Evidence base to support the UK Vision Strategy

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Executive summary

The UK Vision Strategy launch will mark an important new initiative, which should draw support and active co-operation from all involved in eye care. In line with Vision 2020 – a global initiative, coordinated jointly by the World Health Organization (WHO) and the International Agency for the Prevention of Blindness (IAPB) – the UK Vision Strategy aims to promote the elimination of avoidable sight loss, and improvement in the care, quality of life and opportunities of individuals and families affected by sight problems. The objective of this briefing

paper is to provide a review of the current evidence base that will inform, support and underpin these strategic aims. It considers three key areas:

1. the current and future impacts of sight loss, including the health, social and economic impacts;
2. current practice and access to services; and
3. national and local initiatives in eye care which could provide a framework for informing future policy and development. Our paper aims to present a briefing on the challenges and also the opportunities facing eye care

In terms of the challenge, sight loss is now a major health issue, affecting about two million people in the UK. The vast majority are older people, although an estimated 80,000 working age people and 25,000 children are affected by sight problems in the UK[1].

Evidence suggests that over 50 per cent of sight loss is due to preventable or treatable causes. This is most marked in the older population, where it is estimated to be between 50-70 per cent[2].

Significant numbers of people also live with irremediable or certifiable sight loss. RNIB estimates suggest that there could be around 980,000[1]. The leading causes are age-related macular degeneration (AMD), glaucoma and diabetic retinopathy. In England and Wales, the age-specific incidence of all three has increased significantly since 1990-1991 – with changes in diabetic retinopathy being the most marked – particularly in the over 65's where figures have more than doubled[3].

As the population ages and the incidence and prevalence in key underlying causes of sight loss increases, so sight loss is expected to become even more prevalent in the future[4,5]. Recent global estimates predict that, without intervention, there will be a doubling in the number of blind individuals between 2000 to 2020. The evidence points firmly towards major challenges in improving services to meet need.

Sight loss, however, is not only a common and growing problem, but it also exerts significant quality of life impacts, which are often under-recognised by health professionals. One study estimates that very

severe AMD causes a 63 per cent decrement in quality of life, a decrease similar to that associated with advanced prostatic cancer with uncontrollable pain or a severe stroke that leaves a person bedridden, incontinent and requiring constant nursing care[6].

There are also significant adverse health impacts associated with sight loss, such as an increased risk of depression[7] and falls[8]. People with sight problems are also likely to have additional disabilities and are likely to live alone[9]. These factors indicate that those affected by sight loss are among the most vulnerable and isolated. There are thus clear and pressing social arguments to support a strategy for change.

Apart from health and social impacts, there are also significant economic impacts resulting from sight loss. RNIB estimates indicate that the total UK costs are in the region of £4.9 billion a year[10]. These are conservative estimates, however, and more recent and comprehensive Australian studies indicate that vision disorders cost an estimated 0.6 per cent of GDP (Au$9.85 billion in 2004)[5].

Frick and Kymes argue that these findings rank the absolute economic burden of sight loss with that of cancer, dementia and arthritis. “The impact relative to [an] entire…economy also emphasises the non-trivial nature of the burden of visual impairment. The results should catch the attention of health policy makers because they suggest that, even in a developed economy, visual impairment can limit economic development”[11].

As the authors of the Australian study conclude, “a developed economy cannot afford (avoidable) vision loss. Priority needs to be given to prevent preventable vision loss; to treat treatable eye diseases; and to increase research into vision loss that can be neither prevented nor treated”[5].

Improving diagnosis and early intervention is also crucial, because detecting disease at an earlier stage will also enable more to be done to delay disease progression. Strategies for prevention, early diagnosis and intervention are also likely to be cost-effective. An Australian study has found that for each dollar spent on the

prevention of sight loss and eye care, there could be a five dollar return to the community[12].

In the UK, there has been some real progress in terms of improving current service provision and access to services; however, there are still major gaps through the lack of consistent care pathways. Eye care also needs a framework for prevention and early intervention rather than just ad hoc responses to presenting problems. Our review suggests that there has been little official recognition of the important role of eye care services in improving more general care pathways. It was only recently that the Czar for Older People cited strong evidence on the important part played by vision problems in falls: but even so, there is little definition of how PCTs could improve services in this area quickly.

We are entering a period of great potential for improving eye care services on a feasible, fundable basis. Much preparatory work has been done through the excellent report of the National Eye Care Services Steering Group[13] and the NHS Eye Care Programme[14], and PCTs can now use the Step by Step Guide to Commissioning Community Eye Care Services[15]. There have also been important developments in Scotland, with the Review of Community Eye Care Services published in 2006[16], and in Wales, with the Welsh Eye Care Initiative[17]. Local developments are, however, needed to make services more available and accessible, and more relevant to elderly and vulnerable groups. The next challenge is to make this happen.

Section 1: Sight loss: the current and future challenge

Prevalence and incidence of sight loss

RNIB estimates that about two million people in the UK have significant sight loss[1] (based on studies recently reviewed by Tate et al[2]). The vast majority are older people aged 65 and over, however there are also an estimated 80,000 working age people and 25,000 children living with sight problems in the UK.

This estimate includes preventable or treatable causes of sight loss, such as cataract and refractive error. It also includes irremediable blindness and partial sight, usually recommended for certification as severely sight impaired (blind), or sight impaired (partially sighted).

Evidence suggests that over 50 per cent of sight loss in the UK is due to preventable or treatable causes. This is most marked in the older population, where it is estimated to be between 50-70 per cent[2].

Significant numbers of people also live with irremediable or certifiable sight loss. RNIB estimates suggest that there could be around 980,000, although many of these will not be certified or registered[1].

In England and Wales, the most commonly recorded main cause of certifications for both blindness (57.2 per cent) and partial sight (56 per cent), is age-related macular degeneration (AMD)[3]. Glaucoma (blind 10.9 per cent, partially sighted 10.2 per cent) and diabetic retinopathy (blind 5.9 per cent, partially sighted 7.4 per cent) are the next most commonly recorded main causes (based on data for 1999-2000). Overall, the age specific incidence of all three leading causes has increased since 1990-1991 – with changes in diabetic retinopathy being the most marked – particularly in the over 65s where figures have more than doubled[3]. The authors conclude that “these figures can surely be useful as indicators or minimum estimates of the incidence of severe sight loss in the population for planning preventive health care strategies and prioritising research particularly for irreversible causes”.

Dramatic increases in incidence of age-related macular degeneration (113 per cent increase) and diabetic retinopathy (120 per cent increase), have also been observed for Northern Ireland, while numbers registered as a result of glaucoma have stayed relatively stable[18].

Even with the reduction in waiting times the need for services is still substantial. It is clear that there are new problems of eye disease which require a continuing and strong response from the NHS.

Social impacts of sight loss

Sight loss is not only common, but it exerts significant quality of life impacts that are often under-recognised by health professionals. One study reveals that patients with different degrees of severity of age-related macular degeneration (AMD) have a perceived impairment of their quality of life that is 96 per cent to 750 per cent greater than the impairment estimated by treating ophthalmologists[6]. This study estimates that mild AMD causes a 17 per cent decrease in the quality of life of the average patient, a decrease similar to that experienced with symptomatic human immunodeficiency virus infection or moderate cardiac angina. Moderate AMD causes a 40 per cent decrease in quality of life, a decrease similar to that encountered with permanent renal dialysis or severe cardiac angina. Very severe AMD causes a 63 per cent decrement in quality of life, a decrease similar to that associated with advanced prostatic cancer with uncontrollable pain or a severe stroke that leaves a person bedridden, incontinent and requiring constant nursing care[6].

There are also significant adverse health impacts linked with sight loss. Older people with sight loss have an increased risk of depression, at a rate of 13.5 per cent, compared with 4.6 per cent in people with good vision[7]. Older people with sight problems are also 1.7 times more likely to have a fall, and have 90 per cent higher odds of multiple falls than a person with no visual impairment[8].

A significant number of people with sight problems also have additional disabilities or health problems. In a large UK survey of registered blind and partially sighted adults, 70 per cent of all age groups stated they have additional long term health problems or disabilities, and the likelihood increased with age with 73 per cent of those aged 65 and upwards. Difficulty with hearing was reported from 43 per cent of the sample and from 53 per cent of the 75+ age group[9].

At least 2.5 per cent of people over 75 years will have dementia and significant sight loss[19].

50 per cent of blind and partially sighted children also have additional disabilities and this includes 30 per cent with severe or profound and multiple learning difficulties[20]. In those with severe sight loss, 77 per cent have additional disabilities[21].

Additionally, people with sight problems are likely to live alone[9]. These factors indicate that individuals and families affected by sight loss can be among the most vulnerable and isolated. There are thus clear and pressing social arguments to support a strategy for change.

Economic impacts of sight loss

Apart from the health and social impacts, there are also significant economic impacts resulting from sight loss. RNIB estimates indicate that the total costs of sight loss in the UK are in the region of £4.9 billion a year[10]. These are prevalence based estimates of the economic and social costs of vision loss, and are based upon detailed expenditure data for 2001/2, assembled from central and local government, and voluntary and private sector sources. This is considered a conservative estimate, however, not fully accounting for informal care costs, personal costs and quality of life impact costs.

More recent and comprehensive Australian studies indicate that vision disorders cost an estimated 0.6 per cent of GDP (A$9.85 billion in 2004)[5]. Frick and Kymes argue that these findings rank the absolute economic burden of visual impairment with that of cancer, dementia and arthritis[11]. “The impact relative to the entire Australian economy also emphasises the non-trivial nature of the burden of visual impairment. The results should catch the attention of health policy makers because they suggest that, even in a developed economy, visual impairment can limit economic development”[11].

US studies are also consistent with these findings and demonstrate that sight loss is significantly associated with higher health care expenditures, a greater number of informal care days, and a decrease in health utility[22].

When looking at total annual healthcare costs, recent UK studies find that these are more than sevenfold higher for patients with age-related macular degeneration (AMD) compared with non-AMD elderly patients[23].

A substantial proportion of health care costs will be non-eye related. US studies indicate that these are in region of around $2.14 billion (in

2003)[24]. As the authors of the US study conclude, preventing vision loss is not only a medical imperative but also an economic one.

A significant fraction of non-eye related health care expenditure will be the costs arising from depression and the quality of life impact. In the above UK study, patients with AMD reported substantially worse vision-related functioning and overall wellbeing, including higher depression scores[23].

As is now widely reported, another significant fraction of non-eye-related health costs can be attributed to accidental falls. Of the 2.35 million accidental falls in the UK that required hospital treatment in a 12-month period, 189,000 occurred to individuals with visual impairment, and 89,500 could be directly attributed to the visual impairment. The estimated medical costs of these falls were £269 million and £128 million respectively[25].

Total non-health care costs associated with sight loss are also considerable. A recent analysis demonstrates that some of the most significant economic consequences lie beyond healthcare systems, and that sight loss has a considerable negative impact on productivity[26].

A recent study, for example, has shown that the percentage of older persons receiving formal and informal care rises significantly with the level of sight loss. 34.9 per cent and 37.3 per cent of those with no sight loss received formal and informal care, respectively, compared with 51.6 per cent and 69.9 per cent of those with moderate sight loss and 55.6 per cent and 88.9 per cent of those with severe sight loss[27].

In general there is growing evidence from a number of developed countries that the costs of visual impairment are significant and greatly under-estimated. Here, the latter is likely to have led to substantial neglect.

Future impacts of sight loss

Sight loss is both common and exerts significant health, social and economic impacts. It will also become even more prevalent in the

future as the population ages and the incidence and prevalence in key underlying causes of sight loss, such as obesity and diabetes, increases.

Recent modelling of effects of demographic change on the global prevalence and cost of sight loss indicates that without intervention, there will be dramatic increases over the next 25 years[4]. These estimates predict a doubling in the number of blind individuals (between 2000 to 2020), and significant increases in direct and indirect costs.

National estimates from developed country perspectives are also providing consistent findings. The prevalence of visual impairment in Australia is projected to increase from 5.4 per cent today to 6.5 per cent, or nearly 800,000 people, by 2024. Over the same period, blindness may increase by 73 per cent to nearly 90,000 people in the over 40 age group. Costs are also expected to rise significantly[5].

Although detailed estimates for the UK and the devolved countries are needed, we would particularly emphasise the rise in numbers of people with eye disease which has already taken place and the high probability of increased numbers over the next decades. The evidence points firmly towards a major challenge in improving services to meet need.

Prevention and early intervention

The authors of the above mentioned Australian studies conclude that “a developed economy cannot afford (avoidable) vision loss. Priority needs to be given to prevent preventable vision loss; to treat treatable eye diseases; and to increase research into vision loss that can be neither prevented nor treated”[5].

Improving diagnosis and early intervention is also crucial, because by detecting disease at an earlier stage, it will also enable more to be done to delay progression of disease. Early referral to an ophthalmologist, for example, is particularly important for patients with type 2 diabetes and severe non-proliferative diabetic retinopathy, since laser treatment at this stage is associated with a 50 per cent reduction in the risk of severe visual loss and vitrectomy[28,29].

Early intervention might also be important for babies and toddlers and some evidence suggests that developmental setback could be prevented or ameliorated by a programme to promote visual development[30].

Strategies for prevention, early diagnosis and intervention are also likely to be cost-effective. An Australian study which has attempted to assess the impact of a costed intervention package to prevent avoidable sight loss, has found that for each dollar spent on the prevention of sight loss and eye care, there is a AU$5 return to the community. The intervention package would cost AU$188.8 million to implement in its first year but would bring a net return of AU$163.1 million in direct costs in the first year and an overall savings to the country of AU$911.1 million, a 4.8-fold return on investment. The authors conclude that, although specific for Australia, these data can help guide health care policy debate and the priority given to eye care in other developed economies[12].

In the UK a number of specific prevention, early intervention and treatment strategies have been assessed for cost-effectiveness and are now being implemented. This includes systematic screening for diabetic eye disease[31]. A recent Health Technology Assessment has shown that the targeted screening for glaucoma might also be cost effective[32]. In terms of treatment, cataract surgery is considered one of the most cost-effective treatments available[33]. New therapeutic targets for irremediable cause of sight loss are also being identified as a result of emerging insights into diseases such as macular degeneration, and new strategies are also being tested for effectiveness and cost effectiveness which are leading to new potential treatments.

These studies provide strong evidence of the value in investing in improved services for people with sight loss.

2. The services today: what is the level of access?

The improvements

There have been some significant improvements in eye care over the past five years. Access to cataract surgery has improved[34]. Many more elderly people have had rapid access to operations and for many this has been done on a day and short stay basis. There has been an improvement in coverage of retinal exams for people with diabetes at least up to the age of 75 years. The UK record is now the best in the Organisation for Economic Co-operation and Development OECD[35].

There is greater awareness of age-related macular degeneration (AMD) in general optical services and prompt access for suspected “wet” (neovascular) AMD in most secondary care sites. In some centres, access to Low Vision Aid (LVA), Certificate of Vision Impairment (CVI) and social services advice is almost one stop[13]. There are now some therapies also available for macular degeneration, albeit on a limited basis.

Within the optical/primary care services the main activities have still been those of sight-testing and the fitting of spectacles. However, older people are now entitled to free eye tests and to free glasses.

The shortfalls

These have been real gains: however there are still major gaps in services through the lack of consistent care pathways.

There is no formal system for screening for chronic glaucoma in the UK. Individual cases are detected mainly by high street optometrists who use a variable series of tests in order to detect glaucomatous damage[13].

Despite some improvements in low vision care, services are still fragmented and there is wide variation across the country in terms of both access and quality of service provision[13].

Paediatric low vision services are also considered to be disjointed. There are general concerns about children’s services, particularly around delays in diagnosis and referral on to other agencies[36]. Parents of children with additional disabilities are also recognised as having a high level of unmet need.

There can be significant delays in assessments and services for people with severe problems. Such assessments are essential if there is to be a personalised service. This is a problem both for social services and for health services and delays are likely to be longer in deprived areas.

There is a high level of under-registration, and one study suggests that this could be as high as 45 per cent[37]. Partially sighted individuals are more likely to be unregistered than blind individuals and minority ethnic individuals are three times more likely to be unregistered than white individuals[37]. As such, severe visual problems are more likely to remain unrecognised and untreated in these groups.

Poorer access to services is also likely to contribute towards higher risk burdens and resulting health inequalities across minority ethnic and lower socio-economic groups. British Asians, for example, appear to show higher risk of cataract and develop it an average 10 years earlier than their white counterparts[38]. British Black Caribbean or Black African backgrounds are at a four to five times increased risk of glaucoma[39]. Prevalence of diabetes is also increased in British Asians and British Black Caribbean or Black African backgrounds[40]. There is also an increased rate of severe sight problems and blindness in children from minority ethnic and lower socioeconomic groups[21]. Additionally, more than two fifths of those who report poor vision or that are registered blind are in the bottom income quintile for their age group and much more likely than those without impairments to be renting their homes – ELSA: English Longitudinal Study of Ageing (1998-2001)[41]. Services, clearly, need to become more accessible, better designed and better targeted towards meeting the needs of these vulnerable groups.

Our review also suggests that there has been little official recognition of the important role of eye care services in improving more general care pathways and shaping wider government policies. There has been little interest in younger people faced with low vision problems and sight loss. It is difficult to find any mention of the issues in any Department of Health (DH) publication of the last ten years.

For older people the policy framework changed with the National Service Framework for Older People[42]. This set out the intention of creating a new range of intermediate care services. “Intermediate care should be used as an opportunity to maximise people’s physical functioning, build confidence, re-equip them with the skills they need to live safely and independently at home, and plan any ongoing support needed.” Eye care and assistance with low vision should be seen as a vital part of any such service given the effects on morale, confidence and cognitive abilities, yet the issues are not discussed as part of the NHS, with only a single word mention of sight within the list of topics for the single assessment process. There is another brief mention of visual impairment as a risk factor for falls. In general, preventing vision loss is seen as a very minor issue indeed. Nor is the whole area mentioned in the later National Service Framework (NSF) review or progress report: A New Ambition for Old Age[43]. More recently the DH has begun to stress the importance of care pathways for older people with complex needs[44]. The main focus is on better assessment and service organisation for people who have had falls. Again, however, there is no mention of assessment of sight as a step in this care pathway.

There have been some positive references to eye care in relation to the care of older people. The joint report by the College of Optometrists and the British Geriatric Society endorsed by the Royal College of General Practitioners started from the proposition that “visual impairment is strongly associated with falls and hip fractures. In addition to poor visual acuity, reduced visual field, impaired contrast sensitivity and cataract may explain the association”[45]. Since then Professor Philp has confirmed the importance of visual problems in causing falls: but even so, there is little definition of how Primary Care Trusts (PCTs) could improve services in this area quickly.

On the whole, eye care needs more consistent, accessible and inclusive pathways and a framework for prevention and early intervention, rather than just ad hoc responses to presenting problems. This is true for younger age groups but particularly relevant to the many elderly people who are affected by sight loss. Additionally, there needs to be much stronger links between eye care

and the development of wider services such as falls clinics and memory clinics for older people.

Section 3: Developing national and local strategies for improving eye care

Despite the shortfalls identified above, there have been some very important and significant national and local service developments in eye care, which provide a coherent framework for informing policy and practice, both now and in the future.

In England, there has been considerable progress with the publication of The National Eye Care Services Steering Group report[13]. This set out four model pathways for cataract, glaucoma, AMD and low vision. The NHS Eye Care Services Programme oversaw the piloting of the Glaucoma, Age Related Macular Degeneration and Low Vision pathway projects[14]. Local pilot sites, facilitated by PCTs, undertook to apply service improvement and redesign principles to the three eye care conditions with a view to developing new pathways which were timely, accessible and community based. They also had the challenge of working in partnership across traditional boundaries of health, social care and the voluntary sector to deliver a patient focused service.

The Department of Health recommended use of these pathways and a broader range of providers in the guide published in January 2007 in the Commissioning Toolkit for Community-based Eye Care service[15]. This was a good review of the need for improved services stressing that poor visual health was related to a number of risk factors, and a contributor to further decline in those who are already experiencing high levels of disability as a result of one or more longer term medical conditions. It sets out the case for service change and redesign. “Eye care services have traditionally been a strongly hospital based speciality” but now there is a potential for developing more services closer to home. The challenge now is to make it happen.

There has been significant progress in Scotland with the Review of Community Eye Care Services published in 2006[16]. This is the

detailed and practical plan for expanding the role of optometrists/opticians yet to be published in the UK. It grew out of pilot schemes in Glasgow, providing a seamless local service with co-operation between agencies to set out a framework. Since this report, good progress has been made in providing local incentives towards better eye care. The sight test fee has been raised after a review of the actual costs of delivering high quality care so that it is now £36 rather than £18.50 as in England and optometrists are to be reimbursed for carrying out extended care. There have also been a number of projects for investing in eye care.

The Welsh Assembly Government has also funded the Welsh Eye Care Initiative to preserve sight through the early detection of eye disease and to give help to those who have low vision and whose sight is unlikely to improve[17]. There are four strands to the Welsh Eye Care Initiative: Eye Health Examination/PEARS Scheme; Low Vision; The Children's Low Vision Project; and Diabetic Retinopathy Screening.

The new Eye Care contract will also create a potential for new kinds of partnership between opticians/optometrists and the NHS. There is already active discussion with PCTs such as that of Cornwall and the Isles of Scilly about joint programmes. The new commissioning opportunities can lead to more accessible services on a shared basis. Eye care services are set to have a much more important role in practice based commissioning.

The Pharmacy model has given a relevant lead for the development of new contracts in England and Scotland and has shown the way forward. Scotland and Wales have already provided pointers to new local services. For opticians there will be opportunities to develop services beyond sight testing and for optometrists the opportunity to use a wider range of skills. The new partnerships will specify quality as well as access: they could lead to rapid moves towards the new preventive services which are now a key part of the PCT commissioning agenda[46].

The UK government and the devolved administrations have started on a very fundamental redesign of health services moving towards much more local and accessible services.

This recognises that the new challenge for health services is to give much more effective and integrated services to people with long term medical conditions. In eye care the opportunity is there for rapid progress. The programmes in prevention and early detection are well understood and could be delivered within months in many areas through partnership between local opticians/optometrists and the NHS. The new services could also meet the rising demand which will come from the increased prevalence of diabetes and changes in lifestyle. Eye care services could now be in a lead role in the redesign of services.

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