

Report on the Healthwatch Wandsworth Consultation on Eye Health and Preventing Sight Loss in London.

Background

In London, around 193,000 people are currently estimated to be living with sight loss, including over 25,000 with severe sight loss. This figure is projected to rise to almost 268,000 by 2030.

Eye health is a crucial determinant of quality of life. According to the World Health Organisation (WHO), among the many effects of visual impairment on a person's wellbeing people are:

- three times more likely to be unemployed
- three times more likely to fall while walking
- three times more likely to suffer from depression and anxiety disorders.

Regular sight testing and early detection of eye conditions can prevent sight loss. According to WHO 81% of problems related to visual impairment could be avoided if diagnosed and treated early¹. Despite the importance of eye tests, take-up of regular eye screening in London is low, particularly for some at-risk groups. According to one study, those with a visual impairment or severe sight loss are more likely to be of low socioeconomic status, be unemployed and have poor health², although visual impairment affects all ethnic and social groups. A study of a random sample of people aged 65 and older in North London showed that 30% were suffering with cataracts that impaired their vision and that 88% of those with cataracts were not under the care of an eye specialist.³

According to researchers from the Centre for Disability Research at Lancaster University, an estimated 96,500 adults in the UK with learning disabilities are blind or partially sighted (about one in 10 adults with learning disabilities).

The London Assembly Health Committee recently conducted an investigation into eye health and preventing sight loss in London. Healthwatch Wandsworth decided to look into the issues locally to make recommendations and influence the Mayor and the London Health Board's plans.

Our Consultation Survey

Healthwatch Wandsworth ran the eye health survey from 01 June 2017 to 30 September 2017. We circulated it to our networks and at our regular outreach events, and included it on our website and social media. To ensure we gained feedback from people experiencing eye health issues we spoke to people in the waiting area at the Moorfields Clinic at St George's Hospital. We also approached a number of local community organisations that work with groups of people who have poor eye health.

¹ World Health Organisation (2017), Blindness and visual impairment prevention [Online]. Available at <http://www.who.int/blindness/en/> (Accessed October 2017)

² Nazroo, J., Falaschetti, E., Pierce, M. and Primatesta, P. (2009). J EpidemiolCommunity Health, jech.2009.089409.

³ Reidy, A., Minassian, D. C., Vafidis, G., Joseph, J., Farrow, S., Wu, J., Desai, P. and Connolly, A. (1998). Bmj 316(7145), 1643-1646.

Findings

We received 43 responses to our survey. A sample of the questionnaire can be found in Appendix A.

Question one: Why do you think that eye health should be a priority for London?

We first wanted to understand people's thoughts on how important eye health is to people and why.

Almost all respondents felt that the subject of eye health should be a priority in London. Many felt that the importance of eye health was self-evident but that promoting prevention is necessary:

'It's just so important. You have to look after them at any age.'

'It is vital to prioritise eye health in London for many reasons, not least because so much sight loss is preventable if eye conditions leading to sight loss are detected and treated in their early stages. Sight loss is also expensive for London and (unsurprisingly) leads to an increase in falls and incidence of depression.'

Impact on everyday life and wellbeing

Over half of responses (24 of 44) highlighted that good eye health was centrally important to everyday life and that this made it a high priority as the consequences of poor eye health can be far reaching.

'I think it's pretty obvious - people need their eyes for absolutely everything.'

'Your eyesight is precious. It affects every aspect of your life - your freedom.'

'It's important to see and you need to read where you are going. You need to see for instructions and in your spare time you also need to read.'

A couple of respondents suggested it was a particularly important issue in London.

'It is a big and complicated city. Daily living with sight loss must be hugely challenging'

'So important that all can see as well as functionally possible in order to appreciate our world and to avoid accidents in this very crowded environment.'

Consequences and increased vulnerabilities

Nearly a third of respondents (12 of 44) talked about the consequences of poor eye health in more detail, including the limitations it can bring and the added vulnerability it could cause.

Getting around and mobility: a number of responses particularly highlighted that it affects the ability to get around.

'It's a major part of being able to get around - you're limited if you can't see.'

'One of the major things you always want to hold onto is sight. Things in your living environment will be accessible to you.'

Others highlighted concerns about safety:

'Because people are sometimes vulnerable and need all the help they can get.'

'Living in a city without proper eye sight is challenging e.g. buses, crossing roads and busy pavements'

Some people commented on the possible isolation poor eye health could bring, particularly because a lot of information and interaction in society is visual.

'To keep individuals independent and leading a full life. Enabling them to fully function in society'.

'Sight loss does isolate people and as an increasing amount of media and information is of a digital nature, this can make social isolation more complex.'

However, a few respondents didn't feel that eye health is a priority:

'No, shouldn't be a priority. there are too many other things that should be important.'

'I don't think it should be a priority, but people should be clear on where to go should they need treatment.'

Question two: What do you think are the key factors that affect eye health? Which groups do you think are particularly affected?

This question not only asked for people's experiences but also measured their awareness and perceptions of eye health issues and who might be affected.

Awareness

Generally, we found that there was a **limited awareness of factors affecting eye health**. Many people found it quite difficult to answer this question or to provide specific information.

Lack of awareness was mentioned in a number of comments and many highlighted that people might **ignore symptoms** or **not get the necessary help**.

'You don't generally know that you have an issue with your eyesight. You just accept what you see. People don't understand about eyes.'

Some highlighted the importance of **prevention and early detection** for adults and children:

'Middle age[d] people to work on preventative issues to stop sight deterioration.'

Lack of awareness is important because it may have an impact on prevention and seeking help early. Some respondents also mentioned that availability and access to services could be another barrier to getting help. One person said there could be a lack of opticians in an area. Others said:

'Opticians are not seen as part of the health service, but as salespeople.'

'Doctor's neglect, in the fact that when they know you should have drops, you can't get appointments to get the eye drops - doctors not taking you seriously enough.'

Age and aging was mentioned by the majority of people (26 of 44 responses) as the one factor most affecting eye health and the group most affected. The next most common factor and group affected was **diabetes and diabetic people** (15 of 44). The third most mentioned factor was the **genetic and hereditary** element (10 of 44 responses). Glaucoma was only mentioned in two responses and macular disease just once. Other health conditions and overall health and wellbeing were noted in 8 responses.

A variety of **lifestyle related factors** were also mentioned. **Diet** was noted by a quarter of respondents (11 of 44). Only two mentioned specifics such as vitamins A and B12. A number of people mentioned **using computers and technology** which can lead to eye strain issues (6 of 44). **Costs** and barriers for low income earners were referred to four times.

Other factors included **pollution** (including air and water) mentioned by just under a third of people (9 of 44). **Sun and light exposure** were mentioned once. **Work related factors** were commented upon by three people.

Groups most at risk

Other than older people, those with diabetes and hereditary factors (as mentioned above) others identified as likely to be particularly affected by eye health were:

- Certain ethnic groups (mentioned by 5 respondents).

'People from African Caribbean backgrounds have a significantly raised risk from glaucoma. London is very ethnically diverse, and certain communities are more prone to conditions such as Diabetes.'

- Children (3 responses)
- Low income (3 responses)
- Blind people (1 response) and non-registered blind (1 response)
- Substance misusers (1 response)

- Single parent groups (1 response)
- Men (1 response)
- People with learning disabilities are ‘ignored’ (1 response)

Four people suggested that anyone could be affected, and one person highlighted that many eye conditions are unpredictable. This is interesting because if everyone could potentially be affected, it implies that it is very important that all are aware of the issues involved, including the preventable causes of poor eye health. Yet only a small number of people picked up on this during the survey.

Finally, a few people mentioned other issues that poor eye health may contribute to.

‘Not being able to read notices, see the television, ... etc.’

‘The person could be lonely, or get depressed’

‘Their jobs would be an issue because they may not get a job because of their eyes.’

Question three: How aware do you think people are of the importance of maintaining eye health? What are the main barriers to raising awareness?

We wanted to understand awareness of the importance of maintaining eye health to help people avoid preventable eye issues. We asked what people felt might be the barriers to raising awareness.

Most people felt that **people aren’t very aware of the importance of maintaining eye health**. Responses followed the themes below:

- People aren’t very aware (approximately 55% of responses)
- People are aware but there needs to be more awareness (approximately 18%)
- Most people are aware (approximately 11%)

Of those who felt like most people are aware comments included:

‘Most people know where to go to start the ball rolling. There are plenty of ads on the TV, e.g. about glasses, to make people think about it.’

Many people felt that people might **take their eye health for granted or give eye health a low priority until they find themselves with a problem**. This sentiment appeared in 16 of 44 comments about potential barriers to maintaining eye health.

‘I didn't really think about it until it was a problem for me. I went to see my GP and they referred me to A & E’.

‘We aren't very good at balancing different demands of looking after our health. I suspect we all take eye health for granted... An overload of information e.g. health information might be a barrier. People are particularly bad at being aware of areas of keeping well.’

A couple of respondents suggested people were

'conscious about their appearance - they might not want to wear glasses'.

Lack of information and understanding was mentioned in 9 comments. Another person mentioned **cultural awareness** as a problem and another mentioned **language** as a barrier.

'People are probably unaware of protective factors. Even as a sufferer I have little awareness of these.'

'It's not generally discussed in GP appointments.'

Affordability, including the affordability of eye tests and glasses was mentioned by 6 respondents as a barrier. One person said it is hard to **access to services** and another mentioned **having to take time off work** as a problem.

Respondents also suggested some ideas for **overcoming barriers**. Many suggested **publicity campaigns about eye testing and conditions and their causes**. A few said that **education should happen at school**. Others suggested that offers on eye tests and glasses, or free eye tests, would encourage people to take their eye health more seriously, and that reminders for eye tests would be helpful.

'Information has to be more in your face than it already is. This information is rarely on social media... The useful stuff isn't there.'

'Eye health should be addressed in school, this enables children and young people to be aware of the need to maintain eye health throughout their life.'

One person suggested **eye care could be accessed through the NHS**, a place where most people would go for health-related advice, information and support.

'A long-term health campaign (over years), access to eye tests through NHS and not places of sale e.g. pharmacies, opticians.'

Question four: What impact do you think poor eye health and sight loss have on wider health and wellbeing?

Most of the responses we received to this question highlighted the **difficulties people might face with everyday life**. Below are the general themes around aspects of life that poor eye health can affect.

- **General health and wellbeing and quality of life, it can lead to other problems and difficulty maintaining physical activity levels.**

'If you can't see and don't feel like going out all of your health suffers.'

'Isolation particularly for older generation which will lead to other avoidable health conditions'.

- **Mobility, ability to do ‘normal tasks’ and ability to travel leading to isolation and reduced social interaction** (mentioned by a third of people ,14 of 44)

‘It’s harder to do everyday life tasks and get around e.g. getting lunch - reading what is on a packet was difficult.’

‘Things to do with other senses are disappearing. E.g. sounds you get to help you get on trains are in busy areas and you can’t rely on hearing the announcements. Departure boards on train stations are high up as are advanced notices of buses – it’s a good system but you have to be able to read’.

‘Might make interpersonal relationships and social life [difficult] - especially if people don’t know you well.’

- **Independence and reliance on other people to do ‘normal tasks’** (mentioned by a quarter of people (14 of 44).

‘It could be difficult if you don’t have people around you to help you, example if you can’t drive and need to.’

Not being able to read ‘impacts on the ability to access information on health and general wellbeing’.

- **Employment and ability to work** (mentioned by a quarter of respondents,11 of 44). Many highlighted that poor sight might lead to unemployment.

‘My wife has had to give up her job’.

‘A very high number of blind and partially sighted adults are not in work (over 70%)’.

- **Mental Health** (mentioned by a third of respondents, 11 of 44); some highlighted anxiety, depression and loss of confidence.

‘Anxiety, you can become aggressive. - Your whole mood changes once you feel you’ve lost your sight, you feel you’ve lost control. Your independence has been compromised.’

‘Poor eye sight limits people’s activity, employment potential and enjoyment of life.’

‘Loneliness’

- **Safety and accidents** was mentioned by 5 of our respondents.

‘You could be injured by things that are left out on the pavements (bins, cars parked on pavements etc.) – it’s an obstacle course.’

‘Falls, accidents, costing more in NHS departments’

Other comments included the potential impact on children's education, that more people need quicker certification to get access to support, and that there is a need for eye health problems to be treated in a timely way.

One person highlighted that there is a wider impact on **family as well as individual and friends**.

Question five: What do you think are the main challenges around improving screening and eye test uptake, in both adults and children?

The **cost and expense of tests** was mentioned by nearly 30% (13 of 44) of people as a barrier to eye test uptake.

'The cost is exorbitant. If people can't afford it, there's no point in making them go there to get the check in the first place.'

'You have to be a certain person to be able to get a free eye test. I think that's why a lot of young people don't go to the opticians - because of the cost.'

'People worry about the cost. It's not a priority for most people - even if they're starting to struggle.'

Convenience was also a popular theme as was finding time for regular appointments, being able to have tests at a GP surgery and the fact that eye health should be considered alongside other health related issues. One person highlighted that they had relied on their GP for a referral for their problem. Another mentioned that their local supermarket provided free eye checks for customers when shopping.

'Time - in this day and age, a lot of people have busy lives. People might put it on the backburner'. 'Especially those who work or have children.'

'There are no regular milestone MOTs for eyes as part of wider health'.

'It is important as a general health check-up.'

A few particularly highlighted that there should be **better guidance and prompting for more regular appointments**. Some suggested that the fact that eye checks aren't mandatory could potentially have a negative impact on eye health.

'It's only if you are conscientious yourself, and go to get your eyes tested, that the optician can pick up on something.'

'The gap between eye check-up appointments is far too long (e.g. once/twice a year).'

A few comments highlighted that it is up to adults to notice if there is an issue with a child's eye health and to support them to get help. They might get more support at school but once they have left they might not get checked until there is a problem. Schools don't have enough teachers and there are not enough nurses.

The **need to raise awareness and education for the general public** was mentioned by almost a third of people (12 of 44); this echoes earlier comments suggesting that there is a

general lack of information and awareness of how to maintain eye health and what to do if there is a problem.

'Education and access. I am an example where both parents had sight loss, and whilst I am offered regular eye screening, I try to avoid it, don't take the treatment and ignore the issue. I do wear glasses to read and have done for 15yrs. I just bury my head in the sand about the potential consequences and accept the risk. It's not going to kill me. So attitude (even for the educated) is a major challenge.'

Access and cancelled appointments were amongst a few of the other comments.

Question six: What impact is the rising prevalence of eye health problems having on the health care system in London?

A main theme to the responses to this question was that **a system under pressure would bring delays** to treatment which might **affect a patient's outcomes** and may mean that **other health related problems develop**.

Increased demand and pressure on the system and other services was a theme across over a third of responses (36%, 16 of 44). Participants highlighted particular services that might be affected including A & E, clinics and social services. Some specifically highlighted that deteriorating patient health might also mean **greater demand on other services** for conditions like depression, falls and other accidents, care assessments and carer packages. Also, there might be a greater demand for Disability Living Allowance, Attendance Allowance and Personal Independence Payments.

'I would think that it makes things more difficult for the care system, as a patient has more than one issue to be resolved.'

Longer waits were specifically highlighted as a potential problem for the health care system. A long wait for appointments can have a knock-on effect on other aspects of life.

Many suggested that increased demand would impose a **greater financial burden** on the health system (7 of 44). It was also suggested that the **quality of services** might be affected.

Two respondents highlighted issues about the **way that different services work together**.

'Problems booking an appointment, using the booking systems. The communication between the e-booking systems and clinics (the different I.T. systems) is poor. So people end up in A&E because they can't see their GP and can't get an appointment. There's a total lack of cohesion between the different I.T. systems (GPs, hospitals and e-referral service).'

'Eye health needs to be incorporated into the system. There aren't mandatory checks.'

Others highlighted how **cross-system working is important for prevention** and suggested that schools could play a greater role.

'Lifestyle is probably one of the most important things that can affect your eyesight. Perhaps more nutritional advice would be welcome - more emphasis put on it - particularly in schools.'

'Prevention is not only better, it's also cheaper than cure, picking up the issues early can reduce the cost to the health service.'

Question seven: What impact do you think the delay in treatment has on patient outcomes and the wider health and care system?

Increased delays is one of the key issues increased demands on the health system, due to poor eye health, could cause. We asked people what impact this might have on patient outcomes and the health care system.

Most people said that the **impact on patient outcomes** might be that their **condition deteriorates**.

- **Worsening of eye health**, with some irreversible effects (34%, 15 of 44)

'Can be a dramatic impact ... e.g. retinas need seeing to the same day.'

'You could lose more of your sight. Glaucoma needs dealing with swiftly.'

- **Wider health and wellbeing affected**, including potential accidents was highlighted by 8 people

'People can have accidents, poor judgement in lots of things (e.g. signing forms).'

- **Mental health** - 6 people highlighted anxiety, stress and frustration

'Delay makes you anxious, angry and may exacerbate the condition - that means more expense to the health services in the long run.'

- A few respondents said that without help, people might **turn to other avenues** that might not be the best option.

'If there's a delay, then they turn to other resources (e.g. services that can't help them).'

- One person emphasised the **financial issues that affect some people**.

'I have a relative (in Ireland) who has paid for his own cataract operation. He had already lost sight in one eye so was virtually blind. He borrowed money to pay to get it done because he was effectively without any sight and there was

a long wait. He had to get taxis to get about. You could also lose your job which is also a problem if you have a mortgage.'

- Other potential outcomes included extended **recovery** times and **more care in the long-term**.

Some said that long waits for treatment might mean that patient **conditions worsen, ultimately requiring more funding and resources to treat**. Others said that long waits could create **backlogs, unmanageable peaks and higher demands on social care**. One person even suggested that **staff morale** could be affected and that might affect staffing levels.

Question eight: What additional challenges are there in supporting people who are homeless, in prison or have learning disabilities to maintain good eye care?

The London Assembly were interested to hear about additional challenges for taking care of eye health that might be experienced by the above groups of people. Generally, we found that people found it difficult to answer this if they had not had experience of, or connections with, these groups of people.

The main themes were:

- Most people felt that **eye health might not be a priority** for such people because they have **other, more important, priorities** and perhaps **health concerns and complex needs** to be looked after.

'If they are not looking after their wider health, it will have an impact.'

'Life is turbulen[t] and chaotic, often with little stability and regular long term, high quality support. Health needs are complex and need to have a co-ordinated and holistic approach.'

- **Cost.**
- **Lack of a system and resources to support them or difficulty accessing support for checks that they need.**

'In prisons to get referred to a doctor takes forever - health and social care in prisons is inadequate and not helped by privatisation - I used to support women in prisons'.

'I work with homeless people. There's not the facilities for homeless people. Some of the care homeless people get (like haircuts) are only once a week. Even people who are EA/EU nationals may have issues.'

- **Difficulties health and care professionals might have reaching them** (e.g. prison security, location of homeless people).
- **Communication and comprehension barriers.**

[People with learning difficulties] 'may not recognise issues or be able to communicate'.

[It might be difficult to] 'make sure there are support staff to help them engage and understand a care plan.'

- **Difficulty for services to keep in touch and confirm appointments** with patients who don't have an address. These groups of people might **'fall through the net'**.

A couple of people said there would be a higher cost to the health care system to meet the needs of these groups but suggested that services take a proactive approach.

Question nine: What do you think that the Mayor can do further to support better prevention, detection and treatment of eye health issues in London?

We then explored suggestions people had about how the Mayor of London could support eye health issues to help inform the future strategies of the London Assembly.

Most people (21 of 44) suggested an awareness campaign and advertising.

People said that this should include:

- Information about eye health, risks and prevention
- Encouraging more testing
- Raising awareness about what it is like to have vision impairment and that not everyone is able to rely on their eyesight
- Consideration of cultural and language differences
- A consistent campaign to remind people to get their eyes tested
- Specific work with children
- Support for other campaigns and initiatives e.g. **'Croydon Vision among the African Caribbean community highlighting glaucoma risks.'**

Other suggestions included:

Pressing for better eye care and supporting initiatives that provide support.

- Pressing the government for better funding
- Pressing the government and NHS to better use resource to tackle the issues in a holistic and co-ordinated way
- Ensuring more services are available and easier to access, including home visits from opticians, mobile optician units and check-ups in public places like shopping centres and markets.
- Improving availability of appointments and testing, particularly for vulnerable groups and people most at risk
- Improving standards of eye care and information provision
- Encouraging employers to offer free eye-checks
- Better awareness among health and care professionals so that people are certified as visually impaired and can get the support they need. One person suggested this should include allowing ophthalmic consultants to refer directly for to courses **'Finding your Feet'** and **'Living with Sight Loss'**.

A number of people (10 of 44) suggested that the cost issues could be addressed.

Suggestions included increased availability of free eye tests for everyone, a voucher system, standardising eye test costs and financial support for vulnerable or at-risk individuals.

A final suggestion was that the Mayor's transport services could have a role, for example they could 'do more to simplify and enlarge signage for parking and bus lanes.'

Conclusions and Recommendations

Below is a summary of the main themes running through the answers we got to our survey and suggestions about what could be done to tackle the issues.

Promotion, prevention and the need for an awareness campaign

Most people recognised that poor vision can be a problem in later life but potentially anyone could be affected by vision impairment. This implies that it is important that everyone is aware of contributing factors and how to avoid the preventable causes of poor eye health. One thing responses highlighted was that the majority of people are unaware of the specific causes of poor eye health and the preventative measures. In addition, many people felt that eye health is low priority unless they already have a problem.

A high number of people suggested the need to raise awareness and provide more information for the general public on how to maintain eye health and what to do if there is a problem.

Impact of poor eye health

Good eye health was viewed as being central to general health and wellbeing as poor eye health can increase the difficulties people might face day to day, especially in London which is crowded and potentially more difficult to get around. Poor mobility could lead to isolation and other vulnerabilities and safety concerns, as well as loss of independence which could affect a person's mental wellbeing.

Poor eye health, coupled with a lack of preventative measures and timely treatment, might lead to the condition worsening and impacting on a person's wider health.

The Health and Care System

As the above issues develop for a patient and the prevalence of eye health problems increases, there will not only be a greater demand for health services, but also a greater cost to those services, including social care.

The responses to our survey suggest that more should be done to include eye health in the general health management arena and that the different parts of the health system should join up to bring about better outcomes through prevention, greater access to testing and treatments. Proactive support for people at higher risk, earlier diagnosis and timely certification of vision impairment could mean better support and prevent some of the knock-on effects on wider health and wellbeing. This could improve outcomes, and save costs and resources for a stretched health care system.

Many people highlighted the importance of better education and support in schools from a young age contributing to improved eye health literacy and good eye health later in life.

Appendix A - survey questions

1. Why do you think that eye health should be a priority for London?
2. What do you think are the key factors that affect eye health? Which groups do you think are particularly affected?
3. How aware do you think people are of the importance of maintaining eye health? What are the main barriers to raising awareness?
4. What impact do you think poor health and sight loss have on wider health and wellbeing?
5. What do you think are the main challenges around improving screening and eye test uptake, in both adults and children?
6. What impact is the rising prevalence of eye health problems having on the health care system in London?
7. What impact do you think the delay in treatment has on patient outcomes and the wider health and care system?
8. What additional challenges are there in supporting people who are homeless, in prison or have learning disabilities to maintain good eye care?
9. What do you think that the Mayor can do further to support better prevention, detection and treatment of eye health issues in London?