

### Executive Summary

Visual Impairment (VI) includes severe sight loss (blindness) and partial sight loss. It affects an estimated two million people nationally and this figure is predicted to rise by a third to more than 2.7 million by 2030. The increase can be attributed mainly to an ageing population. Sight loss affects people of all ages but is more common in older people, with over 80% of sight loss occurring in people aged over 60 years. However, it is suggested that 50% of sight loss is avoidable if it is detected and treated early enough.

A number of risk factors can contribute to sight loss: genetics, age, ethnicity, socioeconomic deprivation, smoking, diet, diabetes, learning disability and stroke. In children and young people the most common risk factors are: prematurity, low birth weight, south Asian origin and learning disabilities.

Sight impairment affects peoples' quality of life and their mental wellbeing; affecting mobility, ability to socialise, live independently and increases their risk of falls. People with sight loss are more likely than the general population to experience financial hardship due to lower work opportunities and having a lower status job. Sight loss contributes to premature death and is an indicator of deteriorating health in conditions such as diabetes. Those who have sight loss in addition to other conditions such as stroke or dementia often have poorer outcomes than those without sight loss and can often have their sight loss undiagnosed. Sight loss reduces people's resilience to the adverse effects of ill health and injury in general and increases frailty and depression.

In 2016 in Tower Hamlets, there were an estimated 3,980 people living with sight loss, of which 460 were blind (severe sight loss), 910 had moderate sight loss and 2,620 had mild sight loss. However, only 1,075 out of 3,980 people were registered as blind (51%) or partially sighted (49%) with the local authority. This represents an overall rate of 392 people per 100,000 which is lower than in London (489) and England (540). 11% of the people registered as blind or partially sighted in Tower Hamlets had also been recorded by the local authority as having an additional disability.

Registration of VI is voluntary but requires the previous completion of a Certificate of Vision Impairment (CVI) by an ophthalmologist. As per 2015, Tower Hamlets had a lower rate of certification (22 per 100,000 people) compared to 30 in London and 42 in England. Since 2012-13, the number of certificates issued in Tower Hamlets decreased by 19.3% compared to a 0.8% increase in England. Registering as VI can entitle the individual to a range of benefits. However, not everyone with a VI chooses to be registered. This indicates that there may be a large number of people in the borough living with sight loss but not seeking support or accessing services.

By 2030, it is estimated that 5,780 (1.5%) people in Tower Hamlets will be living with sight loss (an increase of 45%). Of these, 670 will have severe sight loss (an increase of 46%).

The main eye conditions associated with sight loss are Age related Macular Degeneration (AMD), glaucoma, cataracts and diabetic retinopathy. The 2015-16 Tower Hamlets crude rates for these conditions are as follow:

- AMD crude rate (people aged 65 and over) was significantly lower (62.2 per 100,000 people)

than those in London (86.7) and England (114).

- Glaucoma crude rate (people aged 40+) was not significantly different (11 per 100,000) than in London (13.4) and England (12.8)
- Diabetic retinopathy crude rate (people aged 12+) was not significantly different (2 per 100,000) than in London (2.5) and England (2.9).

Attendance to the NHS Diabetic Eye Screening Programme (DESP) reduces the risk of sight loss for people with diabetes through early detection, appropriate monitoring and treatment of diabetic. Uptake of DESP in Tower Hamlets to 31st March 2017 was 83.3%. This meets the minimum national standard of  $\geq 70\%$  and the “achievable” standard of  $\geq 80\%$ .

In Tower Hamlets, there are an estimated 116 blind and partially sighted children aged 0-16; 58 of them are estimated to have additional needs. Moreover, there are an estimated 89 blind and partially sighted young people aged 17-25.

There are 88 pupils with a statement of Special Educational Needs (SEN) with VI as their primary SEN.

Screening for reduced vision in children is undertaken as part of the NHS Healthy Child Programme. The aim is early detection and prompt treatment of children aged 4 to 5 years with amblyopia. An audit of the Tower Hamlets vision screening service in 2015-16, showed that the coverage of the programme was 96%. This exceeded the national coverage acceptable standard of  $\geq 90\%$ . The programme also met the national acceptable standard target of 100% of parents being informed of the tests results within 6 weeks.

Evidence shows that public awareness of eye health is poor and more should be done to encourage Tower Hamlets residents to look after their eye health and raise awareness for the need for regular eye tests.

## Recommendations/Priorities

The priorities identified in Tower Hamlets are:

### Prevention

- Increase public awareness of the importance of eye health.
- Detect eye conditions earlier, especially in difficult to reach groups by promoting eye examinations/screening tests. Assess feasibility of including promotion within Making Every Contact Count (MECC).
- Routine eye health check to be carried out to people with learning disabilities.
- Promote eye screening for those aged 65 and over in order to reduce the risk of falls.

- Ensuring links with tobacco control, healthy weight, healthy lives (Obesity), diabetes and falls strategies are in place.
- Embedding the Vision Plan and Eye Health JSNA into the Health and Wellbeing framework and Commissioning Plan.

## Quality

- Review the certification process making sure people who are eligible get certified and registered in a timely manner and that relevant data flows through the whole eye health and sight loss pathway.
- Joined up data: Implement methods of identifying agreed accurate cross-sector figures for the number of local people with sight loss or low vision.
  - The local authority register of blind and visually impaired should be regularly updated.
  - Optometrist claims forms for NHS sight tests performed should be computerised and monitored on a regular basis so that data on the number of sight tests and domiciliary tests could be made routinely available.
- Joined up services:
  - Referral systems: Ensure referral systems between the sectors (Health, Social Services, Adults and Children and Voluntary) are in place and being used effectively.
  - Eye Clinic Liaison Officers (ECLOS): Provide an Early Intervention/Advice and Information Service at all Eye/Low Vision Clinics.
- Maximise opportunities for people with sudden sight loss and long-term degenerative conditions to access on-going rehabilitation and emotional support services.

## Access to services

- Review uptake of services and, where there are gaps, consider whether the provision of optometrists in the communities will facilitate access to eye services.

## Social inclusion and independence

- **Accessible formats:** Increase availability of information on services, social activities and appointments (GP and hospital) in accessible formats in line with the Accessible Information Standards stipulations.
- **Visual awareness training:** Increase visual awareness training for staff who provide public services (esp. with regard to transport, employment services, life-long learning, leisure services, NHS services and council commissioned healthy lifestyle services).
- **Navigation:** Address street furniture, uneven pavements, barriers and bleepers at road crossings, floating bus stops and shared space to enable visually impaired people to travel safely.
- **User led peer support:** User led support services can provide, advice and peer support to visual impaired people to combat isolation. Ensure suitable provision is commissioned locally.
- **Assistive technology:** To investigate ways in which assistive technology can be provided to people with vision impairment.

## 1. What are eye health and sight loss?

### 1.1 Sighting

People's sighting ability is defined by two parameters<sup>1</sup>:

**Visual acuity** is the vision which allows people to see detail. This is called central vision. Visual acuity is measured by reading down an eye chart using the Snellen scale which consists of a number of rows of letters which get smaller than the one above. On the Snellen scale, normal visual acuity is called 6 / 6, which corresponds to the bottom or second bottom line of the chart. If a person can only read the top line of the chart then this would be written as 6/60. This means you can see at 6 meters what someone with standard vision could see from 60 metres away.

**Visual field** is the vision to see around the edge of the eyes while looking straight ahead. Field of vision is measured by a person pressing a button when lights are flashed on.

### 1.2 Vision impairment (sight loss)

Definitions of sight loss are divided into three broad categories<sup>2</sup>:

**Clinical definition** (used by professionals such as optometrists and ophthalmologists): It uses visual acuity as its measure and identifies three levels of sight loss:

*Partial sight*: defined as best-corrected visual acuity of better than 6/12 (<6/12) to 6/60 in the better-seeing eye.

*Sight loss*: defined as partial sight or blindness in the better-seeing eye.

*Blindness* (severe sight loss): defined as best-corrected visual acuity of better than 6/60 (<6/60) in the better-seeing eye.

**Administrative definition** (used by health and social care bodies): It uses information gathered by different services that have identified people as blind or partially sighted. In some cases these are based on clinical measures like the certification of vision impairment, or on others measures (benefit claimants, recipients of social care services, etc.).

A Certification of Vision Impairment (CVI)<sup>3</sup> formally certifies a person as either sight impaired (partially sighted) or severely sight impaired (blind). People with vision loss can voluntarily be registered with their local authority as sight impaired or severely sight impaired. For this, they need to have had a sight test. The consultant will then complete the CVI form and will provide copies to the person, their local social services department and their GP. The CVI provides a formal route to social care services, but is not a pre-requisite for eligibility. However, not everyone with a visual impairment affecting their day-to day life chooses to be registered as sight impaired or severely sight impaired but they may still require the services. Registering as visually impaired can entitle the individual to a range of benefits including: Disability Living Allowance (DLA) or Personal Independence Payment (PIP), a reduction in the TV licence fee, a tax allowance, reduced fees on public transport and parking concessions.

<sup>1</sup> RNIB. The Criteria for Certification; <http://www.rnib.org.uk/eye-health-registering-your-sight-loss/criteria-certification> accessed 23-03-17

<sup>2</sup> RNIB. The State of the Nation Eye Health 2016; <http://www.rnib.org.uk/sites/default/files/RNIB-State-of-the-Nation-2016-APDF%20format.PDF> accessed 21-03-17

<sup>3</sup> RNIB. Criteria for certification: <http://www.rnib.org.uk/eye-health-registering-your-sight-loss/criteria-certification>

**Self-reported definition** (used by people to describe their own sight loss): It relies on people with sight loss identifying themselves in population surveys.

Although some people are born with a sight condition, or have suffered an eye injury, sight loss is more commonly developed during adulthood or older age. In the UK, more than two million people are estimated to be living with sight loss that significantly impacts their daily life. This estimate includes people who are registered as sight impaired and also those who are waiting for treatment, those whose sight could be improved, those who have not registered for whatever reason and people whose sight loss is not at a level that allows them to register. Nearly half of all cases of sight loss in the UK could have been prevented<sup>4</sup>.

Moreover, it is estimated that in the UK, there are over 25,000 blind and partially blind children aged 0-16 and around 15,000 aged 17-25. About half of these children will have additional disabilities and or special education needs<sup>5</sup>.

### 1.3 Sight threatening conditions

The leading causes of sight loss in the UK are uncorrected refractive error, age-related macular degeneration, cataract, glaucoma and diabetic retinopathy. The leading cause of severe sight loss is age-related macular degeneration<sup>6</sup>

**Refractive error:** This term covers a number of eye conditions including myopia (short-sightedness), hyperopia (long-sightedness), astigmatism and presbyopia; these conditions are usually corrected by wearing spectacles or contact lenses. However, under-identification of refractive error remains a problem<sup>7</sup>.

**Age-related macular degeneration (AMD):** Wide-ranging information on AMD is provided by NICE<sup>8</sup> and the Royal College of Ophthalmologists<sup>9</sup>. The following is an extract from these documents.

AMD is the commonest cause of severe visual impairment in older adults and it is responsible for two-thirds of registrations of visual impairment or blindness in the UK. AMD refers to changes which occur in the central area of the retina (macula) in people aged 55 years and above. Vision becomes increasingly blurred, reading becomes difficult, colours become less vibrant and people's faces become difficult to recognise. Severity of AMD varies from early to advanced AMD. Later stages of the disease are associated with vision impairment.

**Cataracts in adults:** Wide-ranging information on cataracts is provided by NICE<sup>10</sup> and the Royal College of Ophthalmologists<sup>11</sup>. The following is a summary extract.

<sup>4</sup> RNIB. The State of the Nation Eye Health 2016; <http://www.rnib.org.uk/sites/default/files/RNIB-State-of-the-Nation-2016-APDF%20format.PDF> accessed 21-03-17

<sup>5</sup> RNIB. Sight Loss Data Tool; [http://www.rnib.org.uk/knowledge-and-research-hub-key-information-and-statistics/sight-loss-data-tool?utm\\_medium=email&utm\\_source=Sight-loss-data-tool-3.2-Time-to-Talk&utm\\_campaign=Sight%20Loss%20Data%20Tool%20v3.2;](http://www.rnib.org.uk/knowledge-and-research-hub-key-information-and-statistics/sight-loss-data-tool?utm_medium=email&utm_source=Sight-loss-data-tool-3.2-Time-to-Talk&utm_campaign=Sight%20Loss%20Data%20Tool%20v3.2;)

<sup>6</sup> RNIB; The State of the Nation Eye Health, 2016

<sup>7</sup> RNIB. The State of the Nation Eye Health 2016; <http://www.rnib.org.uk/sites/default/files/RNIB-State-of-the-Nation-2016-APDF%20format.PDF> accessed 23-03-17

<sup>8</sup> NICE Clinical Knowledge Summaries- Macular degeneration - age-related; <https://cks.nice.org.uk/macular-degeneration-age-related#!backgroundsub:3>; accessed 04-04-17

<sup>9</sup> Royal College of Ophthalmologists (2013) Age-Related Macular Degeneration: Guidelines for Management. [www.rcophth.ac.uk/](http://www.rcophth.ac.uk/) [Free Full-text]

A cataract occurs when changes in the lens of the eye causes it to become less transparent affecting the vision. Symptoms are: difficulty in reading, recognising faces, or watching television and difficulty driving at night due to glare. A cataract may form at any age but most commonly occur in people over the age of 60 years. Cataract surgery is safe and very effective with 95 % of those treated having the sight restored.

**Glaucoma (Chronic open angle glaucoma, (COAG)):** Wide-ranging information on glaucoma is provided by NICE<sup>12,13</sup>. The following is a summary.

Glaucoma encompasses a group of eye conditions that if untreated cause permanent sight loss due to progressive optic nerve damage. It is usually asymptomatic and many people will be unaware of having the condition until severe visual damage has occurred. Therefore, early detection through regular eye tests and timely treatment are crucial as it can often prevent sight loss.

Approximately 10% of UK blindness registrations are attributed to glaucoma. As the population grows and gets older, the number of individuals affected is expected to rise. The treatment usually consist of eye drops although sometimes, it may require laser or surgical treatment.

**Diabetic retinopathy (diabetic eye disease):** Wide-ranging information on diabetic retinopathy is provided by the Royal Colleague of Ophthalmologists<sup>14</sup>. The following is a summary.

Diabetic retinopathy is a complication of diabetes where the small blood vessels in the retina are damaged due to prolonged hyperglycaemia (high blood sugar) and other conditions such as hypertension. It is a leading cause of preventable sight loss among the working-age population in the UK.

Patients who are at greater risk of diabetic retinopathy are those who have had diabetes for a long time; have poorly controlled diabetes; have high blood pressure; are pregnant and those who are of Asian or Afro-Caribbean ethnic background<sup>15</sup>.

Diabetic Retinopathy may not cause symptoms until it is quite advanced and failure to treat it at an early stage can lead to complete loss of vision. This is why it is very important to have the eyes checked annually by attending the national screening programme for diabetic retinopathy<sup>16, 17</sup>.

<sup>10</sup> NICE Clinical Knowledge Summaries –Cataract, September 2015; <https://cks.nice.org.uk/cataracts>; accessed 04-04-17

<sup>11</sup> Royal College of Ophthalmologists (2010) Cataract surgery guidelines 2010. Royal College of Ophthalmologists. <https://www.rcophth.ac.uk/wp-content/uploads/2014/12/2010-SCI-069-Cataract-Surgery-Guidelines-2010-SEPTEMBER-2010.pdf>; accessed 24-04-17

<sup>12</sup> NICE Clinical Knowledge Summaries- Glaucoma, January 2016; <https://cks.nice.org.uk/glaucoma#!topicsummary>; accessed 04-04-17

<sup>13</sup> Glaucoma: diagnosis and management; Clinical guideline [CG85] Published date: April 2009; <https://www.nice.org.uk/guidance/cg85/chapter/1-Guidance#treatment-for-people-with-oht-and-suspected-coag>; accessed 11-04-17

<sup>14</sup> The Royal College of Ophthalmologists; Diabetic Retinopathy Guidelines, December 2012; <https://www.rcophth.ac.uk/wp-content/uploads/2014/12/2013-SCI-301-FINAL-DR-GUIDELINES-DEC-2012-updated-July-2013.pdf>; ; accessed 04-04-17

<sup>15</sup> SIGN; Management of diabetes- A national clinical guideline; March 2010, updated September 2013; <http://www.sign.ac.uk/pdf/sign116.pdf>; accessed 04-04-217

<sup>16</sup> NICE guideline [NG28], 2015; Last updated: July 2016; Type 2 diabetes in adults: management <https://www.nice.org.uk/guidance/ng28/chapter/1-Recommendations#managing-complications>; accessed 06-04-17

<sup>17</sup> NICE guideline [NG17]; August 2015; Last updated: July 2016; Type 1 diabetes in adults: diagnosis and management, <https://www.nice.org.uk/guidance/ng17/chapter/1-Recommendations#managing-complications>; accessed 06-04-17

**Retinitis Pigmentosa (RP):** Comprises a group of hereditary eye diseases characterised by progressive degeneration of retinal photoreceptors. It results in severe visual loss that may lead to blindness.

Symptoms may become manifest during childhood or adulthood, and include poor night vision and constriction of peripheral vision (visual field loss). This field loss is progressive and usually does not reduce central vision until late in the disease. Currently, there is no proven therapy for this condition<sup>18</sup>.

**Sight-threatening conditions in children and young people:** The majority of blind and partially sighted children and young people are born with their VI and around two thirds of children with severe VI and blindness are diagnosed before their first birthday<sup>19</sup>. Children at most risk of severe VI or blindness are those who are born pre-term and of very low birth weight, from socio-economically disadvantaged backgrounds, or of south Asian origin<sup>20</sup>.

Over 25,000 children (aged 0-16) are estimated to be blind and partially sighted in the UK, and around 15,000 aged 17-25. Around half of these children (0-16) will have additional disabilities and/or special educational needs<sup>21</sup>.

The main causes of vision impairment in children are cerebral vision impairment, disorders of the optic nerve and disorders of the retina. Vision defects in children include amblyopia, refractive error and strabismus<sup>22</sup>.

**Amblyopia:** It is one of the main conditions affecting 4 to 5 years old children in which, the eye does not work properly although it appears normal. Amblyopia can be a very mild problem but can become more serious if left untreated. Early detection and treatment are necessary to avoid permanent visual impairment. Treatment involves patching the good eye or use of drops which defocus vision, which results in improved vision in the amblyopic eye<sup>23</sup>.

**Cataract in babies and children:** It can be congenital and developmental. Symptoms and signs of cataracts include poor vision, a white or grey pupil, involuntary eye movements (nystagmus), squint and sensitivity to light or problems with glare. Suspected cataract requires urgent referral to an ophthalmologist. Untreated congenital cataracts in babies cause amblyopia, leading to serious lifelong

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<sup>18</sup> Sobharani Rayapudi, Stephen G Schwartz, Xue Wang, Pamela Chavis, Cochrane Eyes and Vision Group, The Cochrane Library; DOI: 10.1002/14651858.CD008428.pub2; <http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD008428.pub2/abstract;jsessionid=4FBF8BAF354E4EE6C0DCEA9A8F5BB7DC.f04t02>; accessed 04-04-17

<sup>19</sup> Rahi J.S., Cable N., and the British Childhood Visual Impairment Study Group (2003). Severe visual impairment and blindness in children in the UK; *Lancet*, 25;362(9393):1359-65.

<sup>20</sup> Rahi J.S., Cable N., and the British Childhood Visual Impairment Study Group (2003). Severe visual impairment and blindness in children in the UK; *Lancet*, 25;362(9393):1359-65

<sup>21</sup> RNIB Sight Loss Data Tool - Local authority report, 2016; <http://www.rnib.org.uk/knowledge-and-research-hub-key-information-and-statistics/sight-loss-data-tool>; latest accessed 04-05-17

<sup>22</sup> RNIB. The State of the Nation Eye Health 2016; <http://www.rnib.org.uk/sites/default/files/RNIB-State-of-the-Nation-2016-APDF%20format.PDF> accessed 23-03-17

<sup>23</sup> PHE, Childhood Vision Screening for 4 to 5 year olds; Service specification, CVSP Spec V2.1 08/12/2016; under consultation; [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/598639/Vision\\_screening\\_specification\\_draft\\_for\\_consultation.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/598639/Vision_screening_specification_draft_for_consultation.pdf)

visual impairment, even if the cataracts are removed later in life.

**Retinoblastoma (RB)<sup>24</sup>:** It is a rare cancer of the retina which often presents with a white pupil, in much the same way as congenital cataracts present. The condition is not just sight threatening but life threatening. In 60% of cases the cause is unknown and in the other 40% of cases it is due to a faulty gene. Each year, about 50 to 60 children are diagnosed with retinoblastoma in the UK.

The Royal London Hospital is one of the only two centres in the country that treat Retinoblastoma.

#### 1.4 Risk factors for preventable sight loss in adults

A number of factors can contribute to increasing a persons' risk of sight loss. Some people's existing health conditions make sight loss more likely, and some sight conditions are more common for people of a particular age group or ethnicity. Some groups experience barriers to accessing health services, leading to sight problems going undetected or untreated. The following are main risk factors for sight loss:

**Family history and genetic factors:** A Tower Hamlets review<sup>25</sup> reported evidence of a strong genetic link to glaucoma with a risk of developing glaucoma in first degree relatives ranging between three times and nine times that of non-relatives. NICE<sup>26</sup> reported evidence that the risk to a sibling of a person with glaucoma is about four times, and that of a child of a parent with glaucoma is about twice the population risk. Also, the risk of a person developing AMD is up to three times that of the normal population if the person has a first degree relative with AMD<sup>27</sup>.

**Age:** The older you are, the greater your risk of sight loss. Around 79% of people living with sight loss are over the age of 64 and one in every three people aged 85 and over is living with sight loss.<sup>28</sup> Older care homes residents are at high risk of poor eye health with estimates suggesting that up to half of this group have some kind of sight loss.

**Ethnicity:** People from minority ethnic groups are at greater risk of eye disease<sup>29</sup>. For example, black African and Caribbean people are 4 to 8 times more at risk of developing certain forms of glaucoma and at higher risk of diabetic eye disease compared to white people. However, the prevalence of AMD is higher among the white population<sup>30</sup>. Asian people are around 3 times more at risk of diabetic eye disease and cataract than white people<sup>31</sup>. Evidence also suggests that people from these groups do not receive the same level of access to eye care services as most white people<sup>32</sup>.

<sup>24</sup> NHS Choices: <http://www.nhs.uk/Conditions/retinoblastoma/Pages/Introduction.aspx>

<sup>25</sup> Kieran O'Donnell; Eye care in the UK: Epidemiology, intervention and Ethnicity ; PHAST (Public Health Action Support Team) Report; August 2009

<sup>26</sup> NICE Clinical Knowledge Summaries- Glaucoma, January 2016; <https://cks.nice.org.uk/glaucoma#!topicsummary>; accessed 25-04-17

<sup>27</sup> NICE Clinical Knowledge Summaries- Macular degeneration - age-related; <https://cks.nice.org.uk/macular-degeneration-age-related#!backgroundsub:3>; accessed 04-04-17

<sup>28</sup> RNIB; The State of the Nation Eye Health 2016; <http://www.rnib.org.uk/sites/default/files/RNIB-State-of-the-Nation-2016-APDF%20format.PDF>; accessed 21-03-17

<sup>29</sup> RNIB; The State of the Nation Eye Health 2016; <http://www.rnib.org.uk/sites/default/files/RNIB-State-of-the-Nation-2016-APDF%20format.PDF>; accessed 27-03-17

<sup>30</sup> Klein R., Klein B.E., et al (2006). Prevalence of age-related macular degeneration in four racial/ethnic groups in the multi-ethnic study of atherosclerosis. *Ophthalmology*, 113(3), 373-380.

<sup>31</sup> Mark R D Johnson, Vinette Cross, Mark O Scase, Ala Szczepura, Diane Clay, Wesley Hubbard, Keith Claringbull, Philippa Simkiss and Shaun Leamon. A review of evidence to evaluate effectiveness of intervention strategies to address inequalities in eye health care; RNIB, December 2011

**Socio-economic deprivation:** Severity of glaucoma at presentation is associated with socioeconomic deprivation<sup>33</sup>. Research shows that people on low incomes are at greater risk of sight loss as a result of lower uptake of screening, and later presentation for treatment. This seems to be due to limited awareness of eye health and eye disease, difficulties in getting to an optometrist and concerns about the costs<sup>34</sup>.

**Smoking:** Smoking is strongly linked to several eye diseases<sup>35</sup>. Current smokers have a two to three-fold increased risk of developing AMD, and those with a genetic susceptibility are also more likely to develop AMD if they smoke. The risk increases with the number of pack-years of smoking. Stopping smoking reduces the risk of AMD progression in people with existing disease<sup>36</sup>.

**Diet:** Studies show that a diet rich in antioxidants, in particular the carotenoids lutein and zeaxanthin are associated with a reduced risk of developing age related macular degeneration<sup>37</sup>. Green leafy vegetables, Brussels sprouts, broccoli, lettuce, asparagus, carrots and eggs, contain these important nutrients<sup>38</sup>.

**Diabetes:** People with diabetes are at increased risk of developing diabetic eye disease (retinopathy), glaucoma<sup>39</sup> and cataracts<sup>40</sup>. The duration of diabetes is a major risk factor for development of diabetic retinopathy but tight glucose control has been shown to reduce its progression<sup>41</sup>. Early identification diabetic eye disease through the diabetic eye screening programme and timely treatment could reduce sight loss<sup>42</sup>.

**Learning disabilities:** The RNIB suggests that adults with learning disabilities are ten times more likely

<sup>32</sup> Mark R D Johnson, Vinette Cross, Mark O Scase, Ala Szczepura, Diane Clay, Wesley Hubbard, Keith Claringbull, Philippa Simkiss and Shaun Leamon. A review of evidence to evaluate effectiveness of intervention strategies to address inequalities in eye health care; RNIB report, December 2011

<sup>33</sup> Ng WS, Agarwal PK, Sidiki S, McKay L, Townend J, Azuara-Blanco A (2010). The effect of socio-economic deprivation on severity of glaucoma at presentation; <http://dx.doi.org/10.1136/bjo.2008.153312>; <http://bjo.bmj.com/content/94/1/85.full>; accessed 27-03-17

<sup>34</sup> Leamon S., Hayden C., Lee H., Trudinger D., Appelbee E., Hurrell D.L., and Richardson I. (2014). Improving access to optometry services for people at risk of preventable sight loss: a qualitative study in five UK locations. *Journal of Public Health (Oxford England)*, 36(4), 667-73. <https://academic.oup.com/jpubhealth/article/36/4/667/1532051/Improving-access-to-optometry-services-for-people>; accessed 27-03-2017

<sup>35</sup> Chakravarthy U et al; Cigarette smoking and age-related macular degeneration in the EUREYE Study. *Ophthalmology* 2007;114:1157–1163. [https://www.researchgate.net/profile/Mati\\_Rahu/publication/6469859\\_Cigarette\\_Smoking\\_and\\_Age-Related\\_Macular\\_Degeneration\\_in\\_the\\_EUREYE\\_Study/links/0912f50a388d8be861000000.pdf](https://www.researchgate.net/profile/Mati_Rahu/publication/6469859_Cigarette_Smoking_and_Age-Related_Macular_Degeneration_in_the_EUREYE_Study/links/0912f50a388d8be861000000.pdf); Accessed 27/03/17

<sup>36</sup> NICE Clinical Knowledge Summaries- Macular degeneration - age-related; <https://cks.nice.org.uk/macular-degeneration-age-related#!backgroundsub:3>; accessed 04-04-17

<sup>37</sup> The Relationship of Dietary Carotenoid and Vitamin A, E, and C Intake With Age-Related Macular Degeneration in a Case-Control Study; Age-Related Eye Disease Study Research Group (AREDS); AREDS Report No. 22; *Arch Ophthalmol.* 2007;125(9):1225-1232.

doi:10.1001/archophth.125.9.1225; <http://jamanetwork.com/journals/jamaophthalmology/fullarticle/419811>; accessed 04-04-17

<sup>38</sup> American Optometrist Association; Diet and Nutrition- Lutein & Zeaxanthin; <https://www.aoa.org/patients-and-public/caring-for-your-vision/diet-and-nutrition/lutein?ss=y>; accessed 04-04-17

<sup>39</sup> Newman-Casey P.A., Talwar N., Nan B., Musch D.C., and Stein J.D. (2011). The Relationship between Components of Metabolic Syndrome and Open-Angle Glaucoma. In RNIB; *The State of the Nation Eye Health 2016*. <http://www.rnib.org.uk/sites/default/files/RNIB-State-of-the-Nation-2016-APDF%20format.PDF> accessed 21-03-17

<sup>40</sup> Javadi M-A., and Zarei-Ghanavati S. (2008). Cataracts in Diabetic Patients: A Review Article. *J Ophthalmic Vis Res*, 3(1): 52–65. In RNIB; *The State of the Nation Eye Health 2016*.

<sup>41</sup> The Diabetes Control and Complications Trial Research Group: The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus. *The Diabetes Control and Complications Trial Research Group. N Engl J Med* 1993;329:977-986.

<sup>42</sup> Diabetic eye screening: programme overview; <https://www.gov.uk/guidance/diabetic-eye-screening-programme-overview>; accessed 27/03/17

to experience sight loss than the general population<sup>43</sup>. There are an estimated one million people aged 20 and over in the UK with learning disabilities. Of these, research shows that more than half a million experience refractive error but face particular barriers in accessing sight tests<sup>44</sup>.

**Dementia:** Evidence shows a high prevalence of all types of visual impairment in older people with dementia, and it is particularly higher in people with dementia living in care homes. However, nearly 50% of those with visual impairment could have had it corrected with spectacles, and more with cataract surgery<sup>45</sup>.

**Stroke Survivors:** It is estimated that around 60% of stroke survivors experience some type of visual problems post-stroke. For 20 % of the sufferers, these problems still persist three months after the stroke<sup>46</sup>.

### 1.5 Risk factors in children and young people (CYP)

Most blind and partially blind CYP are born VI due to prenatal, perinatal or neonatal conditions<sup>47</sup>. Cerebral visual impairment is the single most common cause of VI in children. It accounts for up to 48% of blindness and between 32% and 45% of all VI in children<sup>48</sup>.

Major risk factors for severe VI impairment in children and young people are: (i) prematurity, low birth weight babies, deprivation, south Asian ethnicity<sup>49</sup> and (ii) children with learning disabilities<sup>50</sup>.

### 1.6 What is the impact of visual impairment on the individual?

The lives of sight impaired individuals are adversely impacted in a variety of ways:

**Quality of life and mental wellbeing:** Any degree of sight loss adversely influences the quality of life of the individual. Evidence shows that impaired visual function is associated with adverse social outcomes and impaired general and mental health<sup>51 52</sup>. There is a significant association between self-reported visual function loss<sup>53</sup> and loss of vision<sup>54</sup> and depression.

<sup>43</sup> <https://www.rnib.org.uk/knowledge-and-research-hub/key-information-and-statistics>

<sup>44</sup> Eric Emerson & Janet Robertson. The Estimated Prevalence of Visual Impairment among People with Learning Disabilities in the UK; Department of Health Learning Disabilities Observatory, 2011; <https://www.rnib.org.uk/sites/default/files/Emerson%20report.pdf>; accessed 27-03-17

<sup>45</sup> Bowen M, Edgar DF, Hancock B, Haque S, et al. The Prevalence of Visual Impairment in People with Dementia (the ProVIDe study): a cross-sectional study of people aged 60–89 years with dementia and qualitative exploration of individual, carer and professional perspectives Health Services and Delivery Research, No. 4.21; 2016; <https://www.ncbi.nlm.nih.gov/books/NBK374272/>; accessed 28-03-17

<sup>46</sup> Rowe F. (2013). Care provision and unmet need for post stroke visual impairment: Final report. Stroke Association and Thomas Pocklington Trust.

<sup>47</sup> Rahi and Cable; 'Severe visual impairment and blindness in children in the UK' The Lancet, Vol 362, Oct 25, 2003.

[http://www.sciencedirect.com/science/article/pii/S0140673603146314?\\_rdoc=1&fmt=high&origin=gateway&docanchor=&md5=b8429449ccfc9c30159a5f9aeaa92ffb&ccp=y](http://www.sciencedirect.com/science/article/pii/S0140673603146314?_rdoc=1&fmt=high&origin=gateway&docanchor=&md5=b8429449ccfc9c30159a5f9aeaa92ffb&ccp=y); accessed 10-07-17.

<sup>48</sup> Mitry, Bunce, Wormald, and Bowman (2013) 'Childhood VI in England: a rising trend'. Archives of Disease in Childhood 2013; Volume 98, Issue 5; <http://adc.bmj.com/content/98/5/378.full>; accessed 10-07-17.

<sup>49</sup> Cumberland P.M., Pathai S., and Rahi J.S. (2010). Prevalence of eye disease in early childhood and associated factors: Findings from the Millennium Cohort Study. Ophthalmology, 117(11), 2184-2190.

<sup>50</sup> Woodhouse J.M., Davies N., McAviney A., and Ryan B. (2014). Ocular and visual status among children in special schools in Wales: the burden of unrecognised visual impairment. Archives of Diseases in Childhood, 99, 500-504.

<sup>51</sup> Cumberland P.M., and Rahi J.S. (2016). Visual Function, Social Position, and Health and Life Chances. The UK Biobank Study. JAMA Ophthalmol. doi:10.1001/jamaophthalmol.2016.1778

<sup>52</sup> Hassell JB, Lamoureux EL, Keefe JE. Impact of age related macular degeneration on quality of life; Br J Ophthalmol 2006;90:593–6; <http://bj.o.bmj.com/content/bjophthalmol/90/5/593.full.pdf>

In an evaluation of emotional support within an Integrated Low Vision Service<sup>55</sup>, the two major issues people wanted help with, apart from visual impairment, were depression or low mood. Other concerns included dependency and isolation, difficulties coping with bereavement, boredom and frustration, relationship difficulties and work or career worries.

**Mobility and social inclusion:** Half of people with sight loss experience difficulties getting into and moving around buildings. People with sight loss are five times more likely than people without a disability to feel as if they had no choice over how they spent their free time<sup>56</sup>.

**Falls:** Visual impairment increases the risk of falling around 2.5 times<sup>57 58 59</sup>.

**Support needs:** Many blind and partially sighted people require support in order to remain independent. Sometimes this is provided by social services, but typically it is provided on an informal basis by family, friends and neighbours. The cost of this informal care is billions of pounds each year<sup>60</sup>.

**Income and Benefits:** People with sight loss are far more likely than the general population to experience financial hardship. Around half of people living with sight loss live in a household where the weekly income is less than £300.<sup>61</sup>

One of the most important benefits paid to blind and partially sighted people is Disability Living Allowance (DLA)<sup>62</sup>. In Tower Hamlets, there were 260 blind and partially sighted people claiming Disabled Living Allowance (DLA) in 2016<sup>63</sup>. The DLA is being replaced by the Personal Independence Payment (PIP). Existing DLA claimants will be contacted by the Department of Work and Pensions stating that their existing claim will end and inviting applications for PIP more details can be found here <https://www.gov.uk/pip>.

<sup>53</sup> Xinzhi Zhang, Kai McKeever Bullard, Mary Frances Cotch, Roy Wilson, Barry W. Rovner, Gerald McGwin Jr, Cynthia Owsley, Lawrence Barker, John E. Crews, Jinan B. Saaddine. Association Between Depression and Functional Vision Loss in Persons 20 Years of Age or Older in the United States, NHANES 2005-2008; JAMA Ophthalmol. 2013;131(5):573-581; March 2013; doi:10.1001/jamaophthalmol.2013.2597.

<sup>54</sup> Huang CQ, Dong BR, Lu ZC, Yue JR, Liu QX. Chronic diseases and risk for depression in old age: a meta-analysis of published literature. Ageing Res Rev. 2010 Apr; 9(2):131-41. doi: 10.1016/j.arr.2009.05.005. Epub 2009 Jun 11.

<sup>55</sup> Hodge S, Barr W, Knox P; Evaluation of Emotional Support and Counselling within an Integrated Low Vision Service - Final Report; Liverpool University, September 2010

<sup>56</sup> Access Economics (2009). Future Sight Loss UK 1: The economic impact of partial sight and blindness in the UK adult population., RNIB.

<sup>57</sup> Rubenstein, L. Z. & Josephson, K. R. (2006) Falls and their prevention in elderly people: what does the evidence show? Medical Clinics of North America, 90, 807-824.

<sup>58</sup> Focus on Falls, 2014 <http://www.college->

[optometrists.org/filemanager/root/site\\_assets/commissioning/falls/focus\\_on\\_falls\\_report\\_240414.pdf](http://www.college-optometrists.org/filemanager/root/site_assets/commissioning/falls/focus_on_falls_report_240414.pdf)

<sup>59</sup> British Geriatrics Society. The importance of vision in preventing falls A joint policy statement by the British Geriatrics Society and the College of Optometrists, 2010

[http://www.bgs.org.uk/index.php?option=com\\_content&view=article&id=410:visionpreventingfalls&catid=47:fallsandbones&Itemid=307](http://www.bgs.org.uk/index.php?option=com_content&view=article&id=410:visionpreventingfalls&catid=47:fallsandbones&Itemid=307)

<sup>60</sup> Access Economics (2009). Future Sight Loss UK 1: The economic impact of partial sight and blindness in the UK adult population., RNIB. [http://www.rnib.org.uk/sites/default/files/FSUK\\_Report.pdf](http://www.rnib.org.uk/sites/default/files/FSUK_Report.pdf); accessed 06-04-17

<sup>61</sup> Slade J, L. C. a. M. S. (2012). The financial situation of people with sight loss, RNIB and Natcen poster, presented at the UK Vision conference June 2012.

<sup>62</sup> Disability Living Allowance (DLA) for adults; <https://www.gov.uk/dla-disability-living-allowance-benefit>; accessed 11-05-17

<sup>63</sup> Source: RNIB Sight Loss Data Tool V3.5; <http://www.rnib.org.uk/professionals/knowledge-and-research-hub/key-information-and-statistics/sight-loss-data-tool>; latest accessed 11-11-17

**Employment:** All-cause impaired visual function has been associated with both an increased risk of being unemployed and having a lower-status job<sup>64</sup>. Only around one in four blind and partially sighted people of working age are in employment<sup>65</sup>. Restrictions such as a lack of access to education and training opportunities, transport and attitudes of employers have all been identified as barriers to obtaining and retaining work (Douglas et al, 2009).

**Impact of visual impairment on children and young people:** Evidence shows that sight plays a vital part in children's development of language, social and cognitive skills<sup>66</sup>. Vision impairment in children creates unique challenges to learning and development, which can have a profound impact on their education and wellbeing. Moreover, many children and young people have more than one sight condition and many have other special educational needs, disabilities or complex needs<sup>67</sup>.

### 1.7 Why is it a public health problem?

In the UK there are an estimated over two million people whose sight loss is severe enough to have a significant impact on their daily lives. Of all the causes of this sight loss, it is estimated that 39% is due to refractive error, 23% AMD, 19% cataract, 7% glaucoma, 5% diabetic retinopathy and 7% to other conditions<sup>68</sup>.

Projections estimate that between now and 2030 the number of people living with sight loss will increase by a third to more than 2.7 million due to an increase in the UK's older population. The increase can be attributed mainly to an ageing population; over 80 per cent of sight loss occurs in people aged over 60 years. An increase in other factors such as diabetes and obesity, are also likely to cause an increase in eye disease<sup>69</sup>.

Moreover, there is even a greater number of people at risk of sight loss because of the type of the sight threatening eye conditions they experience (AMD, glaucoma, cataract and diabetic retinopathy), including those who do not have any symptoms. Estimates by the RNIB based on a number of studies suggest that there are more than 5.7 million people living with sight-threatening eye conditions in the UK<sup>70</sup>.

Partial sight and blindness have a profound impact on other aspects of physical and mental health. For example people with visual impairment have an increased risk of falls<sup>71</sup>, increased incidence of

<sup>64</sup> Cumberland P.M., and Rahi J.S. (2016). Visual Function, Social Position, and Health and Life Chances. The UK Biobank Study. JAMA Ophthalmol. doi:10.1001/jamaophthalmol.2016.1778.

<sup>65</sup> RNIB Sight Loss Data Tool - Local authority report, 2016; <http://www.rnib.org.uk/knowledge-and-research-hub-key-information-and-statistics/sight-loss-data-tool>; latest accessed 04-05-17

<sup>66</sup> RNIB Children and young people England ; RNIB Evidence-based review, 2016 . I accessed the document from here: <https://www.rnib.org.uk/knowledge-and-research-hub-research-reports/evidence-based-reviews> 22-05-17

<sup>67</sup> RNIB Children and young people England, 2016 ; RNIB Evidence-based review, 2016 .

<https://www.rnib.org.uk/knowledge-and-research-hub-research-reports/evidence-based-reviews>; accessed 22-05-17

<sup>68</sup> RNIB; The State of the Nation Eye Health 2016; <http://www.rnib.org.uk/sites/default/files/RNIB-State-of-the-Nation-2016-APDF%20format.PDF>; accessed 21-03-17

<sup>69</sup> RNIB; The State of the Nation Eye Health 2016; <http://www.rnib.org.uk/sites/default/files/RNIB-State-of-the-Nation-2016-APDF%20format.PDF>; accessed 21-03-17

<sup>70</sup> RNIB; The State of the Nation Eye Health 2016; <http://www.rnib.org.uk/sites/default/files/RNIB-State-of-the-Nation-2016-APDF%20format.PDF>; accessed 21-03-17

<sup>71</sup> Alex Black, Joanne Wood; Vision and falls; Clin Exp Optom 2005; 88: 4: 212–222;

<http://onlinelibrary.wiley.com/doi/10.1111/j.1444-0938.2005.tb06699.x/epdf>; accessed 03-04-17

depression, reduced self-confidence, lower wellbeing, are less satisfied with their overall health and are more likely than the general population to experience financial problems<sup>72</sup>.

Thousands of people unnecessarily lose their sight each year. The UK Vision Strategy<sup>73</sup> estimates that over 50% of sight loss is avoidable through regular eye examinations. However, research shows that people have a limited awareness or understanding of eye health. This means that many individuals do not attend preventative eye examinations but attendance to eye checks is driven mainly by symptom-led demand<sup>74 75</sup>.

Moreover, there is evidence on geographical inequality in accessing preventative eye services. A study in Leeds reported that people aged 60 or over or under 16 living in the least deprived quintile are 71% and 23%, respectively, more likely to have an NHS-funded eye examination than someone in that age group in the most deprived quintile, although all are equally entitled<sup>76</sup>. Analysis in Tower Hamlets showed that uptake fell away at walking distances greater than 15 minutes from the nearest sight test centre<sup>77</sup>.

### 1.8 The economic cost of eye health and sight loss

The costs associated with the provision of eye health services, include direct costs and indirect costs. The direct costs include, inpatient procedures, outpatient procedures, residential and community care services and the ongoing treatment of eye conditions. The indirect costs are the consequence of sight loss, and include: reductions in the quality and length of life, unpaid care, loss of productivity, premature mortality, provision of devices and modifications, provision of unpaid care by family and friends to those with sight loss, lower employment and absenteeism<sup>78</sup>.

The RNIB<sup>79</sup> reports on a study<sup>80</sup> showing in 2014, the large economic cost on the UK due to sight loss in the UK adult population at a total of 28.1 billion.

Of these, the direct health care system cost linked to eye health is estimated to be £3 billion per year and the indirect cost £25.1 billion. The NHS vision expenditure in England for 2013-14 was 1.6 billion

<sup>72</sup> McManus S, Lord C; NatCen Report for RNIB 2012; Circumstances of people with sight loss - secondary analysis of Understanding Society and the Life Opportunities Survey; [http://scholar.google.co.uk/scholar?hl=en&q=McManus+and+Lord%2C+2012%2C+&btnG=&as\\_sdt=1%2C5&as\\_sdtpr=](http://scholar.google.co.uk/scholar?hl=en&q=McManus+and+Lord%2C+2012%2C+&btnG=&as_sdt=1%2C5&as_sdtpr=) accessed 03-04-17

<sup>73</sup> The UK Vision Strategy 2013-18 <http://ukvisionstrategy.org.uk/sites/default/files/UK%20Vision%20Strategy%202013-18%201.0.pdf>

<sup>74</sup> Shickle D, Farragher T M; Geographical inequalities in uptake of NHS-funded eye examinations: small area analysis of Leeds, UK; Public Health (Oxf) (2015) 37 (2): 337-345. Published: 11 July 2014; DOI: <https://doi.org/10.1093/pubmed/fdu039> ; accessed 13-07-17

<sup>75</sup> PHAST Report; Tower Hamlets Eye Health Care Needs Assessment- Findings and recommendations; 2009; <http://www.towerhamlets.gov.uk/Documents/Public-Health/JSNA/Eye-health-JSNA-2009.pdf>; accessed 11-05-17

<sup>76</sup> Shickle D, Farragher T M; Geographical inequalities in uptake of NHS-funded eye examinations: small area analysis of Leeds, UK; Public Health (Oxf) (2015) 37 (2): 337-345. Published: 11 July 2014; DOI: <https://doi.org/10.1093/pubmed/fdu039> ; accessed 13-07-17

<sup>77</sup> PHAST Report; Tower Hamlets Eye Health Care Needs Assessment- Findings and recommendations; 2009; <http://www.towerhamlets.gov.uk/Documents/Public-Health/JSNA/Eye-health-JSNA-2009.pdf>; accessed 11-05-17

<sup>78</sup> RNIB. The State of the Nation Eye Health 2016; <http://www.rnib.org.uk/sites/default/files/RNIB-State-of-the-Nation-2016-APDF%20format.PDF> accessed 21-03-17

<sup>79</sup> RNIB. The State of the Nation Eye Health 2016; <http://www.rnib.org.uk/sites/default/files/RNIB-State-of-the-Nation-2016-APDF%20format.PDF> accessed 21-03-17

<sup>80</sup> Pezzullo L., Streatfield J., Simkiss P., and Shickle D. (2016). The economic impact of sight loss and blindness in the UK adult population. RNIB and Deloitte Access Economics. Manuscript submitted for publication.

which represented 3 % of the total Clinical Commissioning Groups budget expenditure.

For the Tower Hamlets NHS programme budgets for 2013-14, (the latest reported available) the combined spend on problems of vision was £ 5,385 million, or £20 per person in the general population. The proportion of overall programme budget spent on problems of vision was 2%. This was lower than for England (3%). The total indirect cost of sight loss was estimated to be £10,870,000 million pounds or £40 per person in the general population<sup>81</sup>.

## 2. What is the Policy Context?

### 2.1 International

The WHO Vision 2020: The Right to Sight<sup>82</sup> is the global initiative for the elimination of avoidable blindness. It is a joint programme of the World Health Organization (WHO) and the International Agency for the Prevention of Blindness (IAPB).

Prevention of avoidable sight loss is a key priority recognised by the WHO to which the UK is a signatory and which is also a key priority for Vision 2020UK and the UK Vision Strategy. This global initiative was set up to “intensify and accelerate prevention of blindness activities so as to achieve the goal of eliminating avoidable blindness by 2020.” This is particularly important in the context of an ageing population.

### 2.2 National

The UK Vision Strategy was launched in 2008<sup>83</sup> as the UK’s response to the World Health Organisation’s Global Action Plan for the Prevention of Avoidable Blindness (formerly the VISION 2020 Action Plan). It was refreshed in 2013<sup>84</sup>. The strategy is a cross-sector initiative, uniting all those in the UK who want to take action on issues relating to vision. It seeks a major transformation in the UK’s eye health, eye care and sight loss services. The aim is to enable those with sight loss to receive timely treatment and support so they can live independent lives. The strategy defines the three outcomes it wants to achieve and the specific priority actions. The three outcomes are:

#### Strategy Outcome 1

##### **Everyone in the UK looks after their eyes and their sight**

- raise awareness and understanding of eye health, particularly focusing on people most at risk of eye disease.
- encourage every individual to develop personal responsibility for their eye health and sight.
- raise awareness of eye health and the impact of sight loss among health and social care practitioners and ensure the early detection of sight loss and prevention where possible.

#### Strategy Outcome 2

##### **Everyone with an eye condition receives timely treatment and, if permanent sight loss occurs, early and appropriate services and support are available and accessible to all**

<sup>81</sup> Source: RNIB Sight Loss Data Tool V3.5; <http://www.rnib.org.uk/professionals/knowledge-and-research-hub/key-information-and-statistics/sight-loss-data-tool>; latest accessed 11-11-17

<sup>82</sup> WHO VISION 2020: The Right to Sight; <https://www.iapb.org/vision-2020>

<sup>83</sup> A VISION 2010 UK initiative led by RNIB; UK Vision Strategy-Setting the direction for eye health and sight loss services, 2008

<sup>84</sup> <http://ukvisionstrategy.org.uk/strategy-2013-2018>

- improve the co-ordination, integration, reach and effectiveness of eye health and eye care services.
- ensure that, when permanent sight loss occurs, emotional support, habilitation and/or rehabilitation will be provided in a timely fashion, enabling people to retain or regain their independence.

### Strategy Outcome 3

#### A society in which people with sight loss can fully participate

- improve attitudes, awareness and actions within education, employment and other services.
- ensure that children and young people with sight impairment can take their place in society.
- achieve improved compliance with equality legislation.

## 2.3 Local

**Vision for Tower Hamlets: A Plan for Eye Care and Inclusion 2013-16.** This plan was developed to implement the UK Vision Strategy and it sets out the current landscape for eye health and visual impairment support and provision in Tower Hamlets. The plan brought together professionals across hospitals, health agencies, the council, voluntary sector, patients and service users to evidence current and future service requirements. It aims to provide a single portal for the planning, commissioning, delivery and evaluation of services for eye health and visual impairment support in Tower Hamlets. It also aims to ensure that Tower Hamlets is able to implement national outcomes linked to eye health and visual impairment set out in the Government's outcomes frameworks for the NHS<sup>85</sup>, Public Health<sup>86</sup> and Adult Social Care<sup>87</sup>. The plan includes an ideal pathway that the user with visual impairment should experience during the process of diagnosis, treatment and rehabilitation.

The Plan identified the following priorities:

- 1. Health and Wellbeing:** Ensuring that the Vision Plan and Action Plan are an integral part of local planning and service delivery.
- 2. Prevention:** Maximise the uptake of eye examinations and raise awareness of eye health to ensure that avoidable sight loss is prevented wherever possible.
- 3. Joined up data:** Ensure that timely comprehensive cross sector data on sight loss and local demographics is routinely collected and shared to inform resource allocation across NHS, Optometry, Social Care and Voluntary organisations.
- 4. Joined up services:** Ensure that an effective and efficient service provision is available, resulting in a clear pathway for people experiencing sight loss from diagnosis through to independent living. This will include optometrists, GPs, eye clinics, social care teams and voluntary services.
- 5. Social inclusion and independence:** Ensure that people with sight loss have good access to key local services - information, transport, leisure, employment, education and welfare rights to obtain and maintain independence and not experience social exclusion, inequality or isolation.
- 6. Children services:** Ensure that the needs of children and young people with VI are addressed including a clear transition pathway from children to adult services.
- 7. Visually impaired people with complex needs:** Ensure that the needs of people with visual impairment as a secondary presenting condition are recognised. Visual impairment is often overlooked in those with, for instance, Dementia, Parkinson's, Learning Disabilities, etc.
- 8. Involve local people in sight loss priorities:** Ensure local people are actively engaged in defining local priorities and providing local feedback on eye health and sight loss support

<sup>85</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/513157/NHSOF\\_at\\_a\\_glance.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/513157/NHSOF_at_a_glance.pdf)

<sup>86</sup> <https://www.gov.uk/government/collections/public-health-outcomes-framework>

<sup>87</sup> <https://digital.nhs.uk/article/324/Adult-Social-Care-Outcomes-Framework-ASCOF->

services. Involve people with sight loss in defining priorities and ask them for feedback on our work.

A Vision Action Plan was developed to accompany the Vision Plan. It gives details to enable the delivery, monitoring and assessing the impact of the Tower Hamlets Vision Plan.

### 3. What are the effective interventions?

#### 3.1 Primary prevention

**3.1.1 Interventions to increase eye health awareness and provision of education:** Targeted media campaigns can increase awareness of eye health. The evidence indicates that it is necessary to identify and use media specific to the at-risk group of interest. General press or media releases, which do not use role models or examples, and do not take into account cultural issues aimed at specific sub-populations, are unlikely to meet their need. Therefore, campaigns should be explicitly targeted at risk groups<sup>88</sup>.

The use of eye health champions have been identified as possibly the best way forward but more evaluation of these interventions should be carried out<sup>89</sup>.

Access economic<sup>90</sup> evaluated the cost effectiveness of four hypothetical eye care interventions in the UK including:

- promote the prevention of eye injuries
- increase regular eye tests for the older population (≥60 years)
- increase access to eye care services for minority ethnic groups (MEGs)
- improve access to integrated low vision and rehabilitation services

They showed that the most effective campaign was expected to be one that focuses on MEGs. This is due to the fact that their access to eye care services is lower than the average population and therefore, their undetected eye conditions are more likely to be severe. They estimated that educational campaigns using media and an educational road show to locations heavily populated with MEGs could be a cost effective intervention.

Results of the other three economic evaluations showed there are gains to be made in investing in the promotion of eye care services.

**3.1.2 Interventions to keep healthy eyes:** Research suggests that the following helps to keep healthy eyes and decreases the risk of developing an eye condition (From NHS CHOICE website):

- **Stop smoking:** Smoking can double the risk of developing age-related macular degeneration, the UK's leading cause of sight loss. The link is as strong as the link between smoking and lung

<sup>88</sup> Johnson MRD, C. V., Scase MO, Szczepura A, Clay D, Wesley H, Claringbull K, Simkiss P and Leamon S, (2011). A review of evidence to evaluate effectiveness of intervention strategies to address inequalities in eye health care., RNIB.

<sup>89</sup> Johnson MRD, C. V., Scase MO, Szczepura A, Clay D, Wesley H, Claringbull K, Simkiss P and Leamon S, (2011). A review of evidence to evaluate effectiveness of intervention strategies to address inequalities in eye health care., RNIB.

<sup>90</sup> Access Economics (2009). Future Sight Loss UK 1: The economic impact of partial sight and blindness in the UK adult population., RNIB

cancer. Smoking is also linked to the development of cataracts and makes diabetes related sight problems worse<sup>91</sup>. Evidence shows that health campaigns that highlight the link between smoking and sight loss increase the number of people who stop smoking<sup>92</sup>. The RNIB<sup>93</sup> recommends to make eye health and sight loss prevention an integral part of public health initiatives on smoking cessation, falls prevention and reducing loneliness. Moreover, optometrists should routinely increase awareness of the relationship between sight loss and smoking and ask patients about their smoking habits.

- **Healthy diet and healthy weight:** The health of the eye is dependent on the health of the body. Therefore, a healthy diet low in saturated fats and rich in green leafy vegetables may help delay the progression of eye conditions. The anti-oxidant vitamins A, C and E seem to provide protection to the lens and retina from oxidative damage<sup>94</sup>. It is also important to maintain a healthy weight. Obesity can increase the risk of developing diabetes, which in turn can cause sight loss.
- **Alcohol consumption:** Epidemiologic studies assessing the relationship between alcohol consumption and the risk of age-related cataracts provide inconsistent results. While the Royal College of Ophthalmologists guidelines 2010 refer to studies that found alcohol to be a risk factor for developing cataracts<sup>95</sup>, a 2014 meta-analysis<sup>96</sup> found no substantial overall increased risk of cataracts due to alcohol intake.
- **Keep the eyes covered in the sun:** UVA and UVB rays in sunlight can harm the eyes and may increase the risk of cataracts and AMD. Wearing sunglasses, glasses or contact lenses with built in UV filter may protect the eyes<sup>97</sup>.
- **Safety issues:** DIY causes thousands of eye related injuries each year. The use of safety goggles (European Standard BS EN 166) is recommended to protect the eyes from flying debris and fine particles. Sport (especially racquet-based sports) also causes lots of eye related injuries each year. A good pair of protective sports goggles will help prevent serious damage to the eyes.
- **People with diabetes** can prevent the onset of eye conditions (e.g.: retinopathy, cataract) and

<sup>91</sup> Chakravarthy U et al; Cigarette smoking and age-related macular degeneration in the EUREYE Study. *Ophthalmology* 2007;114:1157–1163. [https://www.researchgate.net/profile/Mati\\_Rahu/publication/6469859\\_Cigarette\\_Smoking\\_and\\_Age-Related\\_Macular\\_Degeneration\\_in\\_the\\_EUREYE\\_Study/links/0912f50a388d8be861000000.pdf](https://www.researchgate.net/profile/Mati_Rahu/publication/6469859_Cigarette_Smoking_and_Age-Related_Macular_Degeneration_in_the_EUREYE_Study/links/0912f50a388d8be861000000.pdf); Accessed 27/03/17

<sup>92</sup> Thornton J., Edwards R., Harrison R.A., Elton P., Astbury, N., and Kelly S.P. (2007). 'Smoke gets in your eyes': a research-informed professional education and advocacy programme'. *Journal of Public Health (Oxford, England)*, 29(2), 142-146. In RNIB. *The State of the Nation Eye Health 2016*; <http://www.rnib.org.uk/sites/default/files/RNIB-State-of-the-Nation-2016-APDF%20format.PDF>

<sup>93</sup> RNIB. *The State of the Nation Eye Health 2016*; <http://www.rnib.org.uk/sites/default/files/RNIB-State-of-the-Nation-2016-APDF%20format.PDF>

<sup>94</sup> NICHOLAS A. PHELPS BROWN, ANTHONY J. B RON, JOHN J. H, ARDING, HELEN M. DEWAR. Nutrition supplements and the eye. *Eye* (1998) 12, 127-133 © 1998 Royal College of Ophthalmologists; [https://www.researchgate.net/profile/Anthony\\_Bron/publication/13668890\\_Nutrition\\_supplements\\_and\\_the\\_eye/links/0a85e532ed3a109bd4000000.pdf](https://www.researchgate.net/profile/Anthony_Bron/publication/13668890_Nutrition_supplements_and_the_eye/links/0a85e532ed3a109bd4000000.pdf); accessed 21-03-17

<sup>95</sup> Royal College of Ophthalmologists (2010) *Cataract surgery guidelines 2010*. Royal College of Ophthalmologists. <https://www.rcophth.ac.uk/wp-content/uploads/2014/12/2010-SCI-069-Cataract-Surgery-Guidelines-2010-SEPTEMBER-2010.pdf>; accessed 24-04-17;

<sup>96</sup> Wei Wang, Xiulan Zhang\*; Alcohol Intake and the Risk of Age-Related Cataracts: A Meta-Analysis of Prospective Cohort Studies; 2014; <http://journals.plos.org/plosone/article/file?id=10.1371/journal.pone.0107820&type=printable>; accessed 13-11-17

<sup>97</sup> NICE Clinical Knowledge Summaries –Cataract, September 2015; <https://cks.nice.org.uk/cataracts>; Last accessed 25-04-17

the need for eye treatment by controlling their levels of blood sugar, blood pressure and blood cholesterol<sup>98</sup>.

## 3.2 Early detection

**3.2.1 Regular eye tests:** The Royal College of Optometrists and the RNIB recommend that people have an eye sight test every 2 years and every year for those aged 60 and over even if there is no change in their vision. An eye examination can pick up the first signs of an eye condition before any changes in the vision are noticed. This can lead to timely vital treatment which could save the sight<sup>99</sup>.

Early diagnosis and treatment can prevent up to 98% of severe vision loss (Access Economics 2004) and the earlier treatment is received the more likely it is to be effective<sup>100</sup>.

Almost two thirds of sight loss in older people is caused by refractive error and cataract. Both conditions can be diagnosed by a simple eye test. If the diagnosis is uncorrected refractive error, in most cases, the person's sight could be improved by prescribing correct glasses. NHS Choices<sup>101</sup> provides a list of what individuals qualify for a free NHS-funded sight test.

Children should also have an eye test every two years<sup>102</sup>. All NHS sight tests are free for children under the age of 16.

In recognition of the impact of visual impairment, the NHS in England funds eye examinations under a General Ophthalmic Services (GOS1) contract with optometrists, for children, people aged 60 and over, people on low incomes and those suffering from or pre-disposed to eye disease<sup>103</sup>.

**3.2.2 The NHS Diabetic Eye Screening Programme (DESP)<sup>104</sup>:** Attendance to the screening programme reduces the risk of sight loss for people with diabetes through early detection, appropriate monitoring and prompt treatment of diabetic retinopathy. Everyone aged 12 and over with diabetes is offered screening using digital photography, once a year at high risk of sight loss and every two years for those at lower risk (recent UK National Screening Committee recommendations)<sup>105</sup>.

<sup>98</sup> SIGN; Management of diabetes; A national clinical guideline; March 2010, updated September 2013; <http://www.sign.ac.uk/pdf/sign116.pdf>; accessed 04-04-217

<sup>99</sup> RNIB Older people and eye tests -Don't let age rob you of your sight, 2007;

<https://www.rnib.org.uk/sites/default/files/Older%20people%20and%20eye%20tests%20Campaign%20report.pdf>

<sup>100</sup> Access Economics (2009). Future Sight Loss UK 1: The economic impact of partial sight and blindness in the UK adult population., RNIB.

<sup>101</sup> NHS Choices; <http://www.nhs.uk/chq/Pages/895.aspx?CategoryID=68&SubCategoryID=157>

<sup>102</sup> NHS Choices; NHS Services explained; NHS eye screenings and tests for children;

<http://www.nhs.uk/NHSEngland/AboutNHSservices/opticians/Pages/childrens-eyes.aspx>; latest accessed 12-07-17

<sup>103</sup> Shickle D; Farragher T M; Geographical inequalities in uptake of NHS-funded eye examinations: small area analysis of Leeds, UK; Public Health (Oxf) (2015) 37 (2): 337-345. Published: 11 July 2014; DOI:

<https://doi.org/10.1093/pubmed/fdu039>, accessed 13-07-17

<sup>104</sup> NHS diabetic eye screening (DES) programme; <https://www.gov.uk/topic/population-screening-programmes/diabetic-eye>; latest accessed 13-11-17.

<sup>105</sup> UK NSC recommendation on Diabetic Retinopathy screening in adults; Systematic population screening programme; Last review completed January 2016; <https://legacyscreening.phe.org.uk/diabeticretinopathy>

**3.2.3 Newborn, infant and childhood vision NHS screening programmes:** The following are NHS screening programmes aimed to early identification of babies and children eye abnormalities:

- **NHS newborn and infant physical examination screening programme (NIPE)<sup>106</sup>:** This national programme screens all newborn babies within 72 hours of birth, and then once again between 6 to 8 weeks for different health conditions. Examination of the eyes is one of the elements of this programme in order to identify congenital cataracts. About 2 or 3 in 10,000 babies are estimated to be born with problems with their eyes that require prompt treatment. The responsibility for identifying eligible babies remains with the birth unit until responsibility is formally passed to another provider (acute or primary care). As part of the newborn and infant screening programme, GPs and paediatricians also screen for retinoblastoma.
- **Childhood vision screening programme<sup>107</sup>:** Screening for reduced vision is undertaken as part of the NHS Healthy Child Programme. The main aim is to detect children aged 4 to 5 years with amblyopia, a form of cerebral visual impairment, with an estimated prevalence of about 2%. Once amblyopia is identified, early intervention is required to restore or achieve normal vision, usually through occlusion (patching) or refractive correction with glasses.

The programme also identify children with impaired sight in both eyes, children with poorer vision in both eyes are usually identified in infancy through other screening programmes (the Neonatal Infant Physical Examination and the Retinopathy of Prematurity screening programmes), or are detected through their symptoms.

All 4 to 5 year olds, including those children in mainstream, special or independent schools, as well as home schooled or other settings are eligible for screening. Children under recent care by hospital eye services or an optometrist may be excluded as these tests will have been included in their treatment. Those already wearing glasses but not under recent review should still be offered screening. The target of the programme is to screen a minimum of 90% of children aged 4-5 years.

Without screening, reduced vision can go unnoticed and untreated. This can have long term implications for affected children. Early treatment, once anomalies are identified by the screening test, will give the children the chance to reach their full social and educational potential.

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<sup>106</sup> Public Health England; NHS Newborn and Infant Physical Examination Screening Programme Handbook 2016/17; [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/572685/NIPE\\_programme\\_handbook\\_2016\\_to\\_2017\\_November\\_2016.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/572685/NIPE_programme_handbook_2016_to_2017_November_2016.pdf); latest accessed 12-07-17

<sup>107</sup> PHE, Childhood Vision Screening for 4 to 5 year olds; Service specification, CVSP Spec V2.1 08/12/2016; under consultation

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/598639/Vision\\_screening\\_specification\\_draft\\_for\\_consultation.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/598639/Vision_screening_specification_draft_for_consultation.pdf)

Commissioning of childhood vision screening is the responsibility of local authorities as part of the healthy child programme. Providers in the health, social and education sectors deliver these services.

### 3.3 Treatment and rehabilitation- evidence based effective interventions for specific conditions

**3.3.1 Age-related Macular Degeneration (AMD):** To slow disease progression smokers should be advised to stop smoking. A healthy, balanced diet rich in leafy green vegetables and fresh fruit is likely to improve concentrations of macular pigment in the fundus and should be encouraged.

Patients suspected to have neovascular (exudative) AMD (“wet” AMD) should be referred directly for ophthalmology assessment and investigations. Self-referral of exudative AMD should be encouraged, especially in patients who have second eye involvement<sup>108 109</sup>.

Treatments for neovascular AMD involve intraocular injected drugs. Older treatments like laser coagulation are no longer recommended although may have a role for selected people in whom drugs are not recommended. Emerging therapies like an implantable miniature telescope into the lens capsule are currently under investigation<sup>110</sup>.

**3.3.2 Cataract:** No studies have proved how to prevent or medically treat cataracts. Surgery remains the only effective treatment available to restore or maintain vision<sup>111</sup>.

Cataract surgery is generally very safe although a small minority of people can develop complications. 95% of people undergoing cataract surgery have their vision significantly improved providing that they do not present other visually-impairing ocular condition. Moreover, patient satisfaction with cataract surgery is reported to be between 84% and 95%<sup>112</sup>.

**3.3.3 Glaucoma:** The main complication of untreated glaucoma is irreversible loss of vision. Appropriate and timely treatment of glaucoma is needed to prevent or minimise further damage and maintaining a sighted lifetime<sup>113</sup>. Treatment of all types of glaucoma, and of ocular hypertension aims to reduce intraocular pressure (IOP) by using eye drops but sometimes laser or surgical treatments are required<sup>114</sup>.

**3.3.4 Diabetic maculopathy and retinopathy:** The main treatment for diabetic maculopathy and

<sup>108</sup> Royal College of Ophthalmologists (2013) Age-Related Macular Degeneration: Guidelines for Management. [www.rcophth.ac.uk](http://www.rcophth.ac.uk)

<sup>109</sup> NICE Clinical Knowledge Summaries- Macular degeneration - age-related; March 2016; <https://cks.nice.org.uk/macular-degeneration-age-related#!backgroundsub:3>; accessed 24-04-17

<sup>110</sup> NICE Clinical Knowledge Summaries- Macular degeneration - age-related; March 2016; <https://cks.nice.org.uk/macular-degeneration-age-related#!backgroundsub:3>; accessed 24-04-17

<sup>111</sup> Royal College of Ophthalmologists (2010) Cataract surgery guidelines 2010. Royal College of Ophthalmologists. <https://www.rcophth.ac.uk/wp-content/uploads/2014/12/2010-SCI-069-Cataract-Surgery-Guidelines-2010-SEPTEMBER-2010.pdf>; accessed 24-04-17

<sup>112</sup> Royal College of Ophthalmologists (2010) Cataract surgery guidelines 2010. Royal College of Ophthalmologists. <https://www.rcophth.ac.uk/wp-content/uploads/2014/12/2010-SCI-069-Cataract-Surgery-Guidelines-2010-SEPTEMBER-2010.pdf>; accessed 24-04-17

<sup>113</sup> Glaucoma: diagnosis and management; Clinical guideline [CG85] Published date: April 2009; <https://www.nice.org.uk/guidance/cg85/chapter/1-Guidance#treatment-for-people-with-oh-t-and-suspected-coag>; accessed 11-04-17

<sup>114</sup> Glaucoma: diagnosis and management; NICE Clinical guideline [CG85] Published date: April 2009; <https://www.nice.org.uk/guidance/cg85/chapter/1-Guidance#treatment-for-people-with-oh-t-and-suspected-coag>; accessed 11-04-17

proliferative retinopathy is timely delivery of laser retinal photocoagulation. The Royal College of Ophthalmologists<sup>115</sup> provides information on other possible treatments required for a specific group of patients.

**3.3.5 Stroke:** The Royal College of Physicians National Clinical Guidelines for Stroke<sup>116</sup> recommend specialist vision assessment for people with stroke.

### 3.4 Access to services and improving quality of services

A review of evidence on the effectiveness of intervention strategies to address inequality in eye health care<sup>117</sup> provided the following recommendations regarding access to services and improving quality of services:

**3.4.1 Personal support through Eye Care Liaison workers (ECLOs):** ECLOs based in eye clinics (sometimes employed under other job titles) whose primary role is to support people with newly diagnosed sight loss, might play a significant role in supporting those newly diagnosed with sight-threatening conditions in a more preventive/ protective role.

**3.4.2 Transparent care plans** will help many service users, in particular, older, less well educated, or from non-English-speaking backgrounds, to follow care instructions. However, it does not seem to be clear evidence of effectiveness of such approaches and the authors recommended the need for more research.

**3.4.3 Professional development and training of service delivery staff:** There is a lack of staff cultural competence (ethnicity, lifestyle) to recognise need or to support members of at-risk groups to access and adhere to programmes of preventive eye health. Staff need to be trained to improve practice and to better recording and monitoring of users in terms of ethnicity and other characteristics to enable a better picture of service uptake and inequality<sup>118</sup>.

To ensure people have a positive experience of care, staff needs to be aware of peoples' access and communications requirements associated with sensory loss. This can be achieved through structured awareness training which is provided by groups such as East London Vision or RNIB. Active consideration of the needs of people with sight loss in a hospital environment can contribute significantly to patient safety and improve patient experience. Thoughtful, clear signage, for instance, can promote independence and confidence, leading to improved mobility within hospitals and other NHS buildings. Good lighting and effective use of contrasting colours for surfaces, fixtures and fittings also help. Emotional support is fundamental to enabling people to effectively maximise the care and support available<sup>119</sup>.

<sup>115</sup> RCOPHTH; Diabetic Retinopathy

<https://www.rcophth.ac.uk/standards-publications-research/commissioning-in-ophthalmology/diabetic-retinopathy/>; accessed 10-04-17

<sup>116</sup> Royal College of Physicians, Intercollegiate Stroke Working Party. National clinical guideline for stroke, 5th edition 2016; [https://www.strokeaudit.org/SupportFiles/Documents/Guidelines/2016-National-Clinical-Guideline-for-Stroke-5t-\(1\).aspx](https://www.strokeaudit.org/SupportFiles/Documents/Guidelines/2016-National-Clinical-Guideline-for-Stroke-5t-(1).aspx); accessed 04-04-17

<sup>117</sup> Johnson MRD, C. V., Scase MO, Szczepura A, Clay D, Wesley H, Claringbull K, Simkiss P and Leamon S, (2011). A review of evidence to evaluate effectiveness of intervention strategies to address inequalities in eye health care; RNIB

<sup>118</sup> Johnson MRD, C. V., Scase MO, Szczepura A, Clay D, Wesley H, Claringbull K, Simkiss P and Leamon S, (2011). A review of evidence to evaluate effectiveness of intervention strategies to address inequalities in eye health care; RNIB

<sup>119</sup> UK Vision Strategy 2013-18

## 4. What is the local picture?

Information presented in this chapter has been extracted from the RNIB's Sight Loss Data Tool 3.5<sup>120</sup>. This is the UK's biggest collection of eye health datasets.

Based on mid -2016 population estimates used by the RNIB Data Tool, there are 304,854 people living in Tower Hamlets. Of the total local population, 22% are aged 17 or under (compared to 21% in England); 72% are aged 18-64 (compared to 61% in England) and 6% are aged over 65 (compared to 18% in England). Tower Hamlets is ranked as the 9th most deprived local authority in England out of 152 authorities and 54.8% of the total population is from a non-white ethnic group, compared to 14.6% in England as a whole.

The demographic, social and health context of an area have a significant impact on the level of different sight conditions in that area, how the conditions are treated and their outcomes. For example, people from non-white ethnic groups are at a higher risk of certain sight conditions. Moreover, people living with sight loss are likely to be more detrimentally affected by the challenges and costs of their condition in areas of deprivation or where transport and mobility is more of an issue.

### 4.1 Tower Hamlets estimated residents living with sight loss

Accurate numbers of people living with sight loss depends on how many of those who experience sight loss and are eligible for registration, are registered. Sight loss can be undetected for a number of reasons which can include stigma, lack of awareness, inconsistent systems of processing certification and registration documents in the pathway. Moreover, people may be waiting for treatment and not given the certification of vision impairment and others may not understand the benefits of registration. Therefore, the following figures are estimates:

The RNIB data tool local authority report for Tower Hamlets residents<sup>121</sup> shows that as per 2016:

- There are an estimated 3,980 people living with some degree of sight loss. Of these, 2,620 are living with mild sight loss, 910 with moderate sight loss and 460 with severe sight loss (blindness).
- A lower percentage (1.3%) of the total population of Tower Hamlets is living with sight loss, compared to 2.2% in London and 3.1% in England.
- By 2030, it is expected that 5,780 (1.5%) people in Tower Hamlets will be living with sight loss (an increase of 45%). Of these, 670 will have severe sight loss (an increase of 46%).
- However, the Tower Hamlets register shows that there are only 1,075 people registered as blind (51%) or partially blind (49%) (See section 4.3).

### 4.2 Certification of vision impairment (CVI)

A CVI formally certifies a person as either sight impaired (partially sighted) or severely sight impaired (blind). Each CVI form is completed by a consultant ophthalmologist in an eye clinic, with a copy sent to the local social services department. This provides a formal route to access social care services. Table 1 shows that in the year 2014-15 (the latest available), Tower Hamlets had a lower rate of certification (22 per 100,000 people) compared to 30 in London and 42 in England.

<sup>120</sup> <http://www.rnib.org.uk/professionals/knowledge-and-research-hub/key-information-and-statistics/sight-loss-data-tool> ; latest accessed 11-11-2017

<sup>121</sup> RNIB. Sight Loss data tool V 3.5: <http://www.rnib.org.uk/professionals/knowledge-and-research-hub/key-information-and-statistics/sight-loss-data-tool> latest accessed 11-11-17

Since 2012-13, the number of certificates issued in Tower Hamlets decreased by -19.3% compared to London (1%) and England (0.8%).

**Table 1. Number and rates of CVIs. Tower Hamlets, London and England, 2014-15**

	Tower Hamlets	London	England
Total number of CVIs	63	2,555	23,017
Rate of certification per 100,000 people	22	30	42
Percentage change in rate since 2012/13	-19.3%	1%	0.8%

Source: RNIB Sight Loss Data Tool V3.5; <http://www.rnib.org.uk/professionals/knowledge-and-research-hub/key-information-and-statistics/sight-loss-data-tool>; latest accessed 11-11-17

Table 2 shows that age related macular degeneration in people aged 65 and over, resulted in the highest rate of CVIs in Tower Hamlets (76). There were not CVIs certificates recorded due to glaucoma for that year in Tower Hamlets.

**Table 2. CVIs related to specific eye conditions, Tower Hamlets, London and England, 2014-15**

Condition	Tower Hamlets	London	England
Rate of age related macular degeneration CVIs per 100,000 people over 65	76	85	118
Rate of glaucoma CVIs per 100,000 people over 40	0	14	13
Rate of diabetic eye disease CVIs per 100,000 people over 12	3	4	3

Source: RNIB Sight Loss Data Tool V3.5; <http://www.rnib.org.uk/professionals/knowledge-and-research-hub/key-information-and-statistics/sight-loss-data-tool>; latest accessed 11-11-17

### 4.3 Registration in Tower Hamlets

Upon receipt of a completed CVI form, the social services department offer registration as blind or partially sighted and other relevant advice and support. Registers of blind and partially sighted people are maintained by all local authorities to help them plan and deliver services.

The RNIB latest report <sup>122</sup> provides the latest available figures (2013-14) for registrations:

- There were 1,075 people in Tower Hamlets registered as blind or partially sighted. This represents an overall rate of 392 people per 100,000 which is lower than in London (489) and England (540).
- Of the people registered as blind or partially sighted in Tower Hamlets, 51% are registered as blind and 49% are registered as partially sighted.
- Since 2010/11, there has been a -13% change in the number of people registered as blind or

<sup>122</sup> RNIB Sight Loss Data Tool V3.5; <http://www.rnib.org.uk/professionals/knowledge-and-research-hub/key-information-and-statistics/sight-loss-data-tool>; latest accessed 11-11-17

partially sighted (compared to a -3% decrease across England).

- 11% of the people registered as blind or partially sighted in Tower Hamlets have also been recorded as having an additional disability by the local authority.

Table 3 shows the numbers and prevalence of people with sight loss (partially sighted) and visual impairment (blindness) by age in Tower Hamlets and compares these to London and England.

**Table 3: Numbers and prevalence rates of sight loss in TH registered people by age groups.**

<b>Registered as partially sighted</b>	<b>age 0-17</b>	<b>age 18-49</b>	<b>age 50-64</b>	<b>Age 65-74</b>	<b>age 75+</b>
Tower Hamlets (numbers)	5	110	90	50	275
Tower Hamlets (rates per 1000,000)	<b>12.2</b>	<b>62.4</b>	<b>323.5</b>	<b>550.5</b>	<b>3433.6</b>
London (rates per 1000,000)	46.1	68.6	185.0	348.4	2284.9
England (rates per 1000,000)	56.7	77.9	156.9	282.1	2155.1
<b>Registered as blind</b>	<b>age 0-17</b>	<b>age 18-49</b>	<b>age 50-64</b>	<b>age 65-74</b>	<b>age 75+</b>
Tower Hamlets (numbers)	5	120	80	50	290
Tower Hamlets (rates per 100,000)	<b>12.2</b>	<b>68.1</b>	<b>287.6</b>	<b>550.5</b>	<b>3620.9</b>
London (rates per 1000,000)	44.9	85.2	256.2	450.5	2795.7
England (rates per 1000,000)	43.4	83.7	179.1	271.9	2009.7

Source: RNIB Sight Loss Data Tool V3.5; <http://www.rnib.org.uk/professionals/knowledge-and-research-hub/key-information-and-statistics/sight-loss-data-tool>; latest accessed 11-11-17

As expected, prevalence of visual impairment and blindness increases with age with the highest rate in those aged 75 and over (3,433.6 per 100,000). Tower Hamlets rates for the groups aged 50-64, 65-74 and 75+ are significantly higher compared to London and England. This could be due to differences in lifestyle factors and health conditions worsening with age. Furthermore people could experience barriers to accessing health services leading to sight problems going undetected or treated leading to the onset of visual impairment being high in later life.

In the younger age groups however, Tower Hamlets rates are lower than in London and England. This could be due to lower ascertainment of sight problems at younger age groups, due to lack of early identification.

#### **4.4 Children and Young People with visual impairment In Tower Hamlets.**

The latest available figures (2015)<sup>123</sup> show that there were an estimated 59,035 children in Tower Hamlets aged 0-16 years. A total of 118 (0.9%) were visually impaired (30 pupils were blind and 89 were partially sighted). 58 out of 118 were estimated to have additional needs.

In the same period, there were 45,007 young people aged 17-25. Of these, a total of 90 were visually impaired (23 were blind and 67 were partially sighted).

<sup>123</sup> RNIB Sight Loss Data Tool V3.5; <http://www.rnib.org.uk/professionals/knowledge-and-research-hub/key-information-and-statistics/sight-loss-data-tool>; latest accessed 11-11-17

Eighty four pupils (42 in primary school and 42 in secondary school) with a statement of special educational needs (SEN) had vision impairment as their primary SEN<sup>124</sup>.

#### 4.5 NHS sight tests

In the UK, free NHS sight tests are available to people who are aged 60 or over, children aged under 16 or aged 16-18 and in full time education, people diagnosed as having diabetes or glaucoma or having a first degree relative with glaucoma, registered blind or partially blind, and people in receipt of certain benefits.

Currently, there is no routinely published data on the number of NHS sight tests by local authority or CCG. Data on NHS sight tests is managed by the Primary Care Support England which provides administrative and support services for primary care on behalf of NHS England and is part of Capita plc. PCSE does not provide or publish routine data.

The Health and Social Care Information Centre (HSCIC) does not provide data by local authority but for the overall London Area Team. Tower Hamlets sits in the London Area Team.

The RNIB report<sup>125</sup> publishes data based on information from HSCIC for the overall London Area Team. This data only includes NHS sight tests paid for by the NHS as privately funded sight tests are not recorded. In 2015-16:

- There were 1,631,019 sight tests in the London Area Team.
- In 2015/16, the rate of sight tests per 100,000 people in the area team was 19,102 compared to 23,896 across England.
- 532,445 sight tests were taken by people aged 60 years and over; 444,696 sight tests were taken by children aged 0-15; 87,524 sight tests were taken by students aged 16-18; and 335,320 sight tests were taken by benefit claimants.
- The rate of sight tests for people aged 60 and over is 43,153 per 100,000. The rate among children under 16 years of age is 24,508 per 100,000.

#### 4.6 People at risk of or living with sight threatening eye conditions in Tower Hamlets.

The most common sight threatening eye conditions include age-related macular degeneration (AMD), cataract, glaucoma and diabetic retinopathy<sup>126</sup>. The estimated number of people with these conditions also includes people in the early stages of these diseases that have not yet experienced any reduction in their vision. In Tower Hamlets in 2016, it is estimated that:

- 5,080 people are at risk of or living with sight loss due to the early stages of AMD. Of these, 310 people are at risk of or living with sight loss due to late stage dry AMD and 670 people are at risk of or living with sight loss due to late stage wet AMD.
- 1,020 people are at risk of or living with sight loss due to cataract.
- 1,960 people are at risk of or living with sight loss due to glaucoma.

<sup>124</sup> RNIB Sight Loss Data Tool V3.5; <http://www.rnib.org.uk/professionals/knowledge-and-research-hub/key-information-and-statistics/sight-loss-data-tool>; latest accessed 11-11-17

<sup>125</sup> Source: RNIB Sight Loss Data Tool V3.5; <http://www.rnib.org.uk/professionals/knowledge-and-research-hub/key-information-and-statistics/sight-loss-data-tool>; latest accessed 11-11-17

<sup>126</sup> RNIB Sight Loss Data Tool V3.5; <http://www.rnib.org.uk/professionals/knowledge-and-research-hub/key-information-and-statistics/sight-loss-data-tool>; latest accessed 11-11-17

- 5,950 people are at risk of or living with sight loss due to diabetic retinopathy. Of these, 550 have severe diabetic retinopathy, a later stage of the disease that is likely to result in significant and potentially certifiable sight loss.
- 12,570 people are estimated to be living with diabetes, putting them at risk of developing diabetic eye disease.

Due to changes in the population over time, it is predicted that the level of sight threatening conditions will increase. Table 4 shows the projected estimates of number of people living with sight threatening eye conditions in Tower Hamlets from 2016 to 2030. These numbers include people in the early stage of these conditions who have not yet experienced any reduction in their vision.

Although age-related macular degeneration will remain the most common form of sight loss in the UK, Tower Hamlets forecast shows that the number of people with diabetic retinopathy (including severe grade) is already higher (6,500) than people with all grades AMD (6,060) and is predicted to rise by 15% to 7,480 cases by 2030. Of the 6,500 people having diabetic retinopathy, 550 have severe retinopathy, that is, a later stage of the disease likely to result in significant sight loss. Therefore, The condition affecting the second higher number of people is age related macular degeneration with a total of 6,060 with 980 of these being late stage AMD.

**Table 4. Projected estimated number of people living with sight threatening eye conditions in Tower Hamlets**

Condition	2016	2020	2025	2030
Early Stage AMD	5,080	4,750	5,420	6,320
Late stage dry AMD	310	300	330	390
Late stage wet AMD	670	990	700	810
Cataracts	1,020	1,020	1,120	1,310
Glaucoma	1,960	2,430	2,680	2,880
Diabetic Retinopathy	5,950	6,000	6,430	6,850
Severe diabetic retinopathy	550	550	590	630
Adults with diabetes	12,570	13,790	15,430	16,920

Source: RNIB Sight Loss Data Tool V3.5; <http://www.rnib.org.uk/professionals/knowledge-and-research-hub/key-information-and-statistics/sight-loss-data-tool>; latest accessed 11-11-17

#### 4.7 Projected percentage change in levels of sight threatening eye conditions in Tower Hamlets

Table 5 compares the estimated percentage change in sight threatening conditions in Tower Hamlets, London and England between 2016 and 2030. Tower Hamlets is estimated to have the highest percentage change on the number of people with glaucoma (47%) when compared to London (22%) and England (14%).

The percentage change (15%) for the two degrees of diabetic retinopathy is lower than for London (18%) but higher than for England (11%). However, it should be noted that the projected percentage change in the number of adults with diabetes in Tower Hamlets is higher (35%) than in London (26%) and England (18%). This will increase in the number of people at risk of developing diabetic eye disease in Tower Hamlets.

**Table 5: Percentage change in sight threatening conditions between 2016 and 2030**

Condition	Tower Hamlets	London	England
Early stage AMD	24%	39%	35%
Late stage dry AMD	26%	43%	48%
Late stage wet AMD	21%	45%	50%
Cataract	28%	46%	51%
Glaucoma	47%	22%	14%
Diabetic retinopathy	15%	18%	11%
Severe diabetic retinopathy	15%	18%	11%
Adults with diabetes	35%	26%	18%

Source: RNIB Sight Loss Data Tool V3.5; <http://www.rnib.org.uk/professionals/knowledge-and-research-hub/key-information-and-statistics/sight-loss-data-tool>; latest accessed 11-11-17

This increase can be explained by the characteristics of Tower Hamlets population. Tower Hamlets is one of the most socioeconomically deprived areas in the UK and 34% of its population is Bangladeshi. Bangladeshi and black Caribbean groups are 3-4 times a more likely to have a high risk of diabetes compared to the general population. Type 2 diabetes is 40% more common among people who experience high level of deprivation.

#### 4.8 Sight loss, falls and other health conditions and disabilities

As people get older the likelihood of experiencing concomitant health issues and /or disabilities increase and these needs to be taken into account when planning services for blind and partially blind people. Based on 2015 RNIB estimates<sup>127</sup> in Tower Hamlets:

- 349 people with sight loss aged 65 and over experienced a fall and 165 of these were directly attributable to sight loss. 27 out of 349 falls required emergency hospital admission. Further information on falls in Tower Hamlets can be found in the Tower Hamlets Falls in Older People JSNA, 2015<sup>128</sup>.
- 193 (17.4%) out of 1,110 people with dementia had significant sight loss in Tower Hamlets.
- 380 adults with learning disability and blindness or visual impairment (90 and 290 respectively). Further information on learning disabilities in Tower Hamlets can be found in the Tower Hamlets learning disabilities JSNA Factsheet<sup>129</sup>.
- 758 people are living with some degree of dual sensory loss and in 261 of these it is severe.

<sup>127</sup> RNIB Sight Loss Data Tool V3.5; <http://www.rnib.org.uk/professionals/knowledge-and-research-hub/key-information-and-statistics/sight-loss-data-tool>; latest accessed 11-11-17

<sup>128</sup> Tower Hamlets Falls in Older People JSNA, 2015 [http://www.towerhamlets.gov.uk/Documents/Public-Health/JSNA/Falls\\_JSNA\\_Factsheet\\_2015.pdf](http://www.towerhamlets.gov.uk/Documents/Public-Health/JSNA/Falls_JSNA_Factsheet_2015.pdf)

<sup>129</sup> [http://www.towerhamlets.gov.uk/Documents/Public-Health/JSNA/Learning\\_Disabilities\\_JSNA\\_2016.pdf](http://www.towerhamlets.gov.uk/Documents/Public-Health/JSNA/Learning_Disabilities_JSNA_2016.pdf)

## 5. What is being done locally to address this issue?

### 5.1 Wider Tower Hamlets Eye Care Plan

Tower Hamlets Plan for Eye Care and Inclusion 2013-16 sets out the current landscape for eye health and visual impairment support and provision in Tower Hamlets. It identifies service and delivery considerations and sets out recommendations for current and future service provision. These have been described in chapter 2, page 16.

### 5.2 Prevention and early detection services/interventions

**5.2.1 NHS eye examinations** are provided under the General Ophthalmic Services (GOS) Contract, the budget for which is determined by the Department of Health. People are eligible for a free NHS sight test under a number of different criteria, for example aged 60+, aged 16 and under, in receipt of certain benefits.

Currently, there are optometrists services on premises in the high street. There are also services regularly available in residential care homes, sheltered accommodation, and day centres.

**5.2.2 Diabetic Eye Screening Programme (DESP):** This service is commissioned by NHS England and delivered across North East London (NEL) by the Homerton University Hospital NHS Foundation Trust and provides screening for seven local authorities including Tower Hamlets. The trust has increased screening capacity at Mile End by adding another screening room. This is enabling the service to invite and screen more people.

Uptake of screening is defined as the proportion of those offered a routine diabetic eye screening appointment who attend and complete a routine digital screening event. The population invited are people aged 12 and over who have a diagnosis of diabetes.

As per March 2017, Tower Hamlets uptake was 83.3% which meets the minimum national standard of =>70% and the “achievable” standard of =>80%. This is a major improvement from an uptake of 75.7% in March 2016.

**5.2.3 NHS newborn and infant physical examination screening programme (NIPE):** This national programme screens all newborn babies within 72 hours of birth, and then once again between 6 to 8 weeks for different conditions among those, the existence of congenital cataract. All new born babies in Tower Hamlets are invited to the NIPE screening programme<sup>130</sup>.

**5.2.4 Children’s vision screening services:** The vision screening programme for 4-5 year olds is commissioned by the London Borough of Tower Hamlets as part of the healthy child programme. Providers in the health, social and education sectors deliver these services.

An audit of the Tower Hamlets vision screening service in the 2015-16 academic year<sup>131</sup> showed that the coverage of the screening programme was 96%. This exceeded the national coverage

<sup>130</sup> Public Health England; Newborn and infant physical examination (NIPE) screening: programme overview; January 2013 <https://www.gov.uk/guidance/newborn-and-infant-physical-examination-screening-programme-overview>; accessed 11-07-17

<sup>131</sup> Personal communication by Tower Hamlets Deputy Head Orthoptist of the National vision screening programme for 4-5 year olds; Barts Health NHS Trust; The Royal London Hospital

acceptable standard of  $\geq 90\%$ . The programme also met the national acceptable standard target of 100% of parents being informed of the tests results within 6 weeks.

### 5.3 Treatment- specialist eye care services

Most specialist eye care is delivered in hospital eye care departments within outpatient clinics. Below are the services provided in Tower Hamlets:

#### 5.3.1 Moorfields Hospital provides:

- Hospital specialised eye care
- Age-related macular degeneration service
- Accident and emergency outpatient care. Nearly all ophthalmic A&E services are provided at Moorfields Eye Hospital (92% of activity recorded in 2009/10). This service should be available to respond to ophthalmic emergencies only. A review of audit data in 2009/10, revealed that, as many as half of the presentations for emergency services are for non-sight threatening eye conditions requiring either no treatment or non-specialist attention
- Low Vision clinic
- Community clinics at Mild End hospital

#### 5.3.2 Bart's Health provides at the Royal London Hospital:

- A comprehensive ophthalmology service, including cataract, glaucoma, medical retina (AMD and diabetes), and neuro-ophthalmic services
- Eye Paediatric services
- Low Vision
- A hospital based clinic for adults with learning difficulties. This is an Orthoptist and Optometrist led service providing routine eye tests to this group of patients. The community part of this service was decommissioned in 2013
- 24 hours on-call ophthalmology

**5.3.2 Eye Clinic Liaison Officer (ECLO):** There is an ECLO at Moorfields Hospital. The Royal London hospital have a family engagement worker (same role as ECLO) supporting their paediatric services, who is from the Royal Society for Blind Children. This professional works closely with the families of children who have a sight impairment living in Tower Hamlets, providing them with advice and support. However, there is no on-site ECLO to support adults at the Royal London, but they have an agreement with the Bart's Health ECLO based at Whipps Cross, who is able to give advice to patients when needed.

### 5.4 Rehabilitation and support-Tower Hamlets Social Care department:

Rehabilitation and support refers to the structured support that the local authority provides to maximize independence and quality of life for people with sight loss. A Freedom of Information request by RNIB to all local authorities in England in 2014 showed that Tower Hamlets had a structured programme of rehabilitation to offer to people with sight loss<sup>132</sup>.

Within Adults Social Care, the Sight & Hearing service offers and manages the following services:

<sup>132</sup> RNIB Sight Loss Data Tool V3.5; <http://www.rnib.org.uk/professionals/knowledge-and-research-hub/key-information-and-statistics/sight-loss-data-tool>; latest accessed 19-12-17

- Registration and other relevant advice and support to people with visual impairment on receipt of a completed CVI form. Registers of blind and partially sighted people are maintained by all local authorities to help them plan and deliver services.
- Community Care Assessments and Support Planning.
- Information and advice regarding equipment and resources.
- Specialist rehabilitation assessments for people with visual impairment.
- Training in orientation, mobility and independent living skills.
- Specialist equipment/ adaptations for independent living.
- Register of deaf and blind residents.
- Braille classes.

The service is currently provided by 1 nurse senior practitioner, two sensory equipment officers and 2 rehabilitation officers. There is also a team for children with disabilities which provide services to children who have been issued with a CVI by the ophthalmologist.

Data from RINB<sup>133</sup> shows that in Tower Hamlets there were:

- In 2016, 260 blind and partially blind people claiming Disabled Living Allowance (DLA).
- 40 people in receipt of adult social care in 2013-14 with “visual impairment” recorded as their primary disability.
- Since 2012-13, no change on the percentage of people with visual impairment that receive adult social.
- 54 new Blue Badges issued in 2015/16. In 2016, 137 Blue Badges were held by people registered blind which represents 25% of people who were registered blind. “Blue Badges” are parking badges that local authorities issue to individuals and organisations concerned with the care of disabled to help with transport. People who are registered as blind are automatically entitled to a blue badge if they register for one.

**Beyond Sight Loss** is a user led peer support organisation for blind and partially sighted people living and working in Tower Hamlets. Their aim is to reduce isolation, increase self-dependence and enhance the quality of life for visually impaired people. Beyond Sight Loss has over 130 members of which, 85 people are active members. They organise outings, offers advice and signposting information and peer support.

Beyond Sight Loss is supported by East London Vision (ELVIs), an umbrella organisation that provides support and activities to blind and partially sighted people and peer support groups across east London.

**Blind Aid** is a charity which in Tower Hamlets, runs a 16 weeks programme in areas of creative writing, IT, arts & crafts and fitness.

**The Royal London Society for Blind people** is a national charity which Tower Hamlets children can access for different activities.

<sup>133</sup> RNIB Sight Loss Data Tool V3.5; <http://www.rnib.org.uk/professionals/knowledge-and-research-hub/key-information-and-statistics/sight-loss-data-tool>; latest accessed 11-11-17 RNIB Sight Loss Data Tool Version 3.3 - Local authority report, 2016; <http://www.rnib.org.uk/knowledge-and-research-hub-key-information-and-statistics/sight-loss-data-tool> ; accessed 23-03-17

## 6. What evidence is there that we are making a difference?

The Public Health Outcomes Framework Outcomes (PHOFs) indicators<sup>134</sup> help us understand how well public health is being improved and protected and allows us to compare our borough with other boroughs, London and England. Table 7 presents PHOF indicators for “preventable sight loss conditions” (AMD, Glaucoma and diabetic retinopathy and sight loss certifications).

**Table 7. Public Health Outcomes Framework Outcomes (PHOFs) indicators for Preventable sight loss conditions**

Preventable sight loss conditions	Period		TH numbers	TH rates	London rates	England rates
4.12i AMD people aged 65+	2012/13	●	15	93.5	91.7	123.1
	2013/14	●	13	78.3	87.7	118.8
	2014/15	●	13	76.1	84.9	118.1
	2015/16	●	11	62.2	86.7	114
4.12ii Glaucoma People aged 40 +	2012/13	●	16	23	12.5	12.5
	2013/14	●	13	17.7	14.6	12.9
	2014/15	-	*		13.7	12.8
	2015/16	●	9	11	13.4	12.8
4.12iii Diabetic retinopathy People aged 12+	2012/13	●	8	3.6	4.1	3.5
	2013/14	●	11	4.8	4.2	3.4
	2014/15	●	7	2.9	3.8	3.2
	2015/16	●	5	2	2.5	2.9
4.12iv Sight Loss certifications	2012/13	●	75	28.5	29.9	42.3
	2013/14	●	66	24.2	30.2	42.5
	2014/15	●	63	22.2	30	42.4
	2015/16	●	63	21.3	30	41.9

Source: PHOF data tool <http://www.phoutcomes.info/public-health-outcomes-framework#page/4/gid/1000044/pat/6/par/E12000007/ati/102/are/E09000030/iid/41201/age/27/sex/4>; accessed 07-11-17

\*All rates are crude rates per 100,000 population

- Results in Tower Hamlets significantly better than London and England
- Results in Tower Hamlets similar than London and England
- Results in Tower Hamlets significantly worse than London and England

**Age related macular degeneration (AMD):** In the year 2015-16, there were 11 cases registered for age related macular degeneration in Tower Hamlets. This represents a crude rate of 62.2 per 100,000 population which is significantly better than the rate in London (86.7) and England (114). The trends show that following a number of years without significant differences in rates, in 2015-16 there has been an improvement in rates in Tower Hamlets when compared to London and England. However, these are crude rates and therefore do not take into account the differences in populations

<sup>134</sup> <http://www.phoutcomes.info/public-health-outcomes-framework#page/0/gid/1000044/pat/6/par/E12000007/ati/102/are/E09000030/iid/41201/age/27/sex/4>, last accessed 07-11-17

characteristics the three areas.

**Glaucoma:** In the year 2015-16, there were 9 cases registered for glaucoma Tower Hamlets. This represents a crude rate of 11 per 100,000 population which was not significantly different that the rates for London (13.4) and England (12.8). This is an improvement from 2012-13 when the rate in Tower Hamlets (23) was significantly worse than in London (12.5) and England (12.5).

**Diabetic retinopathy:** In the year 2015-16 there were 5 registered cases were the main cause of sight loss was due to diabetic eye disease or where diabetes is a contributory cause. This represents a crude rate of 2 per 100,000 population which is not significantly different that the rates for London (2.5) and England (2.9). Since 2012-13 the rates in Tower Hamlets have not significantly differed from those in London and England.

**Sight loss certifications:** This indicator relates completions of Certifications of Visual Impairment (CVI) (all causes - preventable and non-preventable) by a consultant ophthalmologist. This initiates the process of registration with a local authority and leads to access social care services. Moorfields Eye Hospital acts as the certification office for Tower Hamlets and is responsible for providing the data on certifications.

The rates of new (CVI) presented in the table are crude rates per 100,000 population and therefore, do not take the age distribution of the population into account. In 2015-16 Tower Hamlets had 63 new sight loss certifications and a significantly lower rate of certifications (21.3 per 100,000 population) than London (30) and England (41.9). Whether these figures reflects the real local picture it is debatable as concerns have been raised about how the number of people with sight loss varies to the number of people been registered as having sight loss.

**Diabetic Eye Screening Programme (DESP) Public Health Outcome (PHOI) indicators:** Currently, the PHOF indicators only provide uptake figures for London and England. They do not provide DESP uptake data by local authority and therefore, it does not allow for comparisons with other local authorities or assessing uptake trends. The latest uptake reported (2015-16) for London was 83.6% which is sightless higher than in England (83%).

The NHS Screening Programmes publish quarterly and annual DESP KPIs reports but they do not provide uptakes by CCG or local authority only by DESP provider.

Uptake data by local authority is currently only provided by the respective DESP provider. Tower Hamlets DESP is provided by the North East London Diabetic Eye Screening Service at Homerton hospital. As per 31 March 2017, Tower Hamlets uptake was 83.3 %.

## 7. What is the perspective of the public?

An ad-hoc Eye Health Care Needs Assessment conducted in Tower Hamlets in 2009<sup>135</sup> identified a low uptake of NHS sight tests among older population in Tower Hamlets. Feed-back from a number of focus groups identified a range of reasons for poor access to services:

- People living a long distance from the community optometrist, those who live alone, and who do not live in social housing were much less likely to attend for a sight test. It found that most of the available community optometrists were located in the areas of higher Bangladeshi residences.
- Among the Somali community it was found that low expectation and lack of knowledge were reasons for poor access to eye testing and cataract treatment.
- The Bangladeshi population in Tower Hamlets had a higher uptake of free sight tests. This seemed to be due to a greater access to sight test centres.
- Uptake of tests by older white people was very low at 6%. The report showed that older white population had notably worse geographical access than other groups and this significantly affected the frequency with which they had sight tests performed. Analysis showed that uptake fell away at walking distances greater than 15 minutes from the nearest sight test centre.
- People living in social housing, cohabiting people and people of Bangladeshi origin tended to be nearer to a sight test providers than other groups of the population.
- People were not aware that sight tests are frequently free; vouchers may be available for glasses; and that there is a health benefit to be gained by attending for an eye test regularly.
- Attendance at Moorfields on a recurrent basis was cited as being expensive and time-consuming resulting in non-attendance for people from some parts of Tower Hamlets and this is discussed further.

RNIB<sup>136</sup> reports on research which found that people who do not attend the invitation for the screening programme are confused about the difference between normal eye tests and diabetes screening. Therefore, it has been recommended that diabetes care should be more integrated and that diabetic patients could attend their different diabetic follow-up clinics (eye test, screening, foot care) on the same day.

In 2012 a national consultation of thousands of service users across the UK was undertaken as part of an initiative called 'Seeing it My Way'(UK Vision Strategy 2012). The consultation identified 10 key expectations of patients and service users with visual impairment:

1. That I have someone to talk to
2. That I understand my eye condition and the registration process
3. That I can access information
4. That I have help to move around the house and to travel outside
5. That I can look after myself, my health, my home and my family
6. That I can make the best use of the sight I have
7. That I am able to communicate and to develop skills for reading and writing

<sup>135</sup> PHAST Report; Tower Hamlets Eye Health Care Needs Assessment- Findings and recommendations; 2009; <http://www.towerhamlets.gov.uk/Documents/Public-Health/JSNA/Eye-health-JSNA-2009.pdf>; accessed 11-05-17

<sup>136</sup> RNIB. The State of the Nation Eye Health 2016; <http://www.rnib.org.uk/sites/default/files/RNIB-State-of-the-Nation-2016-APDF%20format.PDF>

- 8. That I have equal access to education and life- long learning
- 9. That I can work and volunteer
- 10. That I can access and receive support when I need it

The Tower Hamlets service user consultation in June 2015 identified a number of things that users felt were top priorities for action for people who are blind or visually impaired:

- Improved navigation support in hospitals
- Installing audio appointment announcements in GP surgeries
- Improve accessibility to leisure services
- Support to receive IT (computer and Smart phone) training
- Generally more information about support services available locally
- All pedestrian crossings in Tower Hamlets to have auditory signalling

## 8. What more do we need to know? Recommendations

Vision for Tower Hamlets: A Plan for Eye Care & Inclusion 2013–2016 (Tower Hamlets 2013) brought together professionals across hospitals, health agencies, the council, voluntary sector, patients and service users to evidence current and future service requirements, resulting in a cross sector plan of action that supports the implementation of Outcome Frameworks for the NHS, Public Health and Adult Social Care.

The priorities identified, which include feedback from consultation with visually impaired people in Tower Hamlets and that still apply are:

### 8.1 Prevention

- Detecting eye conditions earlier, especially in difficult to reach groups.
- Targeted public awareness through advertising campaigns. There is evidence that people are not aware that: sight tests are frequently free; vouchers may be available for glasses; and there is a health benefit to be gained as well as the possibility of spectacles. We should aim to maximise the uptake of eye examinations and eye screening tests and raise awareness of eye health to ensure that avoidable sight loss is prevented wherever possible.
- Routine eye health check to be carried out to people with learning disabilities and those aged 65 as the risk of falls is increased.
- Ensuring links with tobacco control, healthy weight, healthy lives (Obesity), diabetes and falls strategies are in place.
- Embedding the Vision Plan and Eye Health JSNA into the Health and Wellbeing framework and Commissioning Plan.

### 8.2 Quality

- **Improve the certification process** making sure people who are eligible get certified and registered in a timely manner and that relevant data flows through the whole eye health and sight loss pathway.
- **Joined up data:** Implement method of identifying agreed accurate cross-sector figures for the number of local people with sight loss or low vision.
  - The local authority register of blind and visually impaired should be regularly updated.
  - GOS1 forms (optometrist claims forms for NHS sight tests performed) should be

computerised and monitored on a regular basis so that data on the number of sight tests and domiciliary tests could be made routinely available.

- **Joined up services:** Improved guidance on existing services:
  - Referral Systems: Ensure referral systems between the sectors (Health, Social Services, Adults and Children and Voluntary) are in place and being used effectively.
  - Eye Clinic Liaison Officers (ECLOS): Provide an Early Intervention/Advice and Information Service at all Eye/Low Vision Clinics.
- **Ongoing support:** Maximise the opportunities for people with sudden sight loss and long-term degenerative conditions to access on-going rehabilitation and emotional support services.

### 8.3 Access to services

- **Proximity of optometrist services should be improved.** The key to most unmet need or poor take up is proximity. Where the community optician is less than a ten minute walk from home, people are much more likely to take an NHS sight test.

### 8.4 Social inclusion and independence

- **Accessible formats:** Increase availability of information on services, social activities and appointments (GP and hospital) in accessible formats in line with the Accessible Information Standards stipulations<sup>137</sup>.
- **Visual awareness training:** Increase visual awareness training for staff who provide public services (esp. with regard to transport, employment services, life-long learning, leisure services)
- **Navigation:** Address street furniture, uneven pavements, barriers and bleepers at road crossings, floating bus stops and shared space to enable visually impaired people to travel safely.
- **User led peer support:** Local Authority of Tower Hamlets to continue commission Beyond Sight Loss (formerly Beyond Barriers) to provide ongoing activities, advice and peer support to combat isolation.
- **Assistive technology:** To investigate ways in which assistive technology can be provided to people with vision impairment.

## 9. Contacts / Stakeholder involvement

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### Stakeholders

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- Charles Greenwood; Lead Optometrist, Local Optometrist Committee
- Greg Richardson, Deputy Head Orthoptist, The Royal London Hospital, Barts Health NHS Trust

<sup>137</sup> NHS England, Accessible Information Standard; <https://www.england.nhs.uk/ourwork/accessibleinfo/>; accessed 06-06-17

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- Mahendra Rastoig, Beyond Sight Loss (previously Beyond Barriers)
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