Eye Health – preventing sight loss in London

November 2017

Key findings

- Eye health is a growing issue in London and we expect to see many more Londoners presenting with eye conditions in future.
- London faces some particular challenges around prevention, diagnosis and treatment of sight-threatening conditions.
- Eye health must become a greater public health priority, recognising the impact it has on wider health and wellbeing. Better eye health will also boost London's economic output by improving employment chances for people with sight loss and reducing care costs.
- We need to reduce pressure on hospital services and ensure timely treatment for people with sight threatening conditions
- More should be done to encourage Londoners to look after their eye health and raise awareness of the need for regular eye tests.
- The Mayor should challenge London's health and care leaders to integrate eye health into their plans more effectively, and support the development and implementation of a London Eye Health Strategy.

The London Assembly Health Committee held an investigation into eye health for all Londoners. In our formal committee session we spoke to experts from Moorfields Eye Hospital, The Royal National Institute for Blind People, the Thomas Pocklington Trust, the London Eye Health Network and Vision UK. Outside of the committee session we received the views of the Royal College of Ophthalmologists and the College of Optometrists, and a wide range of service providers as well as users, highlighting how the Mayor could better support eye health in the capital. This report sets out our key findings and makes recommendations to the Mayor on potential areas for action.

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Why should eye health be a priority in London?

Eye health is a growing public health concern for London. By 2030 an extra 194,000 Londoners are predicted to be living with a sight-threatening eye health condition and an extra 74,000 living with sight loss. The Royal National Institute of Blind People (RNIB) estimates that there are already 680,000 people– around one in twelve of the adult population – in London living with a sight-threatening eye health condition, including:[1]

- 251,000 people living with early stage age-related macular degeneration (AMD)
- 173,000 living with diabetic retinopathy
- 72,000 living with glaucoma
- 57,000 living with cataract

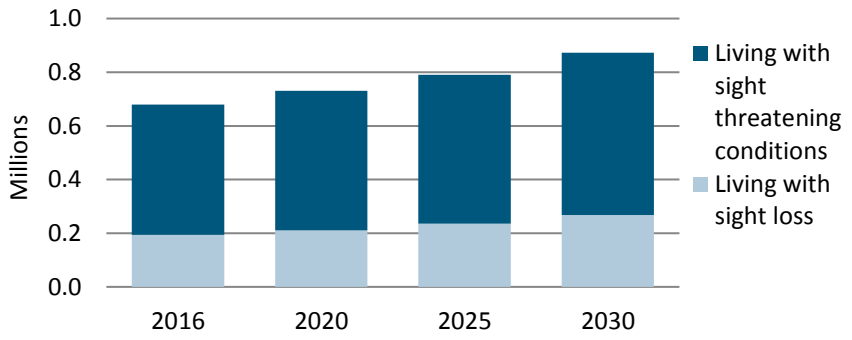
Age-related macular degeneration: 'Dry' AMD usually causes a gradual deterioration over many years. Around 10-15 per cent of people with aged related macular changes go on to develop 'wet' AMD, which can lead to rapid loss of central vision, but can be treated to prevent progression if caught quickly.

Diabetic retinopathy: Diabetic retinopathy is a complication of diabetes that damages blood vessels in the retina, causing them to bleed or leak. Early diagnosis is vital. Most sight-threatening diabetic problems can be managed if treatment is carried out early.

Glaucoma: a group of eye conditions that cause permanent sight loss by damaging the optic nerve. Most types of glaucoma have no symptoms, so a regular eye test is the only way to know you have the condition. Treatment can prevent sight loss, but any sight loss caused is irreversible.

Cataract: A cataract occurs when changes in the lens of the eye cause it to become less transparent. Over time, as a cataract becomes worse it can start to affect vision, eventually requiring surgery.

The number of Londoners living with sight-threatening eye health conditions and sight loss is growing



Source: RNIB Sight Loss Data Tool, Royal National Institute for Blind People, April 2017

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Poor eye health has profound negative impacts on people's wider health and wellbeing

At least 50 per cent of sight loss can be avoided. Many people are needlessly living with sight loss. Almost two thirds of sight loss in older people is caused by conditions like refractive error and cataract which can be corrected.[2] Around three people a month lose their sight because of delayed access to eye health care. In addition, poor eye health can contribute to a variety of other health and wellbeing issues.

Mental health Our recent investigation into mental health found that people who experienced sight loss had higher rates of depression, anxiety and social isolation.[3] This is particularly important for those who lose their sight at a later point in their life. Losing your sight is a life-changing event. Adults tend to be more afraid of losing their sight than they are of developing other serious conditions such as Alzheimer's, Parkinson's, or heart disease, or of having to use a wheelchair.[4] But RNIB found that only 17 per cent of people were offered any emotional support at the time of their diagnosis.[5]

Falls Poor eye health increases the frequency and severity of injury from falls, particularly amongst older people. For those with sight loss, the risk of injury from falls is nearly twice as high (1.7 times) and the rate of hip fractures is also nearly twice (between 1.3 and 1.9 times) as high, compared with people with good eye health.[6] And more than four in ten hospitalisation episodes among the over-65s are caused by falls.

> "what we are finding is that patients are coming in with falls that could be preventable had their eye condition been addressed and of course falls lead to bed-blocking and have a much wider impact on the health system"
>
> *Helen Lee, RNIB*

The combination of poor sight and the subsequent fear of falling can reduce independence and prevent people from leaving their own homes. Losing independence is disastrous for mental health, exercise levels and ultimately quality of life.

Diabetes There are 475,000 people over the age of 17 living with Type 1 or 2 diabetes in London.[7] Within 20 years of diagnosis nearly all people with Type 1 diabetes and almost two thirds of people with Type 2 diabetes have some degree of retinopathy. People with diabetes also have a 50 per cent increased risk of developing glaucoma and a threefold increased risk of developing cataracts.[8] Many people, including those living with diabetes, do not know that diabetes can lead to sight threatening conditions and do not take up screening offers This is a particular concern for younger people diagnosed with the condition: screening uptake in the 12-18 years age range varies between 67 and 89 per cent across London.[9]

Dementia Sight loss is typically under-diagnosed in people with dementia because one condition can mask or be mistaken for another. People with dementia may have visual difficulties (such as problems with perception) but still have healthy eyes. A recent study into the prevalence of dementia and sight loss found nearly one-third of people with dementia also had significant sight loss.[10] Almost half of the participants could have their sight loss corrected by wearing glasses, offering potentially significant improvement to quality of life and reducing the risk of avoidable injuries through falls. Ensuring that people with dementia get regular eye tests is vital.

Self care Maintaining your own health in a sight-dominated society is challenging for those with sight loss. Health promotion information and resources are not always accessible. Being able to see the instructions on a medicine bottle, read a letter about a follow-up appointment, driving or navigating public transport to get to the hospital, and being able to cook and feed yourself, are among the numerous tasks which are made more difficult by even mild sight loss. Assistance technology can help here, but is not universally available to all experiencing sight loss. Encouraging self care is an important factor in reducing dependence on clinical and social care services, so maintaining good eye health is critical.

Integrating eye health into wider public health activity

Eye health in London is being compromised because it is not being considered alongside other associated health conditions and is therefore not given sufficient attention. This means that it is being under-prioritised as a public health issue and by service commissioners. But there is a compelling case for integrating eye health into wider public health action around issues such as smoking cessation, diabetes prevention, weight management and boosting physical activity levels: there is a strong evidence base showing the links between eye health and these factors. The Mayor's Health Inequalities Strategy includes a strategic aim to promote healthy habits: discussing eye health in this context would help raise its profile.

The Mayor should ensure that the Thrive LDN mental health programme and the London Healthy Workplace Charter include eye health as part of efforts to boost prevention efforts and improve wider population health. And forthcoming work on making London a dementia-friendly city should also include work on how to manage eye health and sight loss for people with dementia.

Poor eye health disproportionately affects vulnerable and disadvantaged people

Poor eye health is both a cause and effect of disadvantage and health inequality. The main risk factors for poor eye health are age, genetic disposition, and lifestyle. Socio-economic deprivation is associated with increased risk, as people are less likely to be aware of the issue, have less access to eye health services, and are more likely to smoke and have poor diets, both of which can damage eye health. Children with undiagnosed and uncorrected vision problems tend to struggle more at school and attain lower educational levels, setting them up for a lifetime of further health inequality.

Ethnicity

Some eye conditions are more common amongst black, Asian and minority ethnic (BAME) groups. People of African-Caribbean descent are eight times more likely to develop glaucoma than the general population, and it tends to appear 10-15 years earlier than in other ethnic groups.[11] People of Asian descent are more at risk of cataracts than the general population and both the Asian and Black population are more at risk of diabetic eye disease.[12]

Public health bodies have struggled to get this message across. 39 per cent of people from BAME backgrounds do not think that they are at higher risk of certain eye diseases due to their ethnic origin.[13] London has a particular challenge as a result of its relatively large BAME population.

One approach piloted in Wales has been to use community "champions" as the way to reach BAME groups. Community leaders were trained in delivering eye health messages both through group talks as well as one on one conversations. The pilot showed an increase in attendance at eye health checks.[14]

Homeless people

Research shows that homeless people have more eye problems than the general population. They are more exposed to risk factors such as poor nutrition, trauma, smoking, drug abuse and infections, and suffer from a high prevalence of uncorrected refractive error, cataracts, glaucoma and macular degeneration.[15] Furthermore, general health conditions experienced by homeless people such as diabetes or hypertension can lead to sight loss, if left untreated and uncontrolled. While many people who are homeless may qualify for an NHS funded sight test, too often they are unable to claim a sight test or a voucher to cover the cost of glasses because the relevant forms require an address. These problems could and should be addressed by NHS England, for example, to make clear that a homeless shelter or 'no fixed abode' is acceptable in place of an address. However, in the interim, the Mayor could consider options such as commissioning eye health services to be provided at homeless shelters as part of plans for the GLA to commission additional support for rough sleepers.

People with learning disabilities

People with learning disabilities experience profound health inequalities including eye health. It is estimated that around two per cent of the population have a learning disability, which for London would give an estimated 170,000 people who would have a range of mild to more profound and multiple learning disabilities.[16]

National research by the SeeAbility charity found that:

- 1 in 10 of the learning disability population is blind or partially sighted.
- Adults with learning disabilities are 10 times more likely to have a serious sight problem than other people.
- Children with learning disabilities are 28 times more likely to have a serious sight problem than other children.
- 50 per cent of adults with learning disabilities have not had a sight test in the recommended period.
- 4 in 10 of children in special schools have never had a sight test. [17]
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If someone has more profound disabilities and cannot speak they may not be able to recognise or communicate that they have a sight problem. This means those supporting people with learning disabilities need to be aware of signs of vision problems and make sure people are supported to get a sight test.

It is crucial that people with learning disabilities and their supporters are aware that sight tests are important checks to have, and that you don't have to be able to speak or read to have your sight checked. Currently there is no data collected on access to eye care amongst people with learning disabilities by the NHS. Most people with mild learning difficulties should be able to attend a regular sight test. But for people with more complex learning disabilities additional support is needed across the capital.

Working age adults with learning disabilities are not automatically entitled to NHS funded sight tests. They can be faced with a confusing means test and may have to pay for their sight test as well as their glasses, unlike people in other high-risk groups who are entitled to a NHS funded sight test – such as those with a family history of glaucoma. Extending free eye tests for those with learning disabilities could be considered to assist this group.

The Mayor should use his public influence to highlight particular eye health risks for disadvantaged groups. The Mayor should also support use of community champions to promote eye health messaging to these groups and ask NHS and eye health partners to explore the feasibility of extending free eye tests to people with learning disabilities.

Public awareness of eye health is poor

Londoners do not get their eyes tested regularly enough. The NHS recommends that most people should have an eye test every two years.[18] Yet over a quarter of UK adults have not done so,[19] and eight per cent of people have never had an eye test.[20] The RNIB told us that the people need to understand that "an eye examination is a health check".[21] Large parts of the population associate going to the opticians with selling expensive glasses or contact lenses, rather than as a health check which might help diagnose and prevent eye disease. The Eyecare Trust found that 37 per cent of people have put off having an eye test due to cost concern.[22]

RNIB says that more than 9 in 10 people agree that a routine eye test could save someone's sight[23], but there is still a misconception among the public that sight loss is an "inevitable consequence of ageing; something that must be tolerated or adjusted to".[24] They also told us told us that "once people have had a good experience with opticians, they are then more likely to return and go back".[25] **The Mayor should support a London-wide drive to increase the uptake of eye tests.**

Getting parents to take their children for eye tests is particularly important. A child's eyes do not finish developing until they are approximately eight years old, so identifying eye conditions before then is paramount. The Chair of the London Eye Health Network warned us: "if children do not get some of the treatment at the right age, then it is too late."[26]

However, fewer than one in three parents have ever taken their child to an eye test.[27] Eye checks are mandatory at birth and at eight weeks old, but after it is the parents' responsibility to take their children for eye tests. Many parents assume that eye health is covered by the school system. This assumption likely comes from the fact that all children were previously required to have an eye test when entering school for the first time, age four or five. This is no longer the case. An eye test when entering school is a recommended (but not mandated) part of the Government's Healthy Child Programme. Consequently, not all parts of London commission this programme: local authorities can elect not to, if budgets are constrained.

Improving eye health in children may also be a way to help harder-to-reach communities. Eye Heroes[28] is a child-led campaign to fight avoidable blindness. It argues that children are uniquely placed to overcome traditional barriers to eye health, such as language issues, problems with mobility, perceived costs associated with eye tests, anxiety and the stigma that can be attached to sight loss. Eye Heroes trains children to go home to their parents and family friends and spread the word on the importance of eye health. **The Mayor should promote vision screening for four and five year olds and ensure that eye health is included in health measures promoted by Healthy Schools London and the forthcoming Healthy Early Years programme.**

Poor eye health damages London's economic prosperity

Untreated eye conditions bring high social and economic costs to London. Research has shown that the total cost of sight loss to the UK economy is a staggering £28bn per year, or £6.4bn to London – around £750 per Londoner per year.[29] Costs include direct medical costs, indirect costs of social care provided by friends and family and the cost of productivity loss from much higher unemployment rates amongst blind and partially sighted people. This is a figure which can be reduced by proactive strategies to lower the risk of sight loss in London, alongside greater support for people to manage long-term eye conditions while living independently.

Eye health and employment

Only a third of all registered blind and partially sighted people of working age are thought to be in employment.[30] This compares unfavourably to disabilities as a whole, where almost half of all disabled people are in employment.[31] The employment rate for all adults – non-disabled and disabled – is 75.1 per cent.[32]

Blind and partially sighted people often face additional barriers to employment. Travelling independently to work and navigating London's transport system and street environment may be more difficult for people with sight loss. When out of work, many feel shut out of an application process that often assumes healthy sight. When in work many feel that they won't be able to continue performing their job to the same standard as before their eye condition. But as more and more assistive technology becomes available, specialist support means most people diagnosed with eye health conditions remain eminently employable and able to continue their careers.

RNIB and others do fantastic work, helping blind and partially sighted people into work, but with the help of the Mayor could do so much more. In particular, the Mayor should press ahead with efforts to make London's transport system more accessible to people with visual impairments. London will also soon have additional devolved powers over adult skills and employment programmes.[33] **The Mayor should explicitly recognise people with sight loss in future strategies as a group of people who can be better supported into meaningful work. We also recommend that he supports initiatives such as the #workwithme campaign to help tap into the currently under-used potential for employing people with sight loss and helping them to stay in work. As part of this, the Mayor should review GLA group recruitment practices to ensure that applications from people with sight loss are supported.**

Demand for eye health care is placing avoidable pressure on GPs and hospitals

Eye health problems generate a significant amount of work for primary care and hospital services in London. As many eye health conditions are symptomless in early stages, people tend to wait until they experience vision problems before seeking medical attention. This leads not only to late diagnosis but also to increased visits to GPs: an issue compounded by low awareness of community optometry services. A recent survey of GPs found that eye health is an area where GPs feel low confidence and tend to over-refer to hospitals, as they do not always have the specialist knowledge and equipment to accurately diagnose eye problems.[34]

There are around 1.2 million eye-related hospital outpatient appointments per year – a 30 per cent increase in the last five years.[35] And eye-related casualty attendances are increasing by around 9 per cent each year.[36] Patients present to A&E partly because they perceive their eye problems as sight-threatening and partly because it can be difficult to access other treatment pathways, such as through GP appointments. Approximately 30 per cent of patients attending casualty departments have non-sight threatening/ non-urgent problems, suggesting that increasing public awareness of eye health, combined with a greater focus on managing non-urgent cases outside hospital settings, could reduce pressure on hospital services and ensure those who do need hospital services receive timely care. [37]

Like many health care issues, up-front investment at the right time saves expensive treatment later. Some hospitals in London now have Eye Clinic Liaison Officers (ECLOs), who help patients presenting at eye clinics to take the next step and access services in the community, voluntary sector or social care. RNIB estimates that for every £1 invested in ECLOs the return can be up to £10.57.[38] But currently 9 out of 18 NHS Trusts in London do not have an ELCO service.[39]

The Mayor should support the use of eye clinic liaison services and challenge NHS partners to develop a common service, training and competency specification for ECLOs and ensure there is an ECLO service in every London hospital.

Hospital visits for eye health are costly but there are ways to reduce their number. The Chair of the London Eye Health Network told us that "we have to encourage refinement in primary care to avoid unnecessary referrals getting into the hospitals".[40] There are opportunities to make better use of the existing network of community based eye service providers to reduce pressure on GP and hospital services; for example, through the development of primary eye care services and more multi-disciplinary community ophthalmology-led services. There is also potential to increase the use of these services to deliver post-operative assessment and low vision care, and models such as Lambeth and Lewisham's Minor Eye Conditions Scheme (MECS), a collaborative approach between providers which has reduced the number of referrals to hospitals via GPs and increased community management.[41]

Lack of capacity in eye health services is harming Londoners' sight

Capacity issues are preventing effective eye health interventions. In an RNIB survey of staff in eye clinics across England, over 80 per cent of respondents said their eye department has insufficient capacity to meet current demand. The respondents were also asked about capacity in the longer term, with 94 per cent reporting that future capacity will not meet rising demand.[42] London services are also reporting that the major cause of delays to treatment and follow up appointments is lack of capacity.

There are various reasons why the London system is currently overburdened, beyond the general rise in demand due to population growth:

- **Advances in the treatments** available for eye diseases have increased demand, as previously untreatable conditions can now be better managed.
- **The rising prevalence of eye diseases**, and of conditions like diabetes which have sight threatening elements, has led to more initial appointments being needed.
- **The rise in first time appointments has a knock-on impact** on eye clinics' capacity to schedule and manage appointments, including timely follow-up appointments needed for the ongoing management of conditions.
- **Delays in follow-up appointments can lead to further deterioration of sight**, making the ongoing condition harder to manage effectively. This may lead to further demand for follow-up appointments. Managing chronic sight-threatening conditions effectively is dependent on regular appointments at specified intervals, so the more pressure there is within the system for appointments, the harder it is to prevent deterioration.

Some London commissioners have in the past attempted to manage capacity issues and limited resources by increasing thresholds for intervention and limiting certain treatments, such as cataract surgery. This results in needless delay and harm for the patient, affecting quality of life. But it also increases the risk of that person needing further, and more costly, interventions; whether through social care support, admission to hospital following a sight-related fall, or to treat deteriorating mental health.

Service provision is inconsistent across London

London CCGs spend on average 2.3 per cent of their budgets on eye health, compared to the England average of 2.6 per cent. [43] Ealing and Hammersmith and Fulham CCGs spend the least – £17 per person – and Redbridge and Havering spend the most – £36 per person. Eye health appears to be viewed as a lower health priority in comparison to more 'serious' conditions such as dementia or cancer, even though research shows that people rank sight loss alongside these conditions in terms of impact on quality of life. For example, all of London's five Sustainability and Transformation Partnerships (STPs) address dementia and cancer, but none specifically mentions eye health in their plans. **This is an area the Mayor should encourage STP leadership to address in their developing plans.**

The London Eye Health Network (LEHN) highlighted a lack of a consistent approach to eye health in London. This means that a patient's experience can vary based solely on where they live, and also creates avoidable duplication of activity. LEHN found that:

- Eye health plans are not shared widely between commissioners when they were often dealing with the same Trust.
- There were different specifications for the same eye health services across London.
- Commissioners are not using the VISION 2020UK Portfolio of Eye health indicators.
- Only a third of London CCGs commission glaucoma repeat measures (NICE Quality standard).
- Several London CCGs are reviewing cataract pathways but are doing so separately from each other.
- Opening times for emergency eye services vary: most outer London eye clinics close at 4pm, increasing demands on inner London services.[44]

NHS England told us in its submission that currently there is "fragmentation of services and a more joined-up approach to commissioning eye care services should be adopted."[45] This is reflected in the evidence we heard from the across the eye heath care sector. This suggests that while there is a strong, evidence-based clinical consensus on what would work more effectively to improve care, there remains a lack of strategic oversight to actually put these plans into action.

Action is also needed at a local level, through Health and Wellbeing Boards. The Clinical Council for Eye Health Commissioning (CCEHC) has produced frameworks specifically for commissioning primary eye care, community ophthalmology services and low vision services in a more integrated way. But first, CCGs and local authorities need to have a better understanding of the eye health needs of their local populations, and the organisation and delivery of local services. **The Mayor, through the London Health Board, should urge local authorities to consider eye health more explicitly in joint strategic needs assessments.**

A London-wide strategy for eye health

Community and primary care services, hospital trusts, patient representatives, public health representatives, and the voluntary sector have all highlighted the difficulties posed by the current fragmented system. What appears to be lacking is strong strategic oversight at a regional level to drive forward the changes that are needed to transform eye health care in London and beyond.

We have seen examples of the transformative nature of co-ordinated action to tackle significant health challenges for London. The London Stroke Strategy and the pan-London commissioning of HIV prevention services through Do it London both serve as examples of what can be achieved through effective partnership working with a clearly defined set of common aims.

Greater Manchester has already developed a regional strategy to transform eye health services and is reported to be making good progress on this issue. But London should be at the forefront of efforts to drive forward eye health improvements at a population level.

Leadership from London could galvanise action at a national level. London is fortunate to have some world class eye health services, notably Moorfields Eye Hospital. As a city we are therefore well placed to lead from the front on eye health care. The Mayor, through the London Health Board is well placed to push for a more cohesive, pan-London approach to this issue. The partnership approach which the Mayor is seeking to leverage through the Health Inequalities Strategy could provide the impetus that is needed to finally make these changes happen.

The eye health sector is calling on the Mayor to use his considerable influence to assist in this process. We agree: **The Mayor should work with the eye health sector to help develop and implement a London-wide strategic plan for eye health, with updated data on service activity, quality, organisation and current delivery of services, clear plans to address unwanted variation and duplication in service provision, and an emphasis on reducing health inequalities associated with poor eye health.**

The Health Committee thanks all organisations and individuals who participated in this investigation. For more information on our work see https://www.london.gov.uk/about-us/london-assembly/london-assembly-committees/health-committee

Endnotes

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