Understanding the health needs and well-being of people living with sight loss in Manchester

Confidential - not for circulation

Project Report November 2016

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Executive Summary

In April 2016 Henshaws and NHS North, Central and South Manchester Clinical Commissioning Groups began a partnership project to better understand the health and well-being and health needs of people living with sight loss in Manchester.

The aims of the engagement project were:

- To investigate the barriers people with sight loss experience in accessing health services in Manchester.
- To understand how much access people with sight loss in Manchester have to health information and how this could be improved.
- To understand what people with sight loss in Manchester believe to be good practice in accessing health services.
- To understand how all of the above also impacts on the families and carers of people with sight loss.
- To align the findings with the Manchester Locality Plan and how the aims of the plan can be achieved for people with sight loss.

Overall the results highlight the following major issues:

- People with sight loss in Manchester are experiencing a range of health needs and conditions in addition to their sight loss. They also face a number of lifestyle factors which impinge on their health such as unemployment and social isolation.
- People with sight loss in Manchester are experiencing barriers to accessing health care in a number of ways.
- People with sight loss are not always accessing health information and campaigns which could have a significant impact on their health and well-being.
- Inaccessible patient correspondence could be linked to a large number of missed appointments with its possible impact on health and with significant cost implications.
- GPs were seen as central providers of health information and support and this finding reiterates the important role of the GP at the centre of health provision and communication. Harnessing this more fully by improving the ways GP record sight loss could have huge ramifications for communicating with people with sight loss.
- A single point of access for people who are referred into low vision services from any referral route would significantly improve access to health and social care and health outcomes overall.

Three surveys were carried out with a total of 784 people with sight loss.

Survey 1 with 657 people aged 50 and above from Manchester found the following:

- Over one third or respondents had not had any contact at all from their local sensory team.
- 63% were not currently accessing or had any support from any other organisations regarding their sight loss.
- 39% were only leaving their house once a week and of these journeys 86% were to visit the doctor or hospital.
• 47% of respondents did not get out and about as much as they would like to.
• 45% felt they were unable to access support groups which might help them.
• 44% felt their days were long and boring and they didn’t know how to change that.
• 92% stated information and advice on living with sight loss would be the type of provision that would really improve their lives, health and well-being

Survey 2 with 113 people of all ages across Greater Manchester found the following:
• 43% of respondents also had depression in addition to their sight loss, and 52% also had a physical disability.
• Over the last two years there has been a 34% increase in self-reported depression by people with sight loss.
• 42% of respondents are frightened of falling and this stopped them doing things.
• 27% had actually fallen due to their sight loss and been treated in hospital.
• 40% of respondents stated they were reasonably or very inactive.
• 36% felt they had little or no access to health information.

Survey 3, a more focused bespoke survey, was carried out with 14 people from Manchester to address people’s experiences of health services in Manchester and what they believed the barriers to be. The following findings emerged:
• 50% of respondents described their overall health as fair or bad.
• 71% stated that their day to day activities were limited because of a health problem or disability which wasn’t their sight loss.
• 100% of respondents over 65 received care or support in their day to day lives; 40% for their sight loss and 60% for their sight loss and other conditions.
• 36% of respondents stated they had experienced barriers in accessing health services; this rose to 57% for people from Black, Asian and Minority Ethnic (BAME) communities.
• The two main issues reported as challenges to accessing health services were a lack of accessible information and respondents’ own anxiety or lack of confidence.
• 54% of respondents felt that health service staff did not understand their needs as a person with sight loss.

Two focus groups were carried out with 18 people and participants were an even mix of men and women with varying eye conditions and levels of vision.

The following key themes emerged from the focus groups:

Barriers to accessing health services are:
• Staff awareness and attitudes
• Physical accessibility of health care locations and buildings
• Inflexible systems
• Communication and Information
• Confidence
• Risks of sight loss to health generally
Recommendations for improving access to health services were:

- To provide accessible information: either in the correct, requested format such as large print, audio or braille; or move to communicate appointments and information by phone, text or email.
- Improved training for health services staff – particularly Visual Impairment Awareness Training.
- Sharing information across services – for example flagging sight loss on patient records.
- Accessible venues.
- Logistical accessibility.
- Joint working between sight loss organisations and health care organisations
- More and better patient representation – so people with sight loss are embedded within the organisation and can influence accordingly.

Introduction

Henshaws Community Services enable people of all ages living with sight loss and a range of other disabilities to make informed choices about their future. We are here throughout their journey offering expert support, guidance and skills, helping people to fulfil their potential. Independence and friendship are at the heart of what we do to help people find the confidence to go beyond their expectations.

Our operational delivery model is our Pathway to Independence which can be seen below.
Henshaws Community Services operates across Greater Manchester, Merseyside and the North East of England responding to the specific needs of the communities in which we work and partnering with key organisations across the locations to achieve better outcomes for people with sight loss (Cooper, Ridgway and Doyle 2015).

In Manchester we have been working in partnership with NHS North, Central and South Manchester Clinical Commissioning Groups to better understand the health and well-being and health needs of people living with sight loss in Manchester.

Manchester Clinical Commissioning Groups are responsible for planning and buying high quality, safe health services for the city. Led by local doctors and healthcare professionals with knowledge of their specific communities and patient needs, they are committed to improving the health of Manchester’s population.

Manchester currently has 91 GP practices, three major hospitals, a mental health trust, social care and health improvement services and a large number of voluntary and community organisations (Manchester Clinical Commissioning Groups and Manchester City Council 2016).

**Context**

There have been a number of national and local drivers in the development of this project. Evidence shows that circumstances for people with sight loss are worsening overall while the prevalence of people affected by sight loss is set to grow (Lord and McManus 2002; Byron et al 2013; RNIB Sight Loss Data Tool 2016). Additional drivers are the specific issues related to the health and well-being of people with sight loss, the devolution of health and social care services across Greater Manchester and finally the introduction of the Accessible Information Standard.

It is also important to recognise that there are legal requirements which organisations have to comply with. People with disabilities may find it more difficult to access healthcare or care services than other people. The Equality Act 2010 states that organisations such as hospitals, care homes and GP surgeries must take steps to remove the barriers people may face due to their disability. The Act calls this the duty to make reasonable adjustments.

Health service organisations must ensure people can access and use their services if they are disabled. They must take reasonable steps to remove the barriers which may be faced by someone who is disabled. The duty to make reasonable adjustments should be considered by organisations at all times, rather than waiting to be asked, in terms of what they need to do to make their services accessible to all disabled patients, clients and other people.

Healthcare and care providers must make changes or adjustments to how they provide their services if it is reasonable to do so. Whether something is reasonable depends on the size and resources of the organisation and the type of service they provide. It also depends on what changes or adjustments are needed and how practicable or easy it is to do them. Ultimately the courts will decide if something is reasonable or not.
In addition to their obligations under the Equality Act, healthcare organisations now have further legislation to comply with. The introduction of the Accessible Information Standard (AIS or known by GPs and health professionals as SCCI 1605) brought in by NHS England in April 2016, means that all health and adult social care providers in England are now legally required to provide medical information in a format that blind and partially sighted people can access. It means people with sight loss can request to, and should receive, their health information in their preferred format, whether that is audio, large print, braille or email. The standard covers appointment letters, leaflets, letters regarding treatment and conditions, as well as the dispensing labels on prescriptions (see Appendix 1 for further information).

**National Health and Social Care Developments**

Recent research suggests that the circumstances of people with sight loss or visual impairment (VI) have significantly worsened in recent years and that statutory support is increasingly under pressure due to government cuts (Lord and McManus 2002; Byron et al 2013).

There has been a decline in the number of people receiving local authority provided social care and this has affected people with visual impairment more than some other groups. Between 2005 and 2012 there was a 35% decline in the number of VI people receiving local authority social care compared with a decline of 16% for service users as a whole (Byron et al 2013). Not only was the recession more likely to have had a disproportionate impact on VI adults but they are seven times more likely to feel unhappy or be depressed than those with no VI; half of people with VI experience problems outside the home and are three times more likely to have difficulty accessing health care services (Lord and McManus 2012). In addition people with VI are less likely than the rest of the working age population to be in employment, all of which significantly impacts on their independence, health and well-being (Hewitt and Keil 2014).

Alongside these changes there have been significant developments in the VI field with the inception of the Adult Sight Loss Pathway and the Seeing it my way outcomes. The Adult Sight Loss Pathway constitutes a key part of the UK Vision Strategy and clarifies what people with sight loss should reasonably expect across health and social care, providing a model of best practice (UK Vision Strategy 2013). The Seeing it my way framework outlines 10 key outcomes which VI people should expect to achieve from the provision of eye health and eye care services and are based on what VI people themselves have said they want to gain (UK Vision Strategy 2013).

The 10 outcomes of Seeing it my Way, which are all equal in value, are that I (as a person with sight loss):

- understand my eye condition and the registration process
- have someone to talk to
- can look after myself, my health, my home and my family
- receive statutory benefits and information and support that I need
- can make the best use of the sight I have
- can access information making the most of the advantages that technology brings
- can get out and about
- have the tools, skills and confidence to communicate
- have equal access to education and lifelong learning
- can work and volunteer.
The context of the wider health and social care field is also shifting; social prescribing, information prescriptions and signposting are fast gaining recognition and a clear evidence base. There is increasing emphasis on services which are co-designed and co-delivered by patients, enabling their social, physical and mental wellbeing goals to be met (Langford et al 2013). The challenges facing the NHS and social care are increasing; higher demand and budgetary pressures have led to an emphasis on person-centred care – supporting people to develop the knowledge, skills and confidence they need to be in control of their own condition and make informed decisions about their own health (The Health Foundation 2014).

Local Health and Social Care Priorities

There are a number of developments at local level which are important to consider as background to this report. Greater Manchester (GM) devolution, that is the transfer of certain powers and responsibilities from national government to our region, began on 1 April 2016 where the region took charge of the money spent on health and social care services here. This equates to more than £6 billion each year.

The overall goal is to see the fastest and biggest improvement to the health, wealth and well-being of the 2.8m people of GM so there are skilled, healthy and independent people throughout the region. Devolution provides the opportunity to make decisions in GM about how money is spent on some of the most important things in people’s lives, not just health. It gives far greater control over services and funding which were previously agreed at a national level and it means all the public services working together far more closely than they have before.

The benefit to the 2.8m people in GM is that it will remove false boundaries between hospital care and neighbourhood care and support, to ensure residents receive better joined up care. It will also prioritise early help and support to ensure people are able to take more control over their health and prevent existing illnesses from getting worse.

The devolution of health and social care across Greater Manchester will focus on:

- More work on the prevention of people getting ill and being able to look after themselves.
- Joining up health and social care services to reduce gaps in the system and make services work better together.
- Better community based care near people’s homes.
- Better care for people with mental health problems such as depression.

This work across Greater Manchester will clearly be significant for the citizens and organisations in Manchester and many of the drivers are congruent with the more local plans and strategies being worked in on in Manchester itself. The aims are high and it is crucial that within that, the particular and specific needs of people with sight loss are also considered and met through the changes.
The Manchester Strategy launched in 2016 (Manchester City Council 2016) describes the vision of the city in the future where it will thrive with jobs, wages, education, housing, quality of life and a sense of belonging and community at the centre of its goals. As well as these aspects there is a recognition that the health and well-being of the population is paramount and the strategy states that it ‘will improve the health and well-being of the people who live in the city’.
(http://www.manchester.gov.uk/mcrstrategy)

The Manchester Locality Plan 2016 (Manchester CCGs and Manchester City Council 2016) sets out a clear picture of where the City is now in terms of the health and well-being of the population, where they want to get to and how this will be achieved.
(http://www.manchesterccgs.nhs.uk)

The main findings in the report which provide the backdrop to this engagement project and how they relate to sight loss are highlighted below.

- Approximately 10% of the population of Manchester are 65 or older and this is predicted to double by 2050. The risk of sight loss increases with age (RNIB sight loss data tool 2016)
- Manchester currently has 91 GP practices, three major hospitals, a mental health trust and city wide social care services. However there is recognition that this is a complex system which makes it difficult for people to know where to go for the most appropriate treatment. This can be even more of an issue for people with sight loss who have difficulty accessing information and getting out and about.

- The plan outlines what people want from their health and social care services; for example ‘to not feel lonely in their community’ and ‘to know what services are available in their community and how to use them’. The plan must meet the needs of all the Manchester population so that people with sight loss are able to have their wants and needs met too.

- There is a focus on the finances of health and social care services across Manchester and recognition that savings are important. The plan aims to work with local people to reduce missed appointments and medicine waste and aim to help people live healthier lives so they require less treatment from health services in the future. Further research would be required to uncover the percentage of people with sight loss who miss appointments because they don’t receive information in the correct format and also to ascertain how health promotions and prevention messages reach them.
In order to prevent people becoming ill and supporting them to live healthier lives the plan states health and social care organisations will:

- Address the causes of ill health through a focus on life styles and factors which impact on health including employment and leisure. People with sight loss experience barriers in relation to employment and accessing leisure and sport opportunities (Slade and Edwards 2015).

- Spot illnesses earlier through screening programmes and through GPs identifying and treating people on their lists with conditions such as diabetes and dementia. Screening programmes need to be accessible for people with sight loss and GPs should also be able to identify where people with key conditions also have sight loss as this can cause additional issues for patients.

- Providing support earlier by reaching out via carers and ensuring mental health issues and isolation are tackled early. Depression, loneliness and isolation are major issues for people with sight loss.

- Managing illness by enabling people to manage their own conditions and supporting them to do so. A focus on independence and resilience is key for people with sight loss.

The Locality Plan then sets out the transformation of services which will achieve their aims. Hospital, community health, social care and GP services will be joined up so that people’s care is managed by a single team containing a range of health and social care staff of which there will be 12 across Manchester. There will also be a focus on using technology to keep people well so records can be joined up to ensure all professionals understand fully each person’s needs. These plans would directly benefit people with sight loss: visual impairment truly straddles the health and social care spectrum and many of the barriers people face and have described in this project are around navigating that system and professionals from one area not understanding what their needs are in another area. These fundamental changes, if they are implemented fully and properly, should really help reduce some of those systemic barriers people with sight loss have traditionally faced.

The aims of the Locality Plan have provided context throughout this project in terms of how its aims can be achieved for people with sight loss and this will be focused on further in the recommendations and conclusion.

**Prevalence of Sight Loss in Manchester**

Alongside all the developments and the shifting landscape of health and social care and the circumstances of people with sight loss, there is also evidence to show that there are more people with sight loss than ever before and the prevalence is expected to increase into the near future.
As of 2013/14, there are 2,850 people in Manchester registered as blind or partially sighted. We know the registered figures are only a small minority of the actual number of people living with sight loss with an estimated 9,730 people living with sight loss in Manchester. Of this total, 6,240 are living with mild sight loss, 2,380 are living with moderate sight loss (partial sight) and 1,110 are living with severe sight loss (blindness).

By 2030, it is expected there will be 12,460 people in Manchester living with sight loss, an increase of 28.1%. By 2030, the number of people living with severe sight loss is estimated to be 1,450, an increase of 30.6%.

People from non-white ethnic groups are at a higher risk of certain sight conditions. 33.4% of the total population of Manchester are from a non-white ethnic group, compared to 14.6% in England as a whole.

The costs of sight loss to the local economy are hugely significant:

<table>
<thead>
<tr>
<th>Area</th>
<th>Total healthcare expenditure on problems of vision (£)</th>
<th>Healthcare expenditure on problems of vision per person (£)</th>
<th>Proportion of overall programme budget spent on problems of vision</th>
</tr>
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<tbody>
<tr>
<td>NHS South Manchester</td>
<td>£4,466,518</td>
<td>£24.09</td>
<td>2%</td>
</tr>
<tr>
<td>NHS Central Manchester</td>
<td>£4,585,999</td>
<td>£21.94</td>
<td>2%</td>
</tr>
<tr>
<td>NHS North Manchester</td>
<td>£5,429,066</td>
<td>£24.42</td>
<td>2%</td>
</tr>
</tbody>
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Table 1

The indirect costs of sight loss in Manchester are even more substantial. Indirect costs include a range of factors, the largest element being unpaid care provided to blind and partially sighted people by family and friends. Other significant elements are lower rates of employment and the cost of specialist equipment. The total indirect cost of sight loss in Manchester is estimated to be £28.2 million pounds. The indirect cost of sight loss per person is £55 in the general population. (RNIB Sight Loss Data Tool v3.2, 2016).

This engagement project has been carried out in the context of all these drivers, to highlight how to better meet the health needs of VI people and to ensure that any interventions are proactive rather than reactive. This is working towards the overall aim of people with sight loss being able to get access to the support they need when they need it, so they are better informed and equipped to make the best choices and live as independently and as well as possible.
Project Aims and Methodology

The aims of the engagement project were:

- To investigate the barriers people with sight loss experience in accessing health services in Manchester.
- To understand how much access people with sight loss in Manchester have to health information and how this could be improved.
- To understand what people with sight loss in Manchester believe to be good practice in accessing health services.
- To understand how all of the above also impacts on the families and carers of people with sight loss.
- To align the findings with the Manchester Locality Plan and how the aims of the plan can be achieved for people with sight loss.

The key outcomes of the project will be to provide:

- Top tips for communicating and working with people living with sight loss.
- A full report of findings to include recommendations for quality delivery systems/good practice for people with sight loss.
The report reveals a number of key findings about the experiences of and access to health services of people with sight loss in Manchester and the research was undertaken using a combination of quantitative and qualitative methods to provide breadth and depth to the evidence. The research methods employed were:

- Secondary/ desk-based research to provide context and background and to explore potential future health and care needs – this included analysis of the RNIB sight loss data tool, the Manchester Locality Plan and Manchester CCGs Operational Plan, academic and other specialist sector research into the experiences of people with sight loss.

- Primary research findings from recent surveys carried out by Henshaws were utilised to provide evidence of the health and wellbeing of people with sight loss in Manchester.

- Primary research consisting of a survey and 2 x focus groups to gather experiences of health and well-being and the barriers to accessing health services in Manchester for people with sight loss. The topic guides for the focus groups were developed based on the themes emerging from the secondary research and Henshaws primary research findings. Each group discussion was recorded and audio-transcribed and a themed analysis was carried out to provide actionable and evidence based findings.
The Surveys

The results from three surveys have been used as evidence for this report:

- A survey of 657 people aged 50 and above from across Manchester about their health and well-being and experience of social isolation.
- A survey of 113 people with sight loss of all ages from across Greater Manchester to assess their experiences of the Adult Sight Loss Pathway; to gather information on other conditions which are risk factors for sight loss or which can be associated with sight loss; to explore their experiences of falls, levels of physical activity and access to information provision; and finally to explore what barriers people with sight loss face in their day to day lives and what services or support are of most benefit to them.
- A smaller scale bespoke survey with 14 people designed specifically for this project to assess people’s views about access to health services in Manchester and what could be done to improve access and ultimately their health and well-being.

Focus Groups

A total of 18 people took part in the two focus groups and participants were an even mix of men and women with varying eye conditions and levels of vision, and also varying levels of health and with a range of experiences so that a full representation of views and insights could be obtained.

Results

There is considerable research to highlight the issues people with sight loss have to face regarding their health and well-being and access to health services. Many people who experience vision loss withdraw from social contact possibly because they lose awareness of the nuances of body language which are part of social interactions. This can then lead to increasing social isolation and the ensuing impact on mental health. There is evidence to show that sight loss leads to an increased risk of depression, suicide, falls and cognitive decline all of which may be exacerbated if health providers fail to recognise the particular needs of people with visual impairment (Cupples et al 2012). Problems for people with sight loss in accessing healthcare include:

- Receiving information in inaccessible formats.
- Difficulties communicating with health care professionals.
- Professionals failing to respect people’s ability to participate in their own care.
- Physical difficulties in getting around heath care facilities.

A study of 600 blind and partially sighted people and 500 healthcare professionals in both primary and secondary care highlighted the following (RNIB 2009):

- 95 per cent of blind and partially sighted people feel it is important to have health information in a format they can read for themselves, and most healthcare professionals agree with them on this.
Nine out of ten say they were not asked by NHS staff about what format they required when they were given information.

- Blind and partially sighted people feel a loss of privacy and independence if they have to rely on someone else to access personal information.
- Eight out of ten blind and partially sighted people said they did not get medicine information in a format they could read.
- Appointment letters which are not in accessible formats are directly linked to an increased level of missed appointments.
- General health information is not always accessible to blind and partially sighted people, for example guides on managing a long term health condition, and leaflets on how to stop smoking.
- Nine out of ten say they do not always ask for or obtain information in accessible formats, with four out of ten saying it takes too much effort, and a small minority saying they did not ask for fear of being labelled as needing special treatment.

Receiving information in the wrong format can have serious consequences for people with sight loss:

- Loss of privacy and independence.
- Potential risks to personal safety and health.
- Loss of ability to make informed choices about healthcare. (Sibley and Alexandrou 2009)

The health and well-being of people with sight loss in Manchester

The primary research findings from this project underline the evidence above and provide a local context highlighting a number of areas of concern regarding the health and well-being of people with sight loss in Manchester. Our survey of 657 people aged 50 and over highlighted that 37% of respondents had not had any contact at all with their local sensory team and 63% were not currently accessing or had any support from any other organisations regarding their sight loss. This indicates a level of being cut off and isolated from organisations which could help support them with mobility and independence with the possibly longer-term impact on health and well-being we know this can cause (Lord and McManus 2012).

This survey in particular focused on the levels of social isolation experienced by people with sight loss in Manchester and there were a number of interesting findings.

- 39% were leaving their house at least once a week and 7% were only going out once a month or less (see Fig 2 on page 16).

High levels of social isolation were indicated by the fact that:

- 86% of these journeys were to visit the doctor or hospital with only 18% to get some exercise and 10% to pursue a leisure interest or hobby.
The following statements also provide a real insight into the isolation and lack of support respondents felt:

- 47% of respondents did not get out and about as much as they would like to.
- 45% felt they were unable to access support groups which might help them.
- 44% felt their days were long and boring and they didn’t know how to change that.

Respondents were asked about the type of support that would improve their lives, their health and well-being and their ability to cope with their sight loss. The results can be seen in Fig 3 below.

These findings indicate the type of support people with sight loss in Manchester would find beneficial with 92% stating that more information and advice on living with sight loss would be useful.
Additional Health Issues and Disabilities

It is very important to understand the other conditions that people with sight loss may have that can be risk factors for certain eye conditions or which can mean people have other significant needs and requirements which are potentially not being met. The evidence drawn on here is from the survey of 113 people from across Greater Manchester.

The survey evidence clearly showed that respondents are not only dealing with their sight loss but with a whole range of other conditions:

* NB. The totals do not add up to 100 as people could tick more than one condition.

We can also compare some of these key conditions with the responses from our 2014 survey (see Fig 5 on page 18) which seems to suggest that the needs of people with sight loss are becoming ever more complex. This is particularly evident around the incidence of depression with a 34% increase in self-reported depression in the two year period.
The information also gives us some insight into conditions which we know are risk factors for sight loss such as high blood pressure and diabetes. Knowing there is a high proportion of people with sight loss and high blood pressure can help to inform decisions about key health messages for these groups of people, what the risk factors to eye health are from high blood pressure and what steps can be taken by people to reduce their risks.

Falls

Another area becoming increasingly important is that of falls prevention. There is a considerable body of evidence to suggest that a major risk factor in falls is due to sight loss. Research also indicates that between 40-50% of older people with sight loss limit their activities due to a fear of falling (Thomas Pocklington Trust 2013). Our findings back this research up with 42% of our respondents saying they were frightened of falling and that this stopped them doing things.

In our 2014 survey we wanted to gauge whether our service users had had a fall which resulted in hospital treatment as a result of their sight loss. At this time almost one quarter (24%) of respondents stated that they had fallen due to their visual impairment and been treated in hospital. The 2016 survey asked the same question and found that in Greater Manchester this had risen to 27%; a 12.5% increase overall. In the 2016 survey we expanded our questioning around the area of falls to try and glean some further insight in relation to the experience of falls among respondents and the results can be seen in Fig 6 on page 19.

*NB. The totals do not add up to 100 as people could tick more than one condition.*

![Other Conditions Reported by Respondents](image-url)
The results in relation to falls are significant for two main reasons:

1. It underlines the need for services which are preventative with clear aims to decrease the chances of people with sight loss falling. Support around safer living environments focusing on key risk factors for people, such as trip hazards and poor lighting could also make a significant difference.

2. With increased pressures on health and social care budgets and organisations focused on reducing acute admissions and hospital bed days, providing a preventative service around this key area would fit with the strategic objectives of commissioning bodies in CCGs and local authorities.

Activity Levels

Related to the area of falls, and linked in with what we are beginning to understand about the barriers to accessing sport and exercise facilities for people with sight loss and the links to their health, we wanted to understand a little more about how physically active respondents are and the results can be seen in Fig 7 on page 20.
40% of respondents report that they are reasonably or very inactive, with only 14% stating that they are very active which clearly has significant implications for health and well-being.

### Access to Information

Understanding the barriers to information provision can enable organisations to potentially be more proactive in this area and work to ensure there is equality of access to information for people with sight loss. Respondents were asked to rate on a scale from 1-5 (where 1 = none and 5 = a great deal) how much awareness or information they had access to in two key areas. Figs 8 and 9 on page 21 show how respondents rated their levels of information and awareness in relation to the prevention of sight loss and health information generally.

The results show that 30% of respondents felt they had little or no awareness or information about preventing sight loss. More crucially over one third (36%) of people felt they had little or no access to health information; however 40% of respondents felt they had a great deal of information about the prevention of sight loss and 33% felt they had a great deal of access to health information.

It is therefore a mixed picture in many ways and a large proportion of people with sight loss do feel they are getting access to health information and prevention messages. More specific research would be required to fully understand where people are accessing this information, why it is working for them and how that good practice could be adopted more widely.
These findings can be contrasted with the bespoke smaller scale survey of Manchester residents where we found considerably less access to health information reported with 59% of respondents stating they had little or no access to health information and no respondents saying they had a great deal of awareness (see Fig 10 on page 22).
Experiences of health services

The primary research and engagement work carried out for this project provides some further evidence about people’s health and well-being and their experiences of health services.

Respondents to the survey were asked to describe their overall health excluding their sight loss and the results can be seen in Fig 11, with 50% describing their health as very good or good and 50% as fair or bad. 71% of respondents went on to state that their day to day activities were limited because of a health problem or disability (not their sight loss) which has lasted or is expected to last for at least 12 months.
These findings consolidate the findings from the earlier surveys that people with sight loss are frequently living and coping with other health conditions and disabilities in addition to their sight loss. If they are also finding it difficult to access health information and health services because of their sight loss, this has very significant implications for their future health, the management of their condition and their on-going independence.

We asked respondents whether they had someone who looked after them or provided help and support in their day to day lives and the results can be seen in Table 2.

<table>
<thead>
<tr>
<th>Support Needs</th>
<th>% of respondents overall</th>
<th>% of respondents aged 65 and over</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support for sight loss</td>
<td>29%</td>
<td>40%</td>
</tr>
<tr>
<td>Support for sight loss and other conditions</td>
<td>43%</td>
<td>60%</td>
</tr>
<tr>
<td>Support but not for sight loss</td>
<td>7%</td>
<td>0%</td>
</tr>
<tr>
<td>No support</td>
<td>21%</td>
<td>0%</td>
</tr>
</tbody>
</table>

Table 2

72% of respondents are receiving care and support for their sight loss and other conditions which confirms that the people around the person with sight loss are also important with regard to the targeting of information and messages about health promotion, service uptake and the on-going management of health conditions. However the main objective for health organisations should be the person with sight loss themselves and the focus should be around ensuring accessibility to facilitate the independence of the person with sight loss rather than an on-going reliance and dependence on the people around them.

100% of respondents aged 65 and over have someone who looks after them or provides them with help and support, which is what we might expect as someone gets older and their needs become greater. This again highlights the issue that people with sight loss, especially older people, are dealing with multiple health problems which affect their day to day lives, so it is even more crucial that they receive an equitable health provision.

Interestingly only 40% of the over 65 respondents stated that their day to day activities were limited because of a health problem or disability (compared to 71% of respondents overall and 100% of people aged 25 and under and 50-64 year olds – see Fig 12 on page 24). This could be because 100% of the people aged 65 and over actually had people who looked after them and gave them help or support so were able to continue with their day to day activities due to that support; or it could be that younger people have more activities they wish to participate in. To fully explore the reasons behind this would require some further consultation and research.
Barriers to accessing health services

“When I attend the Manchester Royal Eye Hospital I feel like I am invisible, I am just a number. No one has the time to answer any of my worries about losing my sight. I have never had a discussion about how I am coping, coming to terms with the reality that my sight continues to deteriorate and how that is affecting my life skills. It is a horrible frightening experience and I have no idea what really is best for me. Losing your sight is a lonely experience which most people don’t understand. People deserve the support to explain what is going to happen as their sight deteriorates. I have had so many falls and I have good vision in my left eye.”

(Nigel, Survey Respondent)

This quote from a survey respondent underlines some of the issues people with sight loss face not just in relation to losing their sight but also in a broader sense.

Every person with sight loss is different, not just in terms of varying levels of vision, but differences in opinions, experiences, resilience, confidence, personal circumstances and approaches to life and all of these factors impinge on how barriers in life are experienced and how people react to them. The barriers outlined below are from the results of the survey and from the analysis of the focus groups and, although people had varying opinions about how to tackle them or what to do about them, there was common understanding that they did exist and were experienced commonly by people.

The bespoke survey asked people from across Manchester whether they had ever experienced any barriers in accessing health services due to their sight loss and the results can be seen in the tables on page 25.
Barriers to health services due to sight loss | Yes | No |
--- | --- | --- |
All respondents | 36% | 64% |
Central Manchester | 40% | 60% |
North Manchester | 25% | 75% |
South Manchester | 40% | 60% |

Table 3

There was no significant difference by gender, but there were some marked differences between the experiences of people with sight loss from BAME communities and White British respondents:

Barriers to health services due to sight loss | Yes | No |
--- | --- | --- |
White British | 14% | 86% |
BAME background | 57% | 43% |

Table 4

There were also some differences by age:

Barriers to health services due to sight loss | Yes | No |
--- | --- | --- |
25 and under | 33% | 67% |
26-49 | 75% | 25% |
50-64 | 0% | 100% |
65 and over | 20% | 80% |

Table 5

The survey assessed which health services in particular people had experienced barriers accessing and the results can be seen in Fig 13 below.
Table 5 on page 25 shows that the older people were the less likely they were to report experiencing barriers in accessing health services due to their sight loss, whereas 75% of people aged 26-49 felt they had experienced barriers. There are possible reasons why older people may report this less; it could be they have been living with sight loss for longer and so have developed useful strategies in accessing services which work for them, or it could be that younger people have higher expectations from public services overall. Further research would be required to investigate in more depth why people aged 26-49 from a BAME background and living in central or south Manchester seem to experience barriers more than other groups.

The survey assessed which health services in particular people had experienced barriers accessing and the results can be seen in Fig 13 below.

43% of respondents had experienced barriers in hospital services and 29% stated it was another service. When prompted as to what this was respondents mentioned that it was around information not being provided in their chosen format.

In order to investigate the support people had received from particular health services we asked respondents to rate the services they had experience of. A large proportion of people had no experience of the GP out of hours service or the NHS 111 service but were able to feedback on the other areas mentioned. The results (see Fig 14 on page 27) show that 50% of respondents felt their GP was very helpful and 55% that their hospital was very helpful. There were much lower percentages of people who rated any service as not very helpful or not at all helpful which is clearly very encouraging and indicates that although this work has found some areas for improvement there are a large number of people who reported positive experiences.
Respondents were asked to think about a time when they may have faced a challenge in accessing health services due to their sight loss and what the issues were and the results can be seen in Fig 15 below. The two main issues reported by respondents were a lack of accessible information and also their own anxiety or lack of confidence.

In terms of the accessibility of information, this has been discussed earlier in relation to the AIS and there is further discussion about this in the recommendations section. With regard to peoples’ own anxiety and confidence, there is a clear role potentially for specialist voluntary organisations to build peoples’ resilience and independence to ensure they are confident enough to access services and make their voices heard.
Staff Awareness and Attitudes

There was some evidence to show that people had experienced a range of attitudes from staff, some of which had been experienced by them as a barrier, and the range of attitudes experienced can be seen in the case study and Fig 16 on page 29.

Case Study

The following case study really illustrates the experiences people with sight loss can face when accessing health services. It also clearly shows why it is so important that this type of experience is not common place; not only because every patient should receive an excellent standard of care but also because if the patient experience is a negative one then the potential consequences can be far reaching and costly.

Dave is 48 years old and from north Manchester. He has Diabetic Retinopathy and is registered blind.

“Some years ago I had an operation on my eye and my partner was at work so I was on my own in the hospital. It was on my eye with some sight left in it, my other eye I have no sight, and so when I had the operation I had a patch over the good eye if you like. So I had no sight at all, I was completely 100% blind at that point. I was handed the discharge slip and basically the nurse said ‘we would like you to go now’. I had no one there with me and they knew that this eye was completely blind and I had a patch over the other eye, and she said ‘right you can go now’. I didn’t know what to do so I started to go, there were nurses all around on the ward and I was walking along the corridor very gingerly and there wasn’t a lift either on that particular floor. I was directed to the stairs and I managed to get hold of the bannister but I missed my footing. Fortunately I managed to right myself but I could have fallen top to bottom down the stairs, it was awful. I followed the bannister round and eventually got down to the ground floor. When I got there I was approached by a volunteer who thankfully escorted me to the exit and got me a taxi and the taxi driver got me out and to my front door. That was one of the worst examples I’ve had although there are more. If that volunteer hadn’t approached to help me I could still be there now! To let someone walk out on their own under those circumstances, particularly from a ward where they should know more because the operation was on my eye, it was just a really bad experience. I won’t go to any appointment or anything now on my own and I’m lucky that my partner can come with me. I don’t know how people who haven’t got anyone to go with them actually manage.”
This shows that the overwhelming majority of respondents felt the major attitudinal barrier was that health services staff did not understand their needs with 54% stating they had experienced this.

This was backed up by evidence from the focus groups:

“ When I had breast cancer a couple of years ago, I can pinpoint things that happened. When I had the operation on my breast there was no-one around to take me to the toilet which I needed just after the operation and I didn’t experience any help there so I don’t think they are quite aware of how much help a blind person needs. There was a lack of awareness amongst the staff. I mean normally I can take myself to the toilet but in this particular position when I had just had the operation there was nobody around. So I suppose really just talking to the blind person and telling them how they can access a nurse or a volunteer who might be able to help. I got out of bed myself and you see I could have fallen.”

(Betty, Focus Group Participant)

Other major issues were staff treating people as though they weren’t there and expecting less of them because of their sight loss.

“ I have had staff ask the people with me ‘can she write her own name?’ It is that assumption people make.”

(Annie, Focus Group Participant)

“ When people realise that you’re blind, they automatically think that you are deaf and stupid as well.”

(Lily, Focus Group Participant)

“ People talking to the people with me and not me is frustrating, I am here you know!”

(Ron, Focus Group Participant)
Increased awareness and training for staff in visual impairment awareness would certainly go a long way to improving the situation and focus group participants recognised this need:

“ It is basic staff training required and awareness of VI.”  

(Ron, Focus Group Participant)

**Physical Accessibility of Health Care**

One of the key issues identified by focus group participants was the problems they faced in actually physically accessing the buildings and locations of their health services. Participants spoke about difficulty navigating to health care sites and then these problems persisted once they had managed to get there in terms of finding their way around them once inside:

“I find access to the hospital difficult, I have to go with someone and if I had to go on my own I couldn’t do it.”

(Norah, Focus Group Participant)

“The other thing that I’ve noticed when I go for my eye appointments at the hospital is that the waiting area is like a long corridor. I’m okay because I’ve always got my partner with me, but what they do as well is (and you are in an eye hospital who should know that you are registered blind obviously) but I’ll just hear this disembodied voice right from the other end of the corridor shouting my name. It is fine for me because my partner will then walk me down. But he has told me that there have been occasions where there are people there that are blind and they’re on their own and this nurse will be 100 yards down the corridor calling their name and they’ve got no idea. Why doesn’t the nurse come down for them, you would think it would just be standard, common sense. People might fall or trip or anything on their way down there.”

(Dave, Focus Group Participant)

“Ironically the inaccessibility of the Manchester Eye Hospital – whoever designed that had no visual problems, that big glass atrium when you go in, it kills your eyes, it’s so bright. It should have been designed in collaboration with the people who were going to use it so it was appropriate for them.”

(Sue, Focus Group Participant)

There was a perception that the needs of wheelchair users had been taken into account in some health settings but not necessarily the needs of people with sight loss:

“I do think they have made a lot of places very, very accessible for wheelchairs but not at all for the blind.”

(Len, Focus Group Participant)

“When organisations think of making places and systems accessible they think of wheelchair users and other disabilities like sight loss can be overlooked.”

(Pete, Focus Group Participant)
“Historically someone in a wheelchair has an obvious disability and a lot of us in here have canes which should be a prompt to anybody that is sighted but it’s just not. Even now, visual impairment is still not recognised as much as physical disabilities.”

(Annie, Focus Group Participant)

“I find if you’re in a wheelchair there is somewhere that says they can help if you’re disabled but obviously I wouldn’t see that. So I don’t know, there might be help for people who can’t see but I don’t know. I’ve never been told and I’ve never been able to access it obviously so I have to have somebody with me all the time so I know where to go to.”

(Megan, Focus Group Participant)

“The accessibility of the disabled toilets at the hospital weren’t designed for people with a visual impairment - they currently have white walls, white hand dryers and white doors and would benefit greatly from some colour contrast.”

(Len, Focus Group Participant)

Participants also discussed the fact that at many GP surgeries and health clinics there are systems in place to book in and be informed when it is your turn which are wholly visual and so provide an additional barrier for patients with sight loss:

“So when you go and check in to the doctors, they’ve now got where you check in yourself so that’s another barrier. I can’t do that so I have to go to the receptionist and say ‘can you put me in please because I can’t use the machine.’”

(Dave, Focus Group Participant)

“The other problem I have is the GPs now they have that screen above and your name comes up and what room to go in and which doctor and obviously we can’t read that. It’s a complete waste of time if you can’t see. It is supposed to be agreed for me that the doctor comes out and shouts you. I mentioned it to the receptionist and she says ‘oh yes take a seat the doctor will come out for you’ and a lot of the time they don’t, they forget. So if you aren’t seeing your regular doctor they don’t know you and that you’re blind and you’ve got a guide dog and this information is not passed on by the receptionist so you’re just sat there waiting.”

(Yvette, Focus Group Participant)

“At our doctor’s surgery, there seems to be no concern for people who are blind or visually impaired. If I went on my own I would still be sat there now because it comes up on the screen and I can’t see it. What is the harm for the receptionist just to make someone aware it’s their appointment if they can’t see. It’s not rocket science is it?”

(Phil, Focus Group Participant)
**Inflexible Systems**

It was felt quite strongly by participants that the systems and processes in place across healthcare providers were often too inflexible for their needs meaning they were either ignored, overlooked or made to feel as if they were difficult.

“Sometimes the systems are too rigid to allow for any flexibility which is wrong really.”  
*(Annie, Focus Group Participant)*

The possible impact and risk of being made to feel difficult or a nuisance could be that people with sight loss don’t access services when they should do and the consequences of this to their health could be significant. Again this is something which requires further research but is important to recognise.

“I think there is a chance that people worry about going to the doctors and hospital sometimes because of the problems and that may mean people with sight loss don’t go when they should be.”  
*(Nell, Focus Group Participant)*

**Communication and Information**

There was agreement across the groups and through the surveys that the provision of information, both about their own care and about health services and conditions in general, in an accessible format was very poor.

“I was asked years ago whether I wanted to receive information in braille or in large print, but even though I said ‘yes that would be very helpful’, we’ve never had anything in any other format other than the normal computer printed letter in normal font. You see I have a partner so whenever any of my appointments arrive in the post he can read them as he’s fully sighted but if you lived on your own it would be extremely difficult obviously.”  
*(Dave, Focus Group Participant)*

“It is almost worse being asked what format you would prefer and then nothing happening.”  
*(Norah, Focus Group Participant)*

“I wouldn’t know where to go to get information about health. If you’re not aware that it’s there you don’t know, you don’t know what you don’t know.”  
*(Len, Focus Group Participant)*

“Some places give you hand-outs you know like diagrams etc. and that’s no good to me.”  
*(Sue, Focus Group Participant)*
Confidence

The issue of how confident people feel in accessing services is threaded throughout the primary research. Many participants felt unable to access services independently and were very much reliant on friends and family so there is an issue around building people’s confidence and resilience so they are able to be as independent as possible.

“...I can’t remember the last time I left the house on my own it is so long ago, and one of the reasons I am so nervous about it and using my cane, I mean maybe it’s me being paranoid, but I feel like I have victim stamped on my forehead. It makes me feel vulnerable.”

(Dave, Focus Group Participant)

Risks of sight loss

There are some particular risks with regard to health which people with sight loss face, some of which have been mentioned above, but more specifically there is an issue around the visual cues of illness or injury which can be missed if you are unable to see them.

“...I have cut myself and not realised I was bleeding. It may not be as dramatic as a fall, but it’s a real worry if a blind person can’t see these things and lives alone.”

(Yvette, Focus Group Participant)

“...My friend actually died of bladder cancer because she obviously couldn’t see that there was blood in her urine and by the time she felt unwell and went to the doctors it had spread and it was too late.”

(Nell, Focus Group Participant)

This is an issue which needs to be recognised within this report but which would require some further research to understand more thoroughly.
Recommendations

Throughout our engagement with people with sight loss we asked them what they felt would improve access to health services for people with sight loss in Manchester. The following key areas all emerged as recommendations through the research.

Information Provision

In order to ensure the right information reaches people with sight loss it is important to understand where they are most likely to go to find out the information they may need about health services or health conditions. The majority of people who responded to the bespoke survey stated they would use the internet, followed closely by their GP and the results can be seen in Fig 17 below.

![Fig 17: Where respondents go to access information about health services or health conditions](image-url)

There was recognition throughout the focus groups that firstly not everyone has access to the internet and secondly if they do it is still not always clear where to go for information. There is also a difference between actively searching for health information when you require it and accessing the health messages that are sent by health organisations on a regular basis.

There is a danger that these health messages simply miss people with sight loss and there is a need for further research about the best way for health promotion and campaign messages to reach them. One suggestion would be to harness the websites and information channels of voluntary organisations, using their databases and audiences to communicate key messages and campaigns.

Key channels for communication were identified as:

- Regular face to face meetings/groups at key organisations where people can be told directly about what is on offer and available.
- Use of emails, but targeted and going out at a regular time.
- Use of social media.
- Use of the local radio to promote and advertise.
Another solution would potentially be if GPs were able to flag on their IT systems when someone has a visual impairment they could then ensure health promotion messages and programmes are sent out in a format people can access. The provision of information in the correct, requested format or a move to using phone or text to communicate was seen as crucial by participants:

“Accessible information and or telephone advice.”

(Survey Respondent)

“Information in braille, audio and email.”

(Survey Respondent)

“noticed is it would be helpful for them to leave a message on the answering machine but they never do that either. They know that you’re blind but then they won’t even leave you a telephone message either so it can be quite difficult.’

(Dave, Focus Group Participant)

“Information on CD or large print.”

(Survey Respondent)

“Another thing that would be helpful, I mean I know there’s a lot of patient confidentiality involved but the other thing we have noticed is it would be helpful for them to leave a message on the answering machine but they never do that either. They know that you’re blind but then they won’t even leave you a telephone message either so it can be quite difficult.”

(Dave, Focus Group Participant)

**Improved training for staff**

There was a strong sense that specific in situ training in visual impairment awareness for staff would really be of benefit.

“Better training for staff and better ways to complain if they don’t behave properly towards people with sight loss.”

(Survey Respondent)

“Basic staff training is required around an understanding and awareness of visual impairment.”

(Survey Respondent)
Sharing information

A common experience of focus group participants was that there didn’t seem to be anything that went across their records which stated they were visually impaired and they felt very strongly that this would be a real improvement in terms of their access to health services. It would mean they wouldn’t continually have to explain their sight loss every time they accessed services and also that systems could be put in place to ensure they received an equitable service.

“The thing is, is there something on the system that tells them that a person is visually impaired so it can be highlighted straight off and everyone knows? If they had a system where if you are blind it flags it up, the same as all your meds and that come up, then people are aware of the situation. Where the receptionist sits they don’t necessarily know if you are blind or not so they need something to flag it up.”

(Yvette, Focus Group Participant)

“A common system across GP practices would be much better.”

(Len, Focus Group Participant)

Accessible Venues

It was strongly felt by participants that health settings or venues could be made more accessible for VI users and that these solutions could often be quite straightforward and cost-effective. The following were all suggested:

- Marked steps to get into centres and clearly defined routes using colour contrasting inside venues.
- Use of navigation/GPS technology.
- Use of volunteers to assist and support people with sight loss attending appointments. This buddying system could be piloted by a specialist sight loss organisation which could provide experienced volunteers to trial the approach and support existing hospital volunteers which their specialist knowledge.

“More support for people in hospitals, tactile signage and compatible technology with phone apps to allow independence in finding a department for example.”

(Survey Respondent)

“I’ve been to Wythenshawe hospital and they have volunteers there who will take you to the department you want to go to. The problem can be if you can’t see they are there to help but at Wythenshawe they are at the desk when you come in and they come over. If it can work well there it can work in other places and they could have people on the wards too. If you use volunteers it doesn’t cost them any money either but would make a massive difference.”

(Yvette, Focus Group Participant)
Logistical accessibility

A common experience of focus group participants was that there didn’t seem to be anything that went across their records which stated they were visually impaired and they felt very strongly that this would be a real improvement in terms of their access to health services. It would mean they wouldn’t continually have to explain their sight loss every time they accessed services and also that systems could be put in place to ensure they received an equitable service.

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(Yvette, Focus Group Participant)

“A common system across GP practices would be much better.”

(Len, Focus Group Participant)

Accessible Venues

Participants understood there may be issues implementing changes to where and how different services are delivered, but felt very strongly that aiming to ensure that people can access services in their own communities was very important and to avoid where possible people having to travel to a number of different places for different appointments.

“Use local community halls for clinics rather than large hospitals which are difficult to find your way around with sight.”

(Survey Respondent)

“Avoid having to travel to different centres for appointments.”

(Survey Respondent)

Joint working between sight loss organisations and health care organisations

Focus group participants felt this should be in a three main ways;

1. Providers should be working with sight loss organisations to more directly promote what they have to offer and what is available.

2. Sight loss organisations should directly train staff in Visual Impairment Awareness so that there are always staff who are trained and working at any one time to support the needs of someone with sight loss if required.

3. Organisational barriers need to be broken down so that sight loss organisations, councils or providers are not just promoting their own activities/provision but sharing information about all that is on offer to improve people’s health.
Patient Representation
It was felt very strongly by participants that their voice and views should be reflected within health care organisations so that the issues raised in this report could be heard directly by people within the organisations. A focus group participant was able to give an example of good practice from Salford Royal Hospital which has set up a group to provide patient feedback around accessibility for people with sight loss. As a result, the following have been introduced:
  - Colour contrasted water jugs, crockery and plates so avoiding the use of clear plastic which can’t be seen.
  - Extra hoists.
  - A meet and greet group run by volunteers.

Conclusion
This research has revealed a number of important findings about the landscape of health and well-being for people with sight loss of all ages across Manchester.

Engaging with people with sight loss to hear about their experiences and stories has illustrated that there are changes which can be made which would greatly improve their access to health services and ultimately their health. The aims of the Locality Plan are congruent with the needs of people with sight loss; joining up health and social care and providing services in the community will remove many of the barriers people with sight loss face. However for it to achieve its aims for all Manchester citizens, health and social care providers need to ensure they are proactive to meet the needs of their visually impaired patients and that the develop systems at the outset that ensure fair and equitable services achieving positive health outcomes for all.

Ultimately not only do health care providers have a duty to be equitable in the way they provide their services but the risks of not doing so can have on-going and potentially more costly results in the future.

Further Research
This study provides some key findings and action points to move forward however it is also recommended that further research be carried out to address the following issues:
  - Further understanding of the impact of people with sight loss not having information in the right format; for example in terms of the number of missed appointments or the effects on health through not attending screening or vaccination programmes.
  - Further insight into the needs of different groups of people with sight loss so people from Black, Asian and Minority Ethnic communities, older people and those with additional health needs and disabilities who may be experiencing multiple barriers.
  - Further study into the use of technology to reduce health barriers for people with sight loss through the use of navigation/GPS apps, reading aids and other apps which can be utilised by visually impaired people to increase their independence such as ‘Be my Eyes’ (an iPhone app that lets blind people contact a network of sighted volunteers for help with live video chat) and ‘BeSpecular’ (which lets blind and visually impaired people see through a sighted person’s eyes).
References


Manchester Clinical Commissioning Groups and Manchester City Council (2016) A healthier Manchester: Our vision, your health.


RNIB Sight Loss Data Tool v3.2, 2016


Further Sources of Information

Henshaws:
https://www.henshaws.org.uk/

RNIB:
http://www.rnib.org.uk/

Further information on eye health, risk factors and associated conditions:
http://www.rnib.org.uk/eye-health-eye-conditions

UK Vision Strategy and Seeing it my way outcomes:
http://www.ukvisionstrategy.org.uk/

Accessible Information Standard:
https://www.england.nhs.uk/ourwork/accessibleinfo/

Equality Act 2010:
https://www.gov.uk/guidance/equality-act-2010-guidance

For further information about this report please contact:

helen.doyle@henshaws.org.uk

Registered charity no. 221888
Appendix One – RNIB Letter template to request information in preferred format

Patient’s name:

Address line 1: ____________________________________________
Address line 2: ____________________________________________
Address line 3: ____________________________________________
Postcode: _________________________________________________

Name of GP surgery:

Address line 1: ____________________________________________
Address line 2: ____________________________________________
Address line 3: ____________________________________________
Postcode: _________________________________________________

Date: ______________________________

Dear

As you may be aware, NHS England published a new information standard about accessible information last year. It is called SCCI 1605 and it came into full force from 31st July 2016. The standard sets out new rules for communication formats and represents a real step forward for people who are unable to read standard print to be able to access health information and appointments in a format that they can read.

With this in mind, I would like to notify you that I have a sight impairment and cannot read ordinary print. Therefore I’d like to request that any documentation that you send out to me be in the format indicated below:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
My required alternative format for written communications is:

Please mark as appropriate:

Audio on CD: □
Audio on USB: □
Braille grade 1: □
Braille grade 2: □

Email and my email address is:

Large print 18 point: □
Large print 22 point: □
Large print 24 point: □

Please ensure that my information format needs are captured and flagged up on your patient record system.

The read codes for my request above are located in the SCCI 1605 full specification document at https://www.england.nhs.uk/ourwork/patients/accessibleinfo-2/

I make this request in reference to the Equality Act 2010 and the NHS accessible Information Standard SCCI 1605.

Please confirm (in the format specified above) and within 21 days, that my accessible format needs have been recorded on your patient record system.

Yours faithfully,