are the targets?

Supporting patients, tackling mental illness, integration of services and the promotion of good health are all priorities in "Better health, better care action plan" (Scottish Government 2007), so acting on sight loss is wholly consistent with SGHD's strategy. However, there are gaps in the targets used by the Scottish Government and NHS with respect to eye health:

- “Scotland performs” (Scottish Government 2009a) includes 45 national indicators but none relates directly to the issue of sight loss.
- The SGHD’s 29 HEAT (Health, Efficiency, Access, Treatment) targets for the NHS (Scottish Government 2010a) also make no mention of people with sight loss.

Some targets are undoubtedly helpful, for example, stop smoking campaigns can help to reduce the incidence of age-related macular degeneration. However, sight loss services need their own targets, with the national commitment implied by HEAT and at health board level for progress to continue.

# 1. Introduction

In 2009, RNIB received the results from an independently commissioned research report, which looked at the cost implications of sight loss throughout the UK, focusing in particular on the costs to public services (Access Economics 2009).

This report builds on these findings, highlights the serious impact that sight loss can have on patients' lives and makes the case for strategic investment in prevention and eyecare. With improved investment it is argued that significant improvements could be made in the prevention of avoidable sight loss and, following the Australian example (Hurley and Matthews 2008), enable long-term savings. Part of this approach will be the targeting of improved care for those most at risk, including low socio-economic groups, those at risk of falls, mental health and stroke, black and minority ethnic groups and those with a learning disability.

In line with key Scottish Government policy strands, this report sets out the need to provide a quality eyecare service, which is both innovative and cost-effective and reflects partnership working. Supplementary information on the context within which partial sight and blindness falls in Scotland is set out, including the most up-to-date registration figures and some of the impacts that sight loss can have.

## Indicative costs

Eyecare expenditure is set to grow substantially over the next decade. The primary research findings calculated that the direct annual costs to public services in Scotland are in the region of £194 million a year, with indirect annual costs amounting to around £434 million a year (this figure does not however include the recent additional and substantial costs of new wet AMD treatments which have steadily grown over the last two years). The final report predicts that by 2013, the total cost will rise by around £120 million a year – primarily due to increases in the elderly population.

Interventions to lower the cost of sight loss need to show that they are not only effective for the individual, but also cost-effective for public service budgets. The primary research findings report that the most cost-effective interventions are in the areas of prevention, detection and treatment. The cost-effectiveness of interventions on the basis of quality adjusted life years (QALY) gained and disability adjusted life years (DALY) avoided – an approach recommended by the National Institute for Health and Clinical excellence (NICE) are also calculated (full details of the calculations can be found in the Access Economics report on behalf of RNIB 2009).

The conclusions drawn from the primary research indicate that an intervention rate of £1,230 per DALY avoided will result in both short-term and medium-term overall term savings for health and social care budgets.

The expected increase in the number of people with sight loss will mean an increase in demand for services to prevent and treat eye disease and to better support those with sight loss to live independently.

This document argues for additional strategic investment in the following key areas:

1. Integration of services
2. Prevention
3. Support for patients who lose their sight

## 2. Scottish policy context

### Better health, better care

The Scottish Government set out five strategic objectives to support the creation of a more successful country with opportunities for all of Scotland to flourish as follows:

1. Wealthier and fairer
2. Smarter
3. Healthier
4. Safer and stronger
5. Greener

NHS Scotland, both alone and with its partners, has a significant contribution to make to each of these objectives. “Better health, better care action plan” (NHS Scotland 2007) is a significant step towards a healthier Scotland. Its three main components are: health improvement; tackling health inequalities; and improving the quality of care. Its action plan sets out a programme of comprehensive and targeted action to accelerate progress in each of these components.

The key objectives outlined in “Better health, better care action plan” are directly related to key issues around sight loss:

1. Mental health and well-being
2. Smoking
3. Diet, physical activity and healthy weight

### 1. Mental health and well-being

While Scotland is recognised internationally for some of its work in mental health legislation and services, there is more to do to enhance, support and improve people’s mental well-being so they are able to flourish and have the confidence and capability to make healthy choices in their lives.

Evidence has shown that there are strong links between partial sight and blindness and mental health and well-being (Thurston 2009). Without help to come to terms with their sight loss and support to develop positive practical coping strategies, individuals, particularly the elderly, but also younger people and those of working age can rapidly lose their confidence, leading to both social isolation and a greater potential to develop mental health difficulties (Burmedi et al 2002). This is often manifested through feelings of depression, anger and confusion. Only 19 per cent of patients are offered information and support, and this is rarely at the point of diagnosis (RNIB 2009) when intervention is most required.

Eye clinics across Scotland provide excellent services. They are however constrained by serious resource limitations and a continuous increase in demand. The absence of vision support services for patients can compromise the efforts of clinical staff and impact upon the effectiveness of the care provided. Most significantly, the lack of comprehensive information and basic practical and emotional support at the point of diagnosis can impede patients' long-term well-being. This will ultimately lead to avoidable and costly rehabilitation support.

Vision support services provide practical and emotional support at the optimum point for effective intervention. In Scotland a few major hospitals offer such a service, including Gartnavel Hospital in Glasgow and the Princess Alexandra Eye Pavilion in Edinburgh. The development of similar services in Borders, Shetland, Dundee, Highlands, Ayr and Grampian are currently under discussion. The value of support at the point of diagnosis has been well documented and a business case (RNIB Scotland 2008a) for establishing a national network has been made. It is recommended that a national network covering each of the major eye clinics in Scotland is put in place by 2014.

### Patient perspective

**“ They have a quick look and they try to do their best for you, but your emotional needs are not being catered for, in my experience, and I found that quite hard. It was like. ‘You’re going to have to get on with it because there’s nothing we can do for you’.”**

## 2. Smoking

The Scottish Government's stop smoking plan, put in place in 2008, supported by an additional £3 million a year, highlights the Government's commitment to reduce smoking.

In 2006, RNIB Scotland ran an award-winning public awareness campaign, which highlighted the evidence of the link between smoking and eye conditions. The campaign emphasised that the strongest link was between smoking and age-related macular degeneration (AMD) (Access Economics 2006). Most cases of AMD remain irreversible and largely medically untreatable despite the emergence of new technologies. AMD is by far the largest and most prevalent condition with the indigenous white population.

Further research commissioned by RNIB Scotland (Ayres et al 2007) was carried out to look at the causal links between environmental tobacco smoke (ETS) and sight loss. It was identified that there was a need to explore the wealth of analogous and suggestive evidence from this research to ensure that ETS is considered as a factor for causation and worsening of eye disease. This is particularly the case for AMD, cataracts, uveitis and kerato-conjunctivitis.

#### **Patient perspective**

**“I was diagnosed with AMD and told about the links between smoking and sight loss. I had smoked for most of my adult life and if I had been told that I could lose my sight because of smoking, I am sure I would have given up. I stopped the day I found out.”**

### **3. Diet, physical activity and healthy weight**

Obesity is one of the greatest challenges faced by the Scottish Government today (Scottish Government 2010b). Rising levels of obesity bring with them increasing risks of a range of chronic diseases, particularly type 2 diabetes, stroke, coronary heart disease and cancer.

Research has shown that there are strong links between a person’s general diet and physical activity and, in particular, the development of diabetes (Diabetes Prevention Programme Research Group 2009). In March 2010, diabetes was found to affect just over 228,000 Scots – roughly 4.5 per cent of the population. Diabetic retinopathy is one of the most serious and costly complications of diabetes and the leading cause of blindness among the working age population in the UK. People with diabetes can prevent the onset and progression of diabetic retinopathy (and the need for surgery) by controlling their levels of blood sugar, blood pressure and blood cholesterol.

Early diagnosis and treatment can prevent up to 98 per cent of severe sight loss (Access Economics 2004) and the earlier the treatment is received, the more likely it is to be effective. It is estimated that a diabetic person has a 10–20 times greater chance of being registered as blind than a non-diabetic person.

### **Patient perspective**

**“I wouldn’t be blind if I had gone for regular eye checks, but I was young and thought only old people with diabetes could go blind. Losing my sight was very, very traumatic. It changes your whole life.”**

# 3. Scottish health context

Within the broad objectives set out in “Better health, better care action plan” (Scottish Government 2007), the Scottish Government has agreed 15 National Outcomes which it would like to achieve. Of these, three can be directly related to the economic impact of sight loss in Scotland in the following ways:

## 1. We live longer, healthier lives

The challenges facing the Scottish Government include: an ageing population; existing health inequalities; a shift towards long-term health conditions; and a growing incidence of multiple conditions and complex needs.

There is a growing evidence base highlighting the links between sight loss and falls among the elderly population. There is also a strong link between falls resulting in injury and the provision of community care services and/or admittance to residential nursing care. All of these can incur substantial capital, service and administration costs.

## 2. We realise our full economic potential and increase employment opportunities

The challenges facing the Scottish Government include: the removal of barriers into work; commitment to innovation; and building competitive advantage.

Productivity losses have been well documented within the literature as a consequence of sight loss. A study by Lafuma et al (2006) estimated the loss of income for people with sight loss in the UK at around £3.4 billion in 2004. They concluded that sight loss has a significant impact on productivity, equating to around 22.5 per cent of the total non-medical costs associated with sight loss in the UK.

#### **Patient perspective**

**“I can quite understand an employer’s reluctance to take on a person with sight loss because of their preconceived ideas about what that might entail. That reluctance can be quite easily overcome if you focus on the skills, knowledge and experience that many blind and partially sighted people have. Also, many of the obstacles I face at work are the same as a sighted person would face. If they have to travel for their work for example, they have to plan out where they are going, how they will get there and whether or not they can share a car with a colleague. This is no different to the planning I have to do.”**

RNIB has estimated the cost of productivity loss due to sight loss (Meager and Carta 2008). Using figures from 12 quarters over the period July 2004 to June 2007 from the “Labour force survey”, the study noted that around 184,000 people of working age in the UK reported they were disabled due to “difficulty seeing”. Comparing employment rates of those “not disabled” to the employment rates of those with “difficulty seeing”, the study estimated that there were approximately 95,000 fewer people in employment due to sight loss over this period. Multiplying this “employment gap” by average annual earnings for the 12 quarters over the period July 2004 to June 2007, this equated to a loss in productivity of around £2.367 billion (Lafuma et al 2006).

Productivity loss due to sight loss will depend on the age of the person when sight loss first occurs. Generally the younger the person, the greater the impact sight loss will have on productivity. Those with sight loss have a lower participation rate in paid work (Ethical Strategies 2003, RNIB 2004, Lafuma et al 2006). This is the traditional measure of a loss in productivity from sight loss.

#### **Patient perspective**

**“I did find that at work they were really good, getting the screen and the software – they got it in the office where I work most of the time, and also have it in another building where I sometimes work.”**

### 3. We tackle inequalities in Scottish society

The challenges facing the Scottish Government include: providing accurate data and information about inequalities; identifying where most significant impact can be made; understanding the changing needs of a diverse society; and a responsiveness to policies.

Current service provision within Scotland has indicated that those with a learning disability, stroke or dementia, those from minority ethnic groups and those from low income groups are consistently overlooked in terms of eyecare health. In many cases, this is a result of “hidden sight loss” where patients are not assessed or diagnosed with sight conditions and in addition, services are failing to engage with these groups.

Research has highlighted higher prevalence rates for particular eye conditions among certain minority ethnic groups (RNIB 2006). This area is explored in more detail under section 6, “Hidden sight loss”.

#### Ophthalmologist’s perspective

**“ Accessing eyecare services is very important, as several sight-threatening diseases are highly prevalent among certain ethnic minorities. Diabetic retinopathy, for instance, is more common in individuals of Pakistani, Indian or Bangladeshi descent who make up a sizable minority in Glasgow. Such conditions are potentially blinding and may often affect young to middle-aged people in their working years.”**

## 4. Success so far

Scotland has had notable success in developing eyecare services over the last decade and received international acclaim for developments in optometry, ophthalmology, the provision of support services and in particular for the strength and quality of integrated working.

### Review of community eyecare services (Scotland)

The “Review of community eyecare services” was commissioned in March 2004 to consider the full range of community services available to blind and partially sighted people in Scotland and to make recommendations for modernising the system to ensure that it meets individual needs. The final report was published in December 2006 and included detailed recommendations with the emphasis on the delivery of integrated services provided locally.

While eyecare services had been subject to previous reviews, notably “Sensing progress” (Social Work Services 1998), recommendations from many of these reviews remain outstanding. In December 2007, the Scottish Government committed to the implementation of the “Review of community eyecare services” through the investment of £2.6 million “pump prime” funding to be allocated through health boards and their partners to establish pilot projects across Scotland. In addition, it made a multimillion pound investment in optometry services to ensure access to free eye tests for all and to markedly improve the quality of optometry services through funding new equipment and training.

All these initiatives have supported the implementation of the principles within the Review. NHS boards established pilot projects from January 2008. An “Evaluation framework” (RNIB Scotland 2008b) was developed and implemented over a two-year period and a final report produced in May 2010.

The “Pilot projects evaluation report” (RNIB Scotland 2010) highlighted that NHS boards and their partners “evidenced commitment and enthusiasm to improving services and outcomes for blind and partially sighted people”. The principles within the review were fully embraced with significant modernisation of services being

undertaken, improving the quality and consistency of care being delivered across Scotland.

**Key achievements included:**

1. Systematic development of integrated eyecare networks throughout Scotland with partnership structures and leadership well established.
2. Improved referral pathway and access to local services.
3. Reduced waiting lists for low vision aids through sharing of budgets and improved coordination.
4. Involvement of multidisciplinary professionals and service users in the planning and development of services.
5. Audit and benchmarking activity in place to support continuous improvement.

The report evidenced the positive impact of a structured and supported approach to the implementation of the “Review of community eyecare services”. Ongoing demonstrable outcomes included improved care and treatment pathways, reduced waiting times and improved information supporting decision making.

**A number of areas were identified however where further work is required.**

**These include:**

- Promotion of effective low vision schemes
- Emotional and practical support at the point of diagnosis
- Workforce planning
- Sharing of best practice models in transition services
- Service development within ethnic minority communities
- Further improvement in referral pathways.

The principles within the review have now been embedded within the Scottish Vision Strategy (RNIB Scotland, Eyecare Scotland and Optometry Scotland 2008) and partnership arrangements are in place offering local leadership and governance.

## The Scottish Eyecare Group

The Scottish Eyecare Group is a national alliance between Eyecare Scotland, Optometry Scotland and RNIB Scotland. In support of the Scottish Vision Strategy, the Scottish Eyecare Group aims to improve eyecare services through:

- The implementation of referral care/pathways
- Improved use of information technology
- The implementation of the local MCN plan
- The implementation of a robust programme of patient involvement
- Improved performance assessment and reporting arrangements
- Involvement in communication of stakeholders and the development of shared action plans.

A model of service delivery has been developed in recognition of national policy, to improve the quality of services and to develop local care, where possible. The model has a number of “building blocks” (Scottish Eyecare Group 2009) from prevention and early detection through to aspects of care, monitoring and treatment. It identifies the need for leadership, planning and management of services and proposes integration with national quality assurance arrangements.

Through this model the Scottish Eyecare Group is leading the development of integrated working, improving patient’s referral/pathways and contributing towards:

- Helping to achieve waiting time targets
- Improving the balance of care
- Improving quality of services
- Effective use of resources
- Involving people in the future development of services.

### **Implementing local managed clinical networks**

A commitment to further strengthen the development, authority and influence of Managed Clinical Networks (MCNs) was given in “Better health, better care action plan” (Scottish Government 2007), with guidance issued to NHS boards and local authorities in HDL (Scottish Executive 2007a).

NHS Quality Improvement Scotland (QIS) requires each NHS board to accredit a local MCN within a quality assurance programme which sets a series of requirements including:

- Implementing the core principles set out in HDL
- Establishing agreed standards of care
- Performance assessment and monitoring arrangements.

Local eyecare MCNs should be multi-agency in nature and include NHS and local authority services, both social work and education where services relate to children. There are at present two MCNs relating to eye health: the National Uveitis MCN and an eyecare MCN covering Edinburgh and the Lothians.

The Scottish Eyecare Group is exploring the development of local eyecare MCNs. It is proposed to establish a pilot within a health board area during 2010/11, building upon existing eyecare networks established through the community eyecare pilot projects.

## Central ophthalmic electronic transfer

The Scottish Government has committed to the ongoing modernisation of NHS services through the implementation of innovative information technology. In 2005, through electronic clinical communication implementation (ECCI), a pilot project was initiated in Fife to evaluate the feasibility, safety, clinical effectiveness and cost of the electronic referral of patients directly from optometrists to the Hospital Eye Service (HES) with concomitant information of referral to GPs. In summary, the pilot highlighted that electronic optometrist referrals with images are:

**“Safe, speedy, efficient and clinically accurate given some limitations and avoids unnecessary HES consultations... a highly significant outcome was that 37 per cent of patients were assessed as not requiring an HES appointment... over and above this, electronic referrals with images would appear to save a further 22 per cent of new HES appointments.”**

(Cameron et al 2009)

It is hoped that as optometrists learn from feedback given by ophthalmology that they will become more specific about their referrals and this will in turn lead to more appropriate referrals. The development of a single electronic referral entry to hospitals has significantly improved eyecare services in Fife through instant referral acknowledgement, reduced paper work, correct appointment allocation and the opportunity for E-diagnosis. Discussions with the Government are at an advanced stage, with a view to rolling out the electronic transfer of digital images over the next three years. This roll out would significantly advance the integration of service delivery and improvement of eyecare services in Scotland.

## 5. Sight loss in Scotland

Registering as blind or partially sighted with local authorities is not compulsory. A number of studies commissioned by RNIB (Tate et al 2005, Bunce et al 2009) agree that a degree of under-registration of blind and partially sighted people exists. There is some uncertainty as to the extent of this under-registration, but it is estimated to be around 10 per cent.

In 2009, the number of people registered as blind or partially sighted was estimated to be 35,588 (Scottish Government 2009b). Given the potential under-registration of partial sight and blindness, the figures outlined could be around 10 per cent higher than this with 39,146 people eligible for registration.

There were 2,934 cases registered during the period 1 April 2008 to 31 March 2009, a decrease of 5.8 per cent from 2008 (Scottish Government 2009b).

This latest set of statistics (year ending March 2009) appears to confirm a problematic trend of decreasing registration levels for blind and partially sighted people. Research conducted by the world renowned Moorfields Eye Hospital (Bunce et al 2009) using mathematical models, predicted that the impact of an ageing population on the prevalence of sight loss in the UK would suggest that the number of people who experience sight loss should increase year on year. At a time of population ageing, a fall in numbers appears implausible. The Scottish Vision Strategy Advisory Group have recognised this issue and put forward a proposal for research into the effectiveness of the current registration process.

The Moorfields' research offers a range of possible factors, including that the increasing pressure on eye clinics has led to certification being overlooked by ophthalmologists. Anecdotal evidence from voluntary sector providers in Scotland indicates that the different practices and procedures between eye clinics and social services departments may have a major role to play.

Of those on the register:

- 56 per cent were blind and 44 per cent were partially sighted
- 38 per cent were male and 62 per cent were female.

- 75 per cent were over the age of 65
- 33 per cent (11,798 people) had additional disabilities. Of these, roughly a quarter were deaf.

There are indications that these figures relate mainly to the white indigenous population and do not take account of “hidden sight loss” factors. While the registration statistics do contain some information on additional disabilities, evidence from current practice and pilot studies suggests that this is substantially under-reported. For example, it is estimated that in Scotland there are over 120,000 people with a learning disability (Scottish Government 2000), of which at least 30 per cent will have significant undetected sight loss (Splunder et al 2004). The majority of these individuals are not registered. Minority ethnic and low-income status is similarly not recorded and therefore cannot be quantified. It appears that both of these groups are under-represented within the registration figures for Scotland.

## General ophthalmic services in Scotland

**“Vision impairment ranks sixth in the global top ten causes of burden of disease in terms of disability adjusted life years... Uncorrected refractive error was designated a priority for intervention because it is easily treatable and yet is a substantial cause of avoidable blindness and vision impairment... It affects a large percentage of the population, is costly for national health services and individuals, and reduces quality of life... Strong evidence suggests that failure to address refractive error in childhood has lifelong consequences, and that the large untreated adult population imposes a serious burden on society... Correction of refractive error results in a measurable improvement to quality of life.”**

(Cochrane et al 2010)

On 1 April 2006, a new NHS eye examination was introduced and entitlement was extended to all in Scotland. The initiative, which was viewed as a major step in improving public health and preventative care, is targeted at giving patients access to quality and appropriate treatment as quickly as possible for the benefit of everyone.

The traditional NHS “sight test” has been replaced by a comprehensive eye examination appropriate to the patient’s needs. An initial eye examination is carried out (primary eye examination) and where necessary, this is followed by a second eye examination (supplementary eye examination) where extra information can be gathered and referrals refined. The Information Services Division (ISD) of the NHS collects information on eye examinations for each NHS board in Scotland and reports the findings at the end of each financial year (31 March).

Anecdotal evidence from patients and community-based eyecare providers strongly supports the introduction of the new NHS eye examination. There are also a growing number of examples of effective integration between optometrists and acute care providers, including care pathways, electronic referrals and transfers in the balance of care. Finally there is statistical evidence of the value of the new optometry contract (NHS Scotland 2008 and 2009).

### Statistics

The number of eye examinations conducted during the year ending 31 March 2007 increased by 64 per cent. This included patients who paid for the eye examination prior to free NHS eye examinations being introduced. Since this initial escalation, the number of free NHS eye examinations has continued to increase year on year, but at a more steady rate: an increase of 3.4 per cent from the year ending 31 March 2007 to the year ending 31 March 2008 and then a further increase of 6.4 per cent by year ending 31 March 2009.

### Referrals

During the year ending 31 March 2007, 3.6 per cent of all patients who had an eye examination were then referred to either their GP or hospital for follow up care. This rate was similar for the year ending 31 March 2008, but there was an increase to 4.2 per cent of all patients referred on during the year ending 31 March 2009.

### GOS(3) vouchers

442,944 GOS(3) vouchers (an NHS scheme whereby pairs of glasses are redeemed for vouchers, including complex appliance payments) were reimbursed by NHS boards by the year ending 31 March 2007. This increased by 1.7 per cent for the year ending 31 March 2008 to 450,716, with a more significant increase of 3.8 per cent for the year ending 31 March 2009.

### NHS voucher – exemption categories

Since the year ending 31 March 2007, there has been an increase of 19 per cent in redeemed vouchers for adults claiming job seeker's allowance. Increases have also been seen for children (8.2 per cent); adults claiming tax credits (7.6 per cent) and those claiming pension credit (23.7 per cent). Interestingly, there has been

a decrease in vouchers redeemed for those adults claiming income support (17.5 per cent). The general increase in NHS voucher exemptions indicates that there has been a potential increase in engagement with hard to reach and low income groups.

## NHS boards and eye examinations

Every NHS board in Scotland has observed an increase in the number of NHS eye examinations conducted. For the year ending 31 March 2009, the total number of NHS eye examinations as a percentage of the population was highest in Tayside with 35.7 per cent of the population getting an eye examination. This was closely followed by Greater Glasgow and Clyde with 35.6 per cent of the population having an NHS eye examination.

From the year ending 31 March 2007 to 2009, the Western Isles have seen the greatest percentage increase in uptake of free eye examinations by their population (8.4 per cent). In the year ending 31 March 2009, 27.4 per cent of Western Isles population received an NHS eye examination. This was closely followed by Shetland, which has also seen an increase of 8.3 per cent in uptake with 34.8 per cent of the Shetland population receiving an NHS eye examination in the year ending 31 March 2009.

Although increasing year on year, there were three NHS boards, all servicing rural areas, which had the lowest percentage of their population receiving an eye examination: Orkney (17.9 per cent in 2007 to 24.2 per cent in 2009); Borders (22.8 per cent in 2007 to 26.5 per cent in 2009); and Western Isles (19 per cent in 2007 to 27.4 per cent in 2009).

## Primary eye examinations

There has been an increase of 9.2 per cent in the number of primary eye examinations conducted since the year ending 31 March 2007 resulting in 1,630,600 being conducted for the year ending 31 March 2009. Within each financial year, the biggest proportion of primary eye examinations were conducted for "ordinary residents" with 1,623,160 being conducted for the year ending 31 March 2009. While there was an initial decrease in primary eye examinations conducted for "exempt visitors" (a decrease of 33.2 per cent from the year ending 31 March 2007 to year ending 31 March 2008), there has been a slight increase since 2008 of 9.6 per cent. (Note: "exempt visitors" are those citizens of a member state of the European Economic area or a country with which the UK has reciprocal arrangements regarding health care.)

### Supplementary eye examinations

From the year ending 31 March 2007 to year ending 31 March 2009, there has also been an increase of 33.8 per cent in the number of supplementary eye examinations conducted. Again, the majority of supplementary eye examinations conducted were for “ordinary residents” (99.3 per cent) with 0.7 per cent for “exempt visitors”.

### Information on patient types

The year ending 31 March 2008 saw a surge in different patient types being seen through NHS eye examinations with the following increases:

- cataracts – 18 per cent
- age-related macular degeneration (AMD) – 16.8 per cent
- glaucoma – 12.5 per cent
- diabetic retinopathy – 8.1 per cent

From the year ending 31 March 2009, this tailed off significantly, however increases were still seen (for example 1.2 per cent for patients with diabetic retinopathy). The biggest increase (10 per cent) was seen for those with cataracts.

### Acute care

According to the Scottish Government Information and Statistical Division (ISD), attendance at eye clinics across the country for 2008 was 409,914. Out of this figure, just under a third (122,587) were new patients, with the remainder being made up of return patients.

The breakdown of attendances, new patients and return patients are listed under the 14 health board areas and the Golden Jubilee Hospital (a central NHS resource) in the opposite table.

NHS health board	Total attendance 2008	New patients 2008	Return patients 2008
Ayrshire and Arran	38,646	9720	29,160
Borders	8,761	2,842	5,968
Dumfries and Galloway	9,482	3,686	5,897
Fife	20,691	7,377	13,278
Forth Valley	17,738	4,352	13,497
Golden Jubilee Hospital	2,996	1178	1,767
Grampian	37,323	13,028	24,753
Greater Glasgow and Clyde	105,736	27,901	78,122
Highland	24,967	6,444	18,687
Lanarkshire	37,884	14,808	23,692
Lothian	59,723	18,958	41,707
Orkney	1,545	435	1,131
Shetland	1,061	342	718
Tayside	41,305	10,855	30,394
Western Isles	2,056	661	1,388
<b>Totals</b>	<b>409,914</b>	<b>122,587</b>	<b>290,159</b>

### Eye patient attendance in Scotland in 2008

As a result of the new optometry contract and recent investments in optometry, the service is now much better equipped to hold on to patients in primary care. In comparison with the previous year (2007), there has been a drop in the overall number of attendees at eye clinics from 417,656 to 409,914 (2 per cent). This has mainly resulted from a drop in optometry referrals over that period in line with the introduction of free eye examinations.

However, over the same period, there has been a significant increase in the number of new patients attending eye clinics: 106,672 to 122,587 (an increase of around 15 per cent). The number of return patients remained almost static, with 291,073 return patients in 2007 and 290,159 in 2008. While the substantial increase in new patients confirms the future pressures faced by the NHS, there appears to be further scope through the introduction of an integrated ophthalmic electronic system with attached digital images and new referral/care pathways to reduce return patients and at least to stabilise the flow of new patients.

Across Scotland, 53 health facilities were identified as providing some level of eye clinic service. RNIB Scotland estimates that approximately half can be classed as substantial and five as major facilities serving large regional populations.

Evidence from Northern Ireland (RNIB Northern Ireland 2008) indicates that approximately 12 per cent of all new patients require a vision support type service with a slightly larger percentage requiring a signposting service. If this figure is applied to new patients in Scotland it would equate to 14,700 people requiring access to a vision support service and an additional 18,000 patients requiring basic signposting.

### Patient perspective

**“Although my physical needs were catered for, in terms of offers of low vision aids and rehabilitation, it felt as if my emotional needs were overlooked. Just after my diagnosis, I had lost my job, my income, my identity as a teacher, my driving licence, my social network and my independence.”**

## Eye conditions

The two leading causes of preventable sight loss among the elderly and adults of working age in Scotland are age-related macular degeneration and diabetic retinopathy.

### Age-related macular degeneration (AMD)

In the UK, neovascular age-related macular degeneration (AMD) accounts for more than half of all registered blindness (Owen et al 2003, Bunce and Wormald 2008). There are two types of AMD – wet and dry. Dry AMD, which has a slow onset, accounts for the bulk of referrals. Although dry AMD is not painful and

almost never leads to total blindness (because only the central vision is affected), it is the most common cause of poor sight in people over 60. Wet AMD, although much less common, is a serious, rapidly progressive disease that causes deterioration of the macula and results in progressive loss of central vision, often within weeks. It is an aggressive disease which demands early diagnosis and rapid referral and treatment for the best patient outcomes.

Lucentis was accepted as a treatment for use within Scotland for wet AMD by the Scottish Medicines Consortium (SMC) in May 2007 and in September 2009 NICE recommendations were also accepted as valid for use in Scotland. The treatment of wet AMD has had a seismic impact on acute eyecare services in Scotland. This is a result of:

- The snowball effect – where patients secure ongoing injections which in theory could be for life. Consequently the number of patients is growing at an alarmingly exponential rate
- The requirements for additional clean rooms, operating theatres and OCT equipment
- Substantial increases in pharmaceutical budgets. In a few health board areas Lucentis tops the expenditure list. It has not been possible to ascertain the overall bill for treatment over the last two financial years, therefore the costs have not been included within this report.

While it may be that new treatments and delivery methods can reduce expenditure in this area in the longer term it has to be recognised that the pool of potential patients is enlarging year by year. Across Scotland, the number of patients with wet AMD who required treatment was estimated to be around 1,225 in 2009. Of this number, approximately 300 patients could have avoided “legal” blindness in either one or both eyes through receiving timely treatment. This has been estimated as having the potential to save the NHS £16,041,68. In one health board area (Grampian) during 2008/09 injections doubled from 958 to 1884.

There is agreement among clinical leads that while tremendous progress has been made since the introduction of new wet AMD treatments, the current provision of services across Scotland is below standard, which in turn impacts on patient outcomes. The key challenges relate mainly to resource issues:

1. Improved services for follow-up patients who are currently deemed as receiving an inadequate service. Patient counselling, for example, is below adequate standard in the majority of areas.
2. Regional inequalities in treatment and criteria are particularly evident. There is a clear need for a nationally agreed standard of provision with recognition that resources will vary regionally.

## 5. Sight loss in Scotland

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3. Additional OCT machines to aid decentralisation, improve efficiency and help to provide equality of service across regions. This could be resourced through endowment funds if current restrictions against purchasing “core equipment” were relaxed.
4. Increased accommodation. Both the size and number of rooms are, in many cases, insufficient for the demand, leaving no room for expansion. In Tayside, ophthalmology accounts for a staggering 17 per cent of all outpatient appointments. In Fife, the figure is 16 per cent. Quite simply the allocation of resources has not kept abreast with the huge growth in ophthalmology referrals over the last decade.
5. Staffing. Many centres are currently running with insufficient staff and most centres would also benefit from dedicated administration.

Some of the considerations towards moving Scotland’s current provision forward and ensuring sustainability against what is fast approaching overwhelming demand include:

- Auditing outcomes data against practice patterns and identifying shortfalls in adherence to current best practice.
- Consensus review of best practice for treatment regime, frequency of follow-up and criteria for re-treatment.
- Consensus on minimum requirements and resources in health board areas, with the development of a business plan to meet these minimum requirements.
- Compilation of a formal five-year forward plan for the provision of macular services in Scotland.

### **Patient perspective**

**“For me the lucentis treatment has worked, brilliantly. I have not regained all my lost sight and will be going to the Eye Pavilion for some time to come as the surgeons try to stabilise the macula. But the overall improvement is remarkable, which is why the other day I was able to read a poem at a Burns supper...”**

## **Diabetic retinopathy**

Diabetic retinopathy is the leading cause of preventable blindness in the working age group. The “Scottish diabetes survey” which reports on an annual basis (Diabetes in Scotland 2002/09) shows an increase in the incidence of diabetes in

Scotland over recent years, almost doubling to a total of 228,000. It is predicted that, with the changing demographics, it is anticipated to increase further. In the next ten years, the burden to the healthcare system will not only be a challenge to GP and hospital medical services but also to both community and hospital eyecare services. All diabetes sufferers are at risk of developing diabetic retinopathy. As there are no symptoms of the disease experienced until the condition is advanced, the key to preventing sight loss is to offer annual diabetic retinopathy screening to every diabetic person over the age of 12.

Over the last five years, Scotland has developed a well-structured and effective national diabetic retinopathy screening collaborative. A single programme with a common published standard (QIS standard on DRS) is in place, using national software and image grading performed by the trained and accredited graders, who are quality assured both internally and externally. During 2008/09, 83 per cent of eligible individuals were successfully screened. This percentage has increased year on year. The collaborative involves a cross-section of key health bodies alongside patient representatives from Diabetes UK (Scotland) and RNIB Scotland.

Diabetic eyecare is an integral part of diabetes care and requires regular screening by the national diabetic retinopathy screening (DRS) programme. It is the responsibility of the DRS programme to detect referrals for diabetic retinopathy to the hospital eye service for all diabetics over the age of 12. The appropriately trained hospital eye specialists (with medical retinal experience) then examine, monitor, investigate and treat as needed.

Scotland's collaborative working culture offers the opportunity for professionals to intervene medically as well as surgically so that sight loss can be slowed down or prevented. As a result of the national DRS programme, patients are attending hospital eye clinics and receiving treatment at an early stage of the disease. This early detection leads to a change in patient behaviour through education and active participation in self management of their eye condition. Improved diabetes care not only reduces the risk of blindness but also reduces the incidence of heart attack, stroke, amputation and kidney disease (DRS 2009).

Continual support of the national DRS programme, as well as the recruitment of adequately trained eyecare professionals at the hospital eye departments will be needed in the near future if we are to respond to the increase in people with diabetes in Scotland.

### **Patient perspective**

**“I am glad that I attended the national diabetic retinopathy screening appointment. I thought I was OK as my eyesight was fine, until the result come back to me, informing me to attend the eye clinic.**

**The eye doctor explained to me what was wrong with my eye and why it is happening. I was told to improve my diabetic control and to see my GP. I was also given laser treatment for a few times.**

**Looking back I am very lucky that my eye sight is still good and my diabetic control has much improved as a result of this. I would very much encourage people to attend the national diabetic retinopathy screening appointments. I now appreciate the value of preventing sight loss.”**

# 6. Hidden sight loss

“Hidden sight loss” is a term used to describe when vision is not the presenting condition or disability. Consequently vision issues may be “masked” by the primary condition or disability. The term is also used where standard services are unable to engage with “hard to reach” groups, including black and minority ethnic and low income communities. In Scotland hidden sight loss represents a considerable challenge to managers, planners and practitioners alike.

## Minority ethnic groups and sight loss

The current literature on minority ethnic groups is not established enough to provide an agreed, comprehensive and reliable source of information on the prevalence of partial sight and blindness. However, there is a growing body of literature which highlights the greater risk of selected eye conditions relating to ethnicity (Friedman et al 2004, Das et al 1994, Rauf et al 1994).

- The white population has the greatest risk in developing **refractive error** compared to the black population.
- The black population has a greater risk of developing **AMD** compared to the white population in younger age groups, whereas the white population has a greater risk of developing AMD in the latter years of life. Asians are at lower risk than the white population of developing AMD.
- Asians have a greater risk of developing **cataracts** than both the black and white populations.
- Black and Asian populations have a greater risk of developing **diabetic retinopathy** than the white population.
- The relative risk of **glaucoma** is much higher for the black population than the white population.

### Patient perspective

“It’s very bad, because the doctor ask me what... language you speak... he never ask me what’s really wrong... we go out, I am very angry, because I don’t know anything about my eyes... it’s no good. Not good. Do you understand? This doctor ... he says to me come after six months and I don’t know anything, the doctor... why no speak... ?”

An RNIB Scotland research project (RNIB Scotland 2009) to determine prevalence rates of minority ethnic groups and associated eye conditions within Greater Glasgow has provided more localised prevalence figures relating to particular eye conditions:

- **The white population** is around 546,359. Of this number, it is estimated that: 2.37 per cent have AMD; 3.19 per cent have cataracts; 0.81 per cent have diabetic retinopathy; and 0.65 per cent have glaucoma.
- **The Asian population** is around 21,760. Of this number, it is estimated that: 1.78 per cent have AMD; 0.28 per cent have diabetic retinopathy; and 0.56 per cent have glaucoma. More significantly, while these prevalence rates closely reflect the prevalence rates within the white population, the prevalence rate for cataracts is considerably higher, with an estimated 19.54 per cent of Asians having cataracts, compared with 3.19 per cent of the white population.
- **The black population** is around 1,792. The findings are similar, with an estimated 0.11 per cent with AMD and 2.96 per cent with glaucoma. Significantly, 3.24 per cent have diabetic retinopathy, which is substantially higher than in the Asian population (0.28 per cent). Again, cataracts are almost three times higher than in the white population, with around 8.54 per cent of the black population having cataracts compared with 3.19 per cent of the white population.
- **The Chinese population** of around 3,876 shows similar patterns. It is estimated that: 0.52 per cent have AMD; 0.80 per cent have diabetic retinopathy; 0.80 per cent have glaucoma; and 13.96 per cent have cataracts (compared with 3.19 per cent of the white population).

### Patient perspective

**“The day I was told about my eyesight, I was scared to go to appointments. I was scared at the screening; I was scared in case they said something bad. Scared that they say to me lost completely now or it is affecting my left eye as well. When I go for an eye test I don’t even tell my children I am going for an eye examination. I am always scared to go to these appointments in case they give me bad news...”**

## Learning disabilities and sight loss

The research literature shows strong evidence of both sight loss and of refractive error in people with learning disabilities (LD). The risk of sight loss increases with severity of LD and with age.

As noted by Warburg (2001) and Splunder et al (2004), prevalence rates of sight problems in people with LD vary considerably between studies due to variations in sample size and characteristics of the populations. The most reliable study which has been reviewed is a large-scale study undertaken in the Netherlands by Splunder et al in 2006. The strengths of this study are:

- The large size of the sample.
- The strong likelihood that it represents the majority of people with LD in the Netherlands (those who were omitted are likely to have “mild or borderline” LD, in which the authors expect prevalence to be much lower than in the rest of the LD population).
- It was a screening study.
- It was an age-Down’s Syndrome stratified random sample – a method that allows us to look at the whole population of people with LD and also at differences between groups within the LD population on the basis of age, severity of LD and whether or not it is caused by Down’s Syndrome.

In addition to providing overall prevalence rates, the study also identified causes of sight problems in the different groups, and in comparison with the general (non-LD) population. Importantly, the prevalence estimates for different sight conditions were extrapolated to the general learning disability population (all other studies cited apply only to the sample population). A key finding from this study was that sight loss or blindness had been undiagnosed in 40.6 per cent of users of LD services in the Netherlands.

Although this study provides a good indication of possible prevalence of LD and sight loss, further research must be conducted to ascertain whether or not the LD population in the Netherlands shares the same characteristics as the LD population in the UK.

RNIB Scotland has pioneered work into LD and sight loss. A number of pilot projects have been conducted across Scotland which have put in place an RNIB Project Assessment Worker (PAW) to support adults with learning disabilities accessing eyecare services. Evidence from these pilots has highlighted a number of issues, most importantly the number of undetected sight problems in people with LD (Brady et al 2010).

For example, a project conducted in NHS Forth Valley found that of all those people with LD who were referred to their project, 55 per cent had no previous history of sight loss. Glasses were dispensed in 65 per cent of completed referrals, with most clients having never had glasses before. Similar figures were found with projects run in NHS Greater Glasgow and Clyde and NHS Ayrshire and Arran, with 38 per cent and 29 per cent having never had an eye test or a known history of sight loss, respectively. Forty-five per cent of clients had glasses dispensed following an assessment in NHS Greater Glasgow and Clyde.

It is important to highlight that assessments and referrals were still underway in each of the above projects with an average of three referrals per week at the NHS Greater Glasgow and Clyde service and around four per month for the NHS Ayrshire and Arran service.

In Scotland it is estimated that there are at least 120,000 people with LD. Using a conservative estimate that 30 per cent of that population (10 per cent lower than in the Netherlands) have an undetected and significant sight loss then it is argued that at least 36,000 Scots with LD are effectively being excluded from mainstream eyecare services. RNIB Scotland research has further identified the considerable impact that this can have on the health and well-being of the individual, the requirements for care and support and consequently the economic impact of such exclusion. In some cases, the detection of sight loss as a result of disease or a lack of refraction, has enabled individuals to increase their independence and functionality and reduced the categorisations of the individual's disability.

The under detection of sight loss within the LD population is a cause for concern. The projects conducted highlight the need for successfully supporting people with LD through eyecare services and the value that this can bring to both individuals and the wider community. However more detailed research is required to ascertain

the true value, to the individual and to service providers, of eye examinations and associated functional vision assessments.

## Stroke and sight loss

Stroke is the third most common cause of death and the most frequent cause of severe adult disability in Scotland, with approximately 15,000 new cases a year (SIGN 2002). It is evident from both clinical practice and the literature that visual disorders are prevalent post-stroke, however, internationally, this area of work has been a neglected and poorly researched area. There is currently only limited data available.

Further research has been underway in Ayrshire and Arran, following a study suggesting that after a stroke, 62–71 per cent of patients suffer some form of sight loss, which makes successful rehabilitation for the patient difficult. Through this research, it was identified that patients who had suffered a stroke and had suspected sight problems were not regularly referred for orthoptic assessment. There was a clear need to improve referral criteria, improve the speed of referral and provide a follow-up programme to review the effectiveness of identification and the necessary treatment. A presentation to all staff working in the field of strokes on the links between stroke and visual defects, resulted in a significant rise in the number of referrals for orthoptic assessment. 82 per cent of patients reported beneficial effects from their orthoptic visit while 96 per cent of staff felt that the orthoptic assessment had a positive effect upon patient treatment plans and rehabilitation (Brand D, personal communication).

RNIB Scotland is currently undertaking vital research in collaboration with the Nursing, Midwifery and Allied Health Professionals Research Unit (NMAHP) into the benefits and harms of preventative and therapeutic interventions for the recovery and management of sight problems following stroke using Cochrane systematic reviews (Hazelton et al 2010, Pollok et al 2009).

Four Cochrane systematic reviews are being conducted in the areas of visual field defects, eye movement disorders, age-related sight problems and sight neglect. The ultimate goal of this research is to have a positive impact on patient care, achieved by ensuring that health professionals are able to select the best possible treatment and management strategies for their patients. The evidence will demonstrate which interventions are beneficial or harmful, highlighting no evidence of effect, but also for which interventions further research is required.

Concurrently, further research to determine the current practice for management of sight problems following stroke in Scotland is also being conducted. Both pieces of research will enable services in Scotland to use evidence-based practice to assist in the provision of best quality care to people with sight problems following stroke.

### Falls and sight loss

Older people with sight loss fall more frequently than those with normal sight (La Grow et al 2006). In 2006, the Scottish Executive set up a Falls Working Group to look at how best to both raise the profile of, and progress work on, falls and falls prevention. Research identified by the Falls Working Group indicated that up to 30 per cent of falls among older people living in the community could be prevented through appropriate multi-disciplinary assessment, with associated cost savings for local health services (Falls Working Group, personal communication).

Following the work of the Falls Prevention Group, the Scottish Government issued guidance on 21 February 2007 (Scottish Executive 2007b) which placed a duty on NHS boards and community health partnerships (CHPs) to have a combined falls and bone health strategy in place. The guidance sets out specific action for both NHS boards and CHPs to progress work on falls and falls prevention. It was also issued to local authorities – as robust falls and fracture management and prevention strategies are imperative for residents in care homes – where the incidence of falls and fractures is high.

In May 2009, 18 of the 40 Community Health Partnerships had strategies in place. NHS QIS has appointed a national falls programme manager to establish a network of local falls coordinators to share experiences and provide good practice arrangements for assisting people who are uninjured after a fall.

The literature supports the need for investigating falls and related costs further. Brody et al (2001) showed that the only conditions that were statistically significant and likely to be causally related to partial sight and blindness were falls and depression. These mechanisms can also increase mortality for people with partial sight and blindness.

#### Patient perspective

**“I have a horror of falling outside, but I’m amazed at the amount of places that don’t have a yellow edge or white line on steps. It makes a tremendous difference, especially when you are coming out and going down steps.”**

Older people are more at risk of falls that result in injury and additional health expenditures. Many studies have examined the factors underlying increased risk of falling among the elderly and several have found a significant link between falls and sight loss. For example, Coleman et al (2004) reported that women with declining visual acuity had a 1.85 to 2.08 chance of experiencing a fall.

In a review of 31 studies on the risks and types of injury associated with sight loss, Legood et al (2002) suggest that those with sight loss are 1.7 times more likely to have a fall and 1.9 times more likely to have multiple falls. They also suggest that the odds of a hip fracture are between 1.3 and 1.9 times greater for those with sight loss. Additional research conducted by Visibility and Fife Society for the Blind has reinforced the strong links between sight loss and falls (Visibility and Fife Society for the Blind, personal communication).

Research from New Zealand has found that home safety initiatives can significantly reduce the number of falls among older people both within and outside the home. Falls at home related to an environmental hazard were significantly reduced, but so were falls at home not associated with any hazard (La Grow et al 2006).

Further research – along similar lines to research being conducted for sight loss following a stroke – needs to be carried out for falls and sight loss. This research should include Cochrane systematic reviews to ensure that health professionals have the best evidence available to deliver interventions and to manage falls, and also a survey of current practice across Scotland to determine what is good practice.

## **Mental health and sight loss**

Sight loss has a profound impact on well-being. It can shorten life, increase the risk of other conditions, restrict social participation and independence and impair physical and mental health. Moreover, the cost of sight loss is not limited just to the treatment cost of the various conditions that underlie it. Brody et al (2001) showed that:

- 78 per cent of subjects reported having at least one comorbid condition in addition to the sight loss for which they were receiving medical care
- The depressed group had a higher mean number of comorbidities at 1.67 compared to 1.17 in the non-depressed group.

Sight loss can also cause depression. Most studies find prevalence rates of depression in elderly populations with sight loss to be between 25 per cent to 45 per cent (Burmedi et al 2002). Within the general elderly population, less than 20 per cent have mild dysphoria with less than 5 per cent suffering from severe depression. It is again necessary to control for other comorbidities. Comparing

estimated risk of depression from these studies, the relative risk of depression is estimated to be around 3.5 times higher.

### Patient perspective

**“ My major problem is loneliness. If I walk along the street, I can’t spot people and smile at them. People have to approach me, so I feel like I’m in a world of my own, which is quite damaging at times.”**

A research study involving blind and partially sighted participants from the east coast of Scotland produced empirical evidence regarding the impact of sight loss on mental health (Thurston 2009). Results indicated that participants experienced reduced mental health and decreased social functioning as a result of their sight loss. The study found that many participants felt socially isolated, and most participants recounted experiencing some form of loss. Participants reported that their sense of identity was challenged by sight loss and that they were often treated differently by others because of it. In addition, the study included very powerful evidence from participants about their experiences of being diagnosed with an eye condition and the negative effect this had on their ability to cope with losing their sight.

In response to recommendations within the Scottish Executive Action Plan “Community care service for people with a sensory impairment” (Scottish Government 2004) and as part of the “National programme for improving mental health” (Scottish Government 2003), a review of community care and mental health services for adults with sensory impairment was carried out in 2006. Although a great deal of anecdotal and unpublished research evidence already existed to suggest that adults with sight loss experience difficulties in accessing appropriate community care and mental health services, this report (Scottish Government 2006) was the first comprehensive review of services aiming to identify and examine the community care and mental health needs of adults with sight loss in Scotland.

A range of mental health challenges can be experienced by people with sight loss, including: anxiety, depression and social withdrawal. Distress and anxiety are found to be experienced particularly during periods of transition, for example, from school to work and at the point of onset of impairment where loss is not congenital. There appears to be a need for early intervention for patients with a sudden onset of sight loss, to avoid the development of depression.

**Patient perspective**

**“The only thing I’ve found difficult is coming to terms with blindness. I feel someone should have helped me in that respect. There must be other people in the same position as me with the same problem.”**

While evidence suggests that there are already a number of organisations and individuals in Scotland who are committed to raising public and professional awareness of the challenges faced by people with sight loss, greater efforts are required at both a local and national level to support this.

## 7. Education and sight loss

The social and future health costs of not fully supporting the education of blind and partially sighted children and young people are high. All too often this can lead to underdeveloped skills, creating barriers to accessing the labour market. As identified earlier in this report, there is also a strong correlation between sight loss and mental health issues, which can stem from deficiencies in early education.

It is estimated that there are 1,800 pupils in primary and secondary schools across Scotland who require materials in alternative formats, due to sight loss (RNIB/NFER 2008). From research commissioned by RNIB Scotland (2006), most pupils with sight loss require, on average, 375 texts to complete primary education. Delay and limited choice mean that many blind and partially sighted pupils do not develop reading skills at the appropriate level for their age group and spelling often becomes a lifelong problem.

At secondary school level, an average pupil will require over 750 texts to complete six years of study (Sorenson 2005). The production of these texts is time-consuming and only a few individuals have the skill to produce complex texts at secondary level. While there are some working models of provision including the Royal Blind School Edinburgh, RNIB Scotland's Braille service and a few notable local authorities, the quality and provision of materials in mainstream schools remains inconsistent.

The Education Act 2002 (Disability Strategies and Pupils' Educational Records, Scotland) requires that all disabled pupils are able to access the curriculum and that includes ensuring that they have access to accessible curriculum materials. Recent developments through establishing a database entitled "Books for all" have been introduced by the Scottish Government, through Learning and Teaching Scotland. The database, "Scottish Books for all", is being piloted with local authorities using the national IT support system for teachers, "Glow". Glow is the world's first national intranet for education, funded by the Scottish Government and managed by Learning and Teaching Scotland. The main purpose of Glow is to enhance the quality of learning and teaching in the classroom.

While these initiatives are to be applauded, too many children and young people who are blind or partially sighted are currently still not receiving their curriculum materials in the correct format and at the correct time. In part this is due to access technology not developing at the same pace as the ICT used in the classroom.

Recent research conducted by Guide Dogs (2008) found that “society is failing” blind and partially sighted youngsters. The report identified a level of neglect, leaving many blind and partially sighted children and young people lonely, isolated and “fearful of the future”. The research went on to say that the failure to provide national guidelines and standards for the 1,400 blind and partially sighted youngsters under 17 in Scotland had led to patchy provision by councils.

In partnership with a number of sight loss organisations, the Scottish Government, Learning and Teaching Scotland (LTS) and Her Majesty’s Inspectorate of Education (HMIE) are involved in a partnership project entitled Journey to excellence: improving achievement for children and young people who are blind and partially sighted. While RNIB Scotland, the Royal Blind School and others in the statutory sector are actively taking forward innovative ways of applying a curriculum for excellence to the education of children with sight loss, this area should be strengthened through additional funding.

The purposes of education are to enable all young people to become successful learners, confident individuals, responsible citizens and effective contributors. As outlined above, the cost of not addressing the educational needs of children and young people can have a lifelong and lasting effect on their well-being and health, impacting on the range of opportunities open to them. With growing evidence of the impact that lack of educational support can have on children and young people’s emotional well-being, strategies are required to improve educational opportunities for blind and partially sighted young people throughout Scotland.

# 8. Conclusions

Our report has set out some of the major challenges facing Scotland in relation to eyecare services over the next decade. These include an unprecedented rise in our elderly population, worryingly high rates of diabetes, obesity and smoking, poor lifestyle choices and increasing pressures on our existing services.

We have highlighted many of the unique opportunities that Scotland has to successfully meet these challenges. These include several world-class initiatives, such as the provision of free eye examinations, the pilot project on electronic referrals and the integration of community eyecare services. Scotland has made significant strides in eyecare services. Through continued commitment to innovation and quality, Scotland can secure a world-class eyecare service for everyone.

Throughout this report, a case is made for strategic investment through:

1. Integration
2. Prevention
3. Support.

Specific recommendations are made, including: a review of registration procedures; improved data collection around “hidden sight loss”; screening initiatives; research proposals; and a variety of service enhancements. The broad recommendations are grouped under the following three headings:

## 1. Integration

- Identify areas of best practice between optometry and ophthalmology and promote further integrated service delivery.
- Implement a national electronic referral system based on the Fife pilot.
- Support the development of integrated care pathways and MCNs.
- Establish a standing committee to drive forward the integration of services, promote best practice and design and monitor the implementation of a national prevention strategy for eyecare.

## 2. Prevention

- Embrace prevention as a cornerstone within future investment strategies for Scotland's eyecare services.
- Develop "healthy lifestyle" and "self management" campaigns aimed at improving eye health.
- Undertake economic analysis around eyecare interventions with a dual focus on prevention and cost reduction.
- Commission a formal five-year forward plan for the provision of macular services in Scotland.
- Target the uptake of refractive services for individuals limited by lack of funds or those in marginalised groups, particularly older isolated people and children.

## 3. Support

- Establish a national network of vision support services providing emotional and practical support at the point of diagnosis.
- Develop a national referral system between optometrists and local providers of support services.
- Implement the service standards within the "Review of community eyecare services" (2006) and set associated national targets.

There is considerable evidence that eye examinations provide an invaluable insight into other potential health conditions. It can similarly be argued that eyecare provision offers an unrivalled opportunity to model, test out and drive forward the new approaches required to meet the demographic "tsunami" and economic challenges of the next decade.

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