

Services in Havering for people who have a visual impairment: a review

June 2018



What is Healthwatch Havering?

Healthwatch Havering is the local consumer champion for both health and social care in the London Borough of Havering. Our aim is to give local citizens and communities a stronger voice to influence and challenge how health and social care services are provided for all individuals locally.

We are an independent organisation, established by the Health and Social Care Act 2012, and employ our own staff and involve lay people/volunteers so that we can become the influential and effective voice of the public.

Healthwatch Havering is a Company Limited by Guarantee, managed by three part-time directors, including the Chairman and the Company Secretary, supported by two part-time staff, and by volunteers, both from professional health and social care backgrounds and lay people who have an interest in health or social care issues.

Why is this important to you and your family and friends?

Following the public inquiry into the failings at Mid-Staffordshire Hospital, the Francis report reinforced the importance of the voices of patients and their relatives within the health and social care system.

Healthwatch England is the national organisation which enables the collective views of the people who use NHS and social services to influence national policy, advice and guidance.

Healthwatch Havering is your local organisation, enabling you on behalf of yourself, your family and your friends to ensure views and concerns about the local health and social services are understood.

Your contribution is vital in helping to build a picture of where services are doing well and where they need to be improved. This will help and support the Clinical Commissioning Groups, NHS Services and contractors, and the Local Authority to make sure their services really are designed to meet citizens' needs.

***‘You make a living by what you get,
but you make a life by what you give.’
Winston Churchill***

INTRODUCTION

A significant role of a Healthwatch is to support and enable the most vulnerable members of the community to have a voice and to influence services which have a substantial impact on their day to day lives.

This report on Eye Services responds to the concerns expressed by residents, professional staff and voluntary organisations about the service model, the facilities, the level of support and, above all, the disjointed processes that service users experience. The number of organisations involved in this chain of care has surprised us. This contributes to the inability to be able to clearly describe the Care Pathways, which may result in residents who are blind or partially sighted being without the physical and health and wellbeing support they require.

In this report we look at the journey patients make from attending their optician for routine eye tests and glasses, to being referred to the hospital services at Barking Havering and Redbridge University Trust (BHRUT) for more complex care, to those residents who find themselves with an eye condition that requires them to register a Certificate of Visual Impairment (CVI) with the London Borough of Havering (LBH), and the support available to help our residents and their families to adjust their lives for the long term.

Managing long-term conditions requires all organisations to work together, maximising the opportunity by sharing clinical information and technology. It is a concern that some of the information we requested was recorded on a manual basis and only estimates of CVIs issued could be provided for 2016/17; given the role the CVI has in supporting national epidemiological analyses of the needs of people who have a visual impairment, this is particularly disappointing.

Our report indicates that a lot more could be done to improve the experience of patients, especially the provision of an Eye Clinic Liaison Officer (ECLO) at BHRUT, which we have been advised, continues to be delayed despite the support and offer of funding from the Pocklington Trust, the Royal National Institute for Blind People and the continued lobbying of the local Sight Action Group.

There is information and guidance available from the Royal College of Ophthalmologists for all hospital medical staff, comprehensive advice available for everyone from the RNIB, supportive and responsive local services from the London Borough of Havering, advice and information from CarePoint and the voluntary sector such as Sight Action and Partially Sighted Havering.

Our view is that, unless there is a more comprehensive understanding of the individual parts of the entire process of care needed in eye services and how they are interconnected, then we may only address the symptoms of an inadequate service model. However, the commitment shown from organisations to address this problem indicates that it is possible to achieve a more holistic model of care for our residents.

In preparing this report local organisations and individuals have been enormously helpful and we are very grateful for their support.

Commissioning services, redesigning clinical pathways and working across the boundaries of different organisations is a challenge. This, together with the financial pressures being faced by all organisations, makes it important that commissioners and service providers carefully determine where best value for money can be achieved while still delivering on statutory requirements and quality of service and care.

A good place to start this report is to set out the view of patients and carers which is contained within the UK Vision Strategy:

‘Seeing it my way’

- ✓ That I have someone to talk to
- ✓ That I understand my eye condition and the registration process
- ✓ That I can access information
- ✓ That I have help to move around the house and to travel outside
- ✓ That I can look after myself, my health, my home and my family
- ✓ That I can make the best use of the sight I have
- ✓ That I am able to communicate and to develop skills for reading and writing
- ✓ That I have equal access to education and lifelong learning
- ✓ That I can work and volunteer
- ✓ That I can access and receive support when I need it

PROLOGUE - Karen, a Healthwatch Havering member

I'm one of the members of the Working Group which contributed to this report. I'm also severely sight impaired (blind) myself. Although my eye problems were with me from birth, I only got myself registered as blind when I was in my early 20s. I had muddled through school and my first few jobs somehow, with hardly any support. Although I can't remember exactly who it was that recommended getting registered, I do recall feeling unenthusiastic. I couldn't imagine how being "officially disabled" was going to help me, especially being a young, confident and ambitious person. But as it turns out they were right, and I would now recommend registration (which is called a Certificate of Visual Impairment, or CVI) to anyone.

I believe the many positives of getting a CVI are largely unknown and for some reason under-publicised, so I've listed * a few of them that have made my life easier and often more financially comfortable - you can read them in section 9 of this report. Let me make it clear that even once you have a CVI, you always have the option to use or not use it. No one is going to "out" you as sight impaired without your permission. It's just a tool you have at your disposal but if you choose never to use it that's fine, and you won't be forced to. I carry a credit-card-style registration card in my wallet as proof of my status, which was provided to me by my local authority. It's convenient and discreet.

KAREN

** Karen's suggestions are listed on page 39 onward*

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1 RECOMMENDATIONS

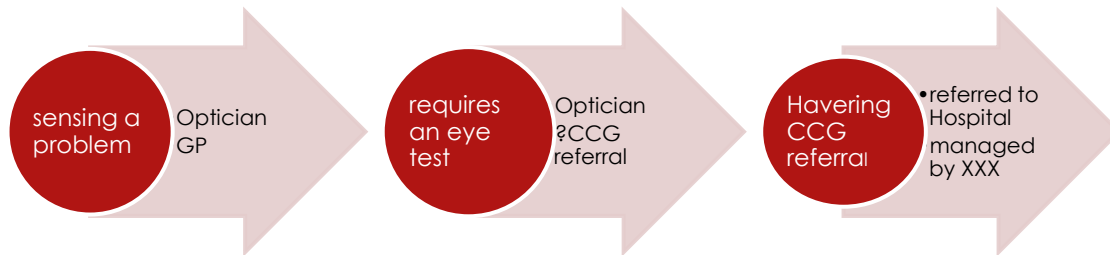
1. That all organisations work together to streamline the referral/assessment process, with the aim of reducing the expenditure and providing a faster service
2. That the CCG review and streamline the assessment, referral and treatment process, with the aim of giving patients a faster diagnosis and possibly saving money by reducing the number of clinical visits
3. That the CCG commission a more holistic model for non-emergency care, based on Care Pathways, drawing on expert opinion, evidenced based practice and mapping clearly what the patient and carer can expect
4. That the CCG review:
 - The care pathway for emergency eye care
 - The guidance and advice provided by the NHS111 service, and
 - The arrangements for patients needing to be transferred to Moorfields
5. That BHRUT and the CCG accept the offer which has been made by the RNIB and the Pocklington Trust to fund/support the appointment of an ECLO to enable the role to be provided as soon as possible, and that BHRUT and the CCG commit to funding and maintaining the role.
6. That all organisations:
 - Recognise that diagnoses of irreversible vision loss can have a traumatic impact on people's lives
 - Develop a Service Level Agreement (SLA) with a voluntary organisation to provide a support service to patients at both Queens and King George Hospital
 - Provide a suitable confidential space with equipment and furniture
7. That everyone be given access to an environment that supports and enables high quality eye care for the prevention and treatment of eye disease to optimise, preserve and restore vision

8. That BHRUT build on current good practice models to develop a Patient and Carer Partnership group facilitated by BHRUT staff
9. That BHRUT create a more dynamic, integrated relationship between the A&E Department and the Outpatients Department to better support both staff and patients
10. That BHRUT and LBH use their best endeavours to ensure that staff and residents are aware of the DVLA Patient and Doctor Guidance and the information provided on the RNIB website regarding visual disorders and driving
11. That care be taken to ensure that all relevant data is shared with Moorfields in order to support a robust needs assessment for those who have visual impairments
12. That BHRUT update their manual recording of CVIs to an electronic database which can provide information in a timely and accurate way to support both BHRUT and the wider health and social care community
13. That BHRUT review its procedures to ensure that all medical staff are complying with the Royal College guidelines and that all Consultant staff and Hospital Eye Clinic staff observe the Guidance note from DH England published 17 August 2017
14. That BHRUT and LBH work together to share the data on CVIs and RVIs to support the appropriate commissioning models for both health and social care and support the epidemiological analysis work which is reported via an NHS England Public Health Indicator
15. That LBH consider incorporating the RNIB database information into its commissioning intentions and requirements to support both current and predicated service models
16. That LBH continue to support voluntary services such as those meeting at Yew Tree Lodge and the opportunities that they provide for residents and, in particular, the highly valued evening club

17. That LBH accept that people who are not digitally literate or able to access digital systems require support to ensure that they can continue to be involved in their community and the opportunities this offers
18. That all organisations aim to achieve the highest possible standards of information, ensuring that they enable people to make informed choices and decision

2 WHERE THE JOURNEY BEGINS AND THE ROLE OF THE CLINICAL COMMISSIONING GROUP

The Journey



- Sensing a Problem

For most of us the recognition that our vision is deteriorating can come from finding it more difficult to read small text, maybe when driving the car or that feeling of eye strain at the end of a busy day. Some people then contact opticians for an eye test, others seek an appointment with their GP.

- Requires an eye test

Residents told us about their experiences and it seemed that there was no standard pathway and, in some cases, a meandering and time-consuming pathway. Examples are

- Patients who attend their local optician were sometimes referred to their GP, others were referred directly to the Westland.
- Patients who attended their GP were sometimes referred to the Westland Clinic for assessment and Westland clinic referred patients back to the GP for further referral,
- Patients were referred to the Westland Clinic for assessment and treatment,
- Patients were referred to BHRUT for assessment and treatment and some to the Treatment Centre.

- In discussion with groups of patients when they began to share their experiences, it became evident that in many cases the current care pathway seemed more like a lottery than clinical efficacy.

Consider

Does this referral journey provide the simplest, most cost effect and optimal route?

We understand that other parts of the country do not have a referral/assessment centre as part of the referral from GP/Optician to Hospital. In many places, the optician can refer directly to the hospital

Recommendation 1:

That all organisations work together to streamline the referral/assessment process, with the aim of reducing the expenditure and providing a faster service

Recommendation 2:

That the CCG review and streamline the assessment, referral and treatment process, with the aim of giving patients a faster diagnosis and possibly saving money by reducing the number of clinical visits

The role of the CCG

Within the NHS service provision, commissioners are required to assess the needs of their individual populations and then purchase services from local providers of care. As part of this role, the CCG assesses how many residents will need care during the year.

The CCG commission services locally from BHRUT, Westland Clinic and the Treatment Centre and more specialist services from hospitals such as Moorfields.

Commissioning services requires detailed specifications and clear performance monitoring techniques, below are areas where concerns have been raised regarding performance.

- Residents' thoughts on what a quality experience should have

Residents told us that, for them, quality is the total experience and although they valued highly the work of the clinical staff, they identified areas where there was a lack of quality in the total experience:

- Lack of an Eye Clinic Liaison Officer - *'An investment of £1 can net a return of £10.57 to health and social care budgets - RNIB'*
- Support in the overall experience for older people with sight problems
- Congested treatment areas making it hard to manoeuvre walking frames
- Need for a range of good practical information being easily available for patients recognising the need for language translation and Easy Read
- Need for more equipment for patients to support them at home and work - Low Visual Aids - particularly important for young people

- Patients' thoughts on what performance standards should deliver

Patients and carers were seeking to be more informed about the standards of service available in outpatients. Patients suggested that a charter or similar should be displayed setting out the service delivery standards, examples given were

- How the clinic operated - many found it a very confusing environment

- What to expect and how to prepare themselves, prior to their first attendance.
 - More adherence to appointment times - many people said that when they had an appointment for 2.00pm they never expected to be able to leave before 4.30pm, others commented you needed to allocate the entire day if you had to attend the clinic.
 - Explanations to patients when the clinic was delayed or running late
- **Involving patients in designing services**

The assessment of residents' needs is an important part of commissioning; however, we could not find evidence to demonstrate involvement with service users. The Low Vision Service was criticised for lack of engagement and accessibility for service users and their families
 - **Improving the emergency eye care facilities in A & E**

Patients have told us that although the care is good in the A & E Emergency Eye Unit, the area is very congested and the facilities poor. Patients said that GPs were very reluctant to care for eye accident conditions. When attending on the advice of GPs or 111 some patients found the experience distressing and have stated that they have been turned away as the visit was not necessary or told to come back the next day. Some were told to go to Moorfields without any conversation about how with an eye injury the patient travelled to Moorfields.

Consider

How can the CCG by working in partnership with BHRUT enhance and maximise the service commissioned on resident's behalf?

How is the CCG preparing for the increasingly older generation who are very high users of the service?

Our research indicates that the clinical teams are very keen to improve the service model. Patients value the service and voluntary organisations who work closely with the hospital are also very supportive and keen to help with improving the service model.

Recommendation 3:

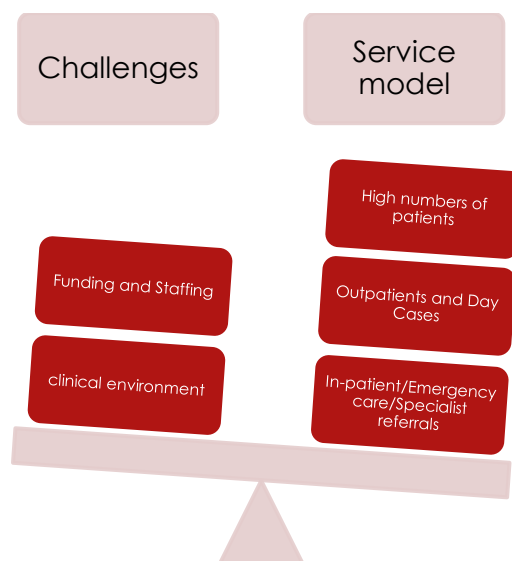
That the CCG commission a more holistic model for non-emergency care, based on Care Pathways, drawing on expert opinion, evidenced based practice and mapping clearly what the patient and carer can expect

Recommendation 4:

That the CCG review:

- The care pathway for emergency eye care
- The guidance and advice provided by the NHS111 service, and
- The arrangements for patients needing to be transferred to Moorfields

3 THE ROLE OF BARKING, HAVERING AND REDBRIDGE UNIVESITY HOSPITALS TRUST (BHRUT)



BHRUT are the main provider of Ophthalmology care for the residents of Havering. The hospital currently provides outpatients' appointments, outpatient treatments, day case procedures and in-patient operations. There are also facilities for patient to be treated for emergency eye care.

There has been nothing that would indicate a lack of confidence in the clinical staff, on the contrary it is well regarded by both staff and patients. Everyone to whom we spoke offered their opinions as a way of achieving the approach of 'a valued service that gets better'. Patients said that their care often exceeded their expectation.

For such a large service provider, crucially, there is no ECLO. It is highly possible that partially sighted residents and blind residents have been leaving the eye clinic not knowing, or unsure of, the name or nature of their eye condition. In addition, patients have not been offered formal counselling either at the time or later.

- What does an Eye Clinic Liaison Officer (ECLO) do?

ECLOs provide people recently diagnosed with an eye condition with the practical and emotional support which they need to understand their diagnosis, deal with their sight loss and maintain their independence.

CVI Guidance Notes from the DH England provide the following advice on ECLOs

“16. It is good working practice to have ECLOs in hospitals as this helps to create a good link between health and social care and enhances joined up support for the patient. Clinic staff should be suitably trained to be able to manage what may be an emotional and upsetting time for the patient. The patient should be asked to sign if they consent to their information being shared. It is important to document the patient's decision in their notes and to advise them of the benefits of sharing their information. The patient does not have to consent to share information, and they can also withdraw their consent at any point by contacting the relevant organisations.”

Consider

Being diagnosed with an eye condition that will considerably change someone's lifestyle can be difficult to come to terms with, and everyone reacts differently. People can be worried about unemployment, at a higher risk of falls and social isolation. It can be an extremely confusing and uncertain time and, in many cases, emotionally traumatic.

- ❖ People with learning disabilities are 10 times more likely to have serious sight problems than other people.

Recommendation 5:

That BHRUT and the CCG accept the offer which has been made by the RNIB and the Pocklington Trust to fund/support the appointment of an ECLO to enable the role to be provided as soon as possible, and that BHRUT and the CCG commit to funding and maintaining the role.

Consider

It is recognised good practice to provide Specialist Advisers on a voluntary basis in services where there is trauma or potentially a negative diagnostic outcome. For fourteen months this service has not been available at BHRUT to patients who receive a diagnosis that their condition is untreatable and will result in them becoming partially sighted or blind. A life-changing diagnosis with no ability to link with an organisation whose networks and advice can provide that vital stepping stone, helping an individual and their family maintain their emotional balance in the months ahead of them.

- ❖ People with sight loss are three times more likely to suffer depression.

Recommendation 6:

That all organisations:

- Recognise that diagnoses of irreversible vision loss can have a traumatic impact on people's lives
- Develop a Service Level Agreement (SLA) with a voluntary organisation to provide a support service to patients at both Queens and King George Hospital
- Provide a suitable confidential space with equipment and furniture

- Patients' and Relatives' concerns

Patients and relatives have raised many concerns:

- There is no ECLO or Voluntary Sector support available to patients on diagnosis
- Difficulty contacting the appointments department
- Waiting times for appointments, often confusion with personal and clinical details
- Overcrowding and delays in the outpatient areas
- There has been no information - leaflets/pamphlets, posters or audio material, plus a lack of information in the Accessible format, and equipment from December 2016 to December 2017
- Recently a table with leaflets and useful information has been placed in the main waiting room: it would be helpful if there was signage indicating who patients and carers should speak to, to get advice
- Patients reported a cupboard has been put up with Sight Aids on display. It is placed in a dark corner of the main waiting room and people with sight problems find it difficult to identify Aids in the cupboard.
- Cramped treatment areas
- Lack of the full range of clinical expertise expected in an ophthalmology department
- Clinical staff looking stressed and demoralised, both in Outpatients and A&E
- Lack of appropriate facilities for counselling and support
- No obvious support for patients with Learning Disabilities or patients with other physical needs such as poor mobility
- Royal College of Ophthalmologists together with RNIB have developed a Certificate of Visual Impairment Information poster template for hospital clinics this is not on display.
- Emergency Eye Care in the A & E has very poor facilities and patients complained that they are shuttled between A&E to Team 2 Outpatients.

Consider

The issues raised in this report are very similar to those contained in a CQC report for Moorfields resulting in a rating of Requires Improvement. Is it worth considering the possibility of BHRUT linking with Moorfields to learn about the development and progress they are undertaking as they strive to achieve a Good rating?

Recommendation 7:

That everyone be given access to an environment that supports and enables high quality eye care for the prevention and treatment of eye disease to optimise, preserve and restore vision

Recommendation 8:

That BHRUT build on current good practice models to develop a Patient and Carer Partnership group facilitated by BHRUT staff

Recommendation 9:

That BHRUT create a more dynamic, integrated relationship between the A&E Department and the Outpatients Department to better support both staff and patients

4 THE CERTIFICATE OF VISUAL IMPAIRMENT (CVI)

How this process works and which organisations are responsible for which part seems to have caused a lot of confusion. To assist with a better understanding of the roles and responsibilities of local organisations this section contains extracts from a range of nationally recognised bodies. In the Background Reading section at the end of this report we have identified the sources that we have considered. This process is recognised as complex and to quote the RNIB:

‘At the moment, however, as RNIB and others have identified, the process of certification isn’t always working completely smoothly: certainly, when it is combined with registration: and in fact, it is often incorrect to assume that an area with comparatively low certification rates has relatively few blind and partially sighted residents. A vast range of professionals are involved, all of whom can slow down or block the process’

The CVI formalises the status of someone as visually impaired and acts as a referral for a social care assessment if the individual is not yet known to social services.

Guidance from the Department of Health (DH)

The DH document published on 17 August 2017 “Certificate of Vision Impairment: Explanatory Notes for Consultant Ophthalmologists and Hospital Eye Clinic Staff in England”, advises:

“Purpose of the CVI form

“4. Hospital clinic staff should explain the importance of certification and the sharing of information with their local authority, their GP and the Royal College of Ophthalmologists Certifications Office at Moorfields Eye Hospital. If the patient still does not consent to sharing information they should be

made aware they may miss out on valuable support and information.

“5. Completing and sending off the CVI in a timely manner is not only beneficial for the patient but will enable community health and social care agencies to plan appropriate services as part of local strategies such as falls prevention or loneliness and isolation.

“6. If the patient has also provided consent to share the CVI form with the Certifications Office at Moorfields Eye Hospital, the CVI will be used to record diagnostic and other data that is used for epidemiological analysis and reported via an NHS England Public Health Indicator.”

For this process, three statutory organisations are involved:

- BHRUT
- LBH
- The DVLA

BHRUT

It is the role of the senior medical staff at BHRUT to make the assessment and decision to issue a CVI. This process is part of a nationally-designed pathway with clear guidelines available to support medical staff and hospitals in performing this responsibility efficiently and with care.

The Royal College of Ophthalmologists guidelines state:

“The College believes that an important component of good clinical care by ophthalmologists is the offer of a Certificate of Vision Impairment (CVI) to eligible patients and encourages its members to promote the uptake of the CVI amongst patients who are likely to benefit from it and to facilitate the process of registration as far as it is in their power to do so.”

The Guidance adds:

Certificate of Vision Impairment Form

'Part 1 of the CVI form clearly indicates the section that must be completed by the consultant ophthalmologist and they should also complete the visual acuity and diagnosis section as set out in Part 2 of the CVI as well. The CVI should be completed fully and accurately. The patient should be actively involved in completing the form which may be completed in part by members of the eye clinic staff where indicated on the form, such as by an Eye Clinic Liaison Officer (ECLO).

16. It is good working practice to have ECLOs in hospitals as this helps to create a good link between health and social care and enhances joined up support for the patient. Clinic staff should be suitably trained to be able to manage what may be an emotional and upsetting time for the patient. The patient should be asked to sign if they consent to their information being shared. It is important to document the patient's decision in their notes and to advise them of the benefits of sharing their information. The patient does not have to consent to share information, and they can also withdraw their consent at any point by contacting the relevant organisations.'

The next stage involves the patient and the decision that they make as to whether to register with the local council (in Havering, LBH):

'Being registered as partially sighted or blind enables a person to access a range of benefits to help them manage their condition and the impact it may have on their lives. Registration is voluntary, and access to benefits and social services is not dependent on registration.'

Registration is voluntary, and whilst it is essential to obtaining some benefits and concessions, it is not a prerequisite for accessing support from social services.

However, we would strongly encourage all patients to seek access to the assessment process provided by the borough. By completing the form, the borough is required to undertake a full assessment of an individual's needs and to provide the necessary help and support needed.

The College also states that:

'The Referral of Vision Impairment (RVI) letter is used where registration is not appropriate or where the patient has declined registration but wants advice and information about the difficulties caused by loss of vision.'

LBH

LBH is responsible for assessing the needs of the Borough's population and delivering a range of support and social care provision for people with sight disabilities, and this includes working with voluntary organisations. Under the Care Act 2014, local authorities continue to have specific duties to assess and provide information, rehabilitation and support to visually impaired people. This includes making contact with people within 2 weeks of receiving their CVI. LBH is also responsible for the formal registration process of CVI. For more detail, see section 6 of this report.

The DVLA

Albeit that registration as blind with the local authority is voluntary, an individual who is a driver and is diagnosed with a visual impairment is obliged by law to comply with Driver and Vehicle Licensing Authority (DVLA) requirements (which in many cases will result in disqualification from driving). The DVLA provide a patient and doctor guidance document regarding visual disorders, as do the RNIB.

Consider

Some of the information we requested using FOI was only recorded on a manual basis and only estimates of CVI issued could be provided for 2016/17. This is disappointing given the role the CVI has in supporting epidemiological analysis which is reported via an NHS England Public Health Indicator.

Where a patient consents to registration, the CVI form is also shared with the Certifications Office at Moorfields Eye Hospital, producing data that is ultimately used to shape and commission the local services through the Joint Strategic Needs Assessment (JSNA). If the data is inadequate or inaccurate, it will lead to levels of need not being properly identified.

Recommendation 10:

That BHRUT and LBH use their best endeavours to ensure that staff and residents are aware of the DVLA Patient and Doctor Guidance and the information provided on the RNIB website regarding visual disorders and driving

Recommendation 11:

That care be taken to ensure that all relevant data is shared with Moorfields in order to support a robust needs assessment for those who have visual impairments

5 DOES THE CURRENT INFORMATION AND TECHNOLOGY PROVIDE AND MEET EXPECTATIONS?

Concerns have been expressed to Healthwatch that there is no adequate way of measuring those patients issued with CVI by the consultants at BHRUT and people registering a CVI for assessment and support being received by LBH. Without the right information, LBH cannot allocate sufficient resources to people with Visual Impairments.

Healthwatch have tried to consider how best to address this on-going concern. Our approach, admittedly basic, was to issue FOI requests to BHRUT and LBH.

According to the FOI responses received from both organisations, the position for 2016/17 is:

- BHRUT Ophthalmology Department only keeps information in a manual record by patient name and not date; about 300 CVIs were issued in that year
- LBH received in total from all ophthalmology units (i.e. mainly from BHRUT but also from elsewhere) - 93 CVIs

Below are the formal responses from both organisations:

- BHRUT

Healthwatch's FOI request was sent on 20 February 2018, but the response was not received until 21 May 2018.

Question: In 2016/17, how many Certificates of Visual Impairment (CVI) were issued by the Ophthalmology Department for people resident in Havering?

Response:

'Further to your request dated 20 February 2018, please find our response to your enquiry below. Please also accept our apologies for the delay in getting back to you.'

“Our Ophthalmology department keeps a manual record of this information; however, it is not split by CCG/area. Details are recorded by patient name and not date. We can only estimate that there were circa 300 CVI’s in 2016/17.”

- LBH

Question: For the year 2016/17 - How many Certificates of Visual Impairment were received by the Council (distinguishing between those issued by BHRUT and those issued by other ophthalmic units, if any)

Response:

93 Certificates of Visual Impairment. This information is not held in the way requested and cannot distinguish between BHRUT and other Ophthalmic units

Question: How many assessments of need were made following the receipt of a CVI. How many assessments, if any, were made of individuals needs for support as a result of visual impairment were made without the issue of a CVI

Response:

With CVI - 87

Without CVI - 149

Question: How many people, if any, refused registration as blind despite the issue of a CVI

Response: Information not held

Consider

To make good commissioning decisions and plan appropriately for health and social care, managing all long-term conditions requires all organisations to work together, maximising the use of, and sharing, clinical information and technology.

Recommendation 12:

That BHRUT update their manual recording of CVIs to an electronic database which can provide information in a timely and accurate way to support both BHRUT and the wider health and social care community

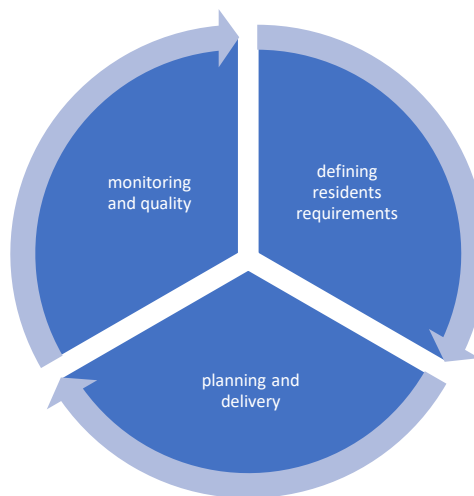
Recommendation 13:

That BHRUT review its procedures to ensure that all medical staff are complying with the Royal College guidelines. All Consultant staff and Hospital Eye Clinic staff observe the Guidance note from DH England published 17 August 2017

Recommendation 14:

That BHRUT and LBH work together to share the data on CVIs and RVIs to support the appropriate commissioning models for both health and social care and support the epidemiological analysis work which is reported via an NHS England Public Health Indicator

6 WHAT IS THE ROLE OF THE LONDON BOROUGH OF HAVERING (LBH)?



LBH is responsible for assessing the needs of the Borough's population and delivering a range of support and social care provision for people with sight disabilities, and this includes working with voluntary organisations. Under the Care Act 2014, local authorities continue to have specific duties to assess and provide information, rehabilitation and support to visually impaired people. This includes making contact with people within 2 weeks of receiving their CVI. LBH is also responsible for the formal registration process of CVI.

- **Numbers of patients registering**

Concerns have been expressed to Healthwatch that there has been a decline in the number of patients registering for assessment with the borough, the rationale for this concern being that a deterioration in people's eyesight predominantly affects the older generation and Havering has the oldest population in London which is also steadily growing, so a decline in registering seemed counter-intuitive.

This was tested by another FOI request.

Question: Please provide the number of people registered with the Council as blind as of 31 March (or the nearest available date) in each of the years 2010, 2011, 2012, 2013, 2014, 2015, 2016 and 2017.

Response:

- 2010-11 = 1258
- 2013-14 = 1284
- 2016-17 = 1134

LBH explained that the number of registrations is measured only once every three years, hence it was not possible to provide data for each of the years specified.

Healthwatch followed this up with a meeting with the Service Manager for Disabilities in December 2017, at which he offered the view that Havering's numbers registered appeared lower than other boroughs because, as part of the preparation for the registration review in 2016/17, they carried out a comprehensive review of the existing register and removed from it people who were no longer in the borough, including those that had died or moved away - in some cases, a while earlier, because the service is not notified of every death or move outside the borough.

This explanation goes some way to explaining the apparent statistical anomaly but may not be a complete answer.

Social Care Information Centre

The Health and Social Care Information Centre data for 2014 does demonstrate a similar trend however, the report raises its concern about the accuracy of the 152 councils reporting.

“The statistics relating to blind people who have an additional disability may understate the true numbers.

“Due to additional guidance on deaf blind registration where there was information on additional disabilities for people having multiple disabilities including deaf or hard of hearing,

councils were advised to count this under the category of deaf or hard of hearing. This could lead to a bias towards deaf or hard of hearing disabilities” (emphasis added)

Consider

It has not been possible for Healthwatch to assess whether there is a genuine decline in the number of patients seeking assessment as part of the CVI and RVI process. As LBH has recently undertaken a comprehensive review of the list, going forward, LBH is in an advantageous position to be able to monitor accurately the number of residents with a CVI or an RVI.

The FOI response from BHRUT has demonstrated, however, that record keeping for CVIs is by use of a manual system and is only able to offer very approximate confirmation of numbers of CVI's undertaken by the Ophthalmology Department, seemingly and crucially without being able to identify the borough of residence so that neither the local authority can be confident of the number of residents eligible to be registered nor the CCG can be confident that it is paying through its commissioning arrangements for the right number of patients .

The RNIB's Sight Loss Data Tool is the UK's biggest collection of eye health datasets. It collates a wide range of publicly available datasets enabling a tailored story about the local area; and the benchmarking report shows users how local areas compare to their region and nation, across a set of key indicators.

Recommendation 15:

That LBH consider incorporating the RNIB database information into its commissioning intentions and requirements to support both current and predicated service models

Voluntary Sector services

During the process of completing this report we have had the pleasure of working with three voluntary groups, Havering Over Fifties Forum (HOFF), Sight Action Havering and the Partially Sighted Group. It has been invaluable spending time with their members to seek their views on eye services. The Partially Sighted Group and the Havering Over Fifties Forum both benefit from LBH support, particularly with the use of premises as they average between 50 - 120 members each.

LBH is undertaking a 'Review' to ascertain if they can continue to provide the Yew Tree Resource Centre on a Monday evening. This is a much-valued focus point for Havering residents who are partially sighted or blind.

While it is necessary to ensure that public funds and resources are used to best effect, it is easy to create an impression that out-of-hours provision are subordinated more to the convenience of staff and cost control than to addressing the inequality of disadvantaged people being unable to access facilities others take for granted.

Consider

There is good access to information and personal support in the borough. In addition, there is on-going development to support further use of electronic systems.

The challenge for LBH is to consider ways in which individuals who are not able to access electronic services such as email or use or afford a smart phone are kept informed and aware of services and

opportunities as these people may be some of the most vulnerable in the community.

People who have a visual impairment are not always able to access clubs or other social gatherings and facilities that others are able to use.

Recommendation 16:

That LBH continue to support voluntary services such as those meeting at Yew Tree Lodge and the opportunities that they provide for residents and, in particular, the highly valued evening club

Recommendation 17:

That LBH accept that people who are not digitally literate or able to access digital systems require support to ensure that they can continue to be involved in their community and the opportunities this offers

7 THE IMPORTANCE OF GOOD AND ACCESSIBLE INFORMATION

Healthwatch England gives the following advice on ‘What should you expect from the NHS when it comes to accessible information?’

The aim of the standard is to make sure that people who have a disability, impairment or sensory loss get information that they can access and understand, and any communication support that they need.

This includes making sure that people get information in different formats if they need it, for example in large print, braille, easy read or via email.

It also includes appropriate support to help individuals communicate, for example, support from a British Sign Language (BSL) interpreter, deafblind manual interpreter or an advocate.

All organisations that provide NHS or adult social care are required to follow the new standard, including NHS Trusts and Foundation Trusts, and GP practices.

Five things that you should expect from organisations that provide NHS or adult social care:

- You should be asked if you have any communication needs, and asked how these needs can be met
- Your needs should be recorded in a clear and set way
- Your file or notes should highlight these communication needs so people are aware and know how to meet them
- Information about your communication needs should be shared with other providers of NHS and adult social care, when they have consent or permission to do so
- Information should be delivered to you in a way you can access and understand, with the option for communication support if needed

Consider

The evidence we have seen suggests that some people leave the Eye Clinic not fully realising the implications of the diagnosis that they have a visual impairment.

The support of an ECLO, highlighted earlier in this report, would go some way to alleviating this; but the ready availability of detailed information would also assist in understanding at a time in the affected people's lives when they are particularly vulnerable.

Recommendation 18:

That all organisations aim to achieve the highest possible standards of information, ensuring that they enable people to make informed choices and decision

8 WHAT IS AVAILABLE WITHIN THE COMMUNITY TO SUPPORT HAVERING RESIDENTS?

The following is a brief summary of information available to local residents; it is not an exhaustive guide.

✓ London Borough of Havering

‘Information and service guide for people who are vision impaired’

This useful guide is available on line and in printed format. It is **available by contacting the Customer Services, Adult Social Care** on 01708 432000

www.haveringcarepoint.org/care-advice/living-with-a-sensory-impairment/

‘browsealoud’ software is available to improve accessibility of webpages. It enables users to change the colour scheme, alter text size and have information read aloud:

www.texthelp.com/en-gb/products/browsealoud/

✓ CarePoint

CarePoint are the Council’s Information Service point. They can provide advice on a wide range of issues related to Sight Impairment, such as which concessions people are entitled to and they actively promote residents registering as it helps the council improve the support available for those living with sight impairment in Havering.

CarePoint offer Drop-In clinics across the borough, and to contact them for more information you can

Telephone 01708 776770 selecting option 2

Email carepoint@peabody.org.uk

✓ Sight Action (Havering)

Sight Action (Havering) is a local voluntary sector society for vision impaired people in Havering. Sight Action is also a registered charity (1078815).

It is supported by East London Vision (ELVis). ELVis is designed to provide an effective and efficient way of ensuring that vision impaired people living in East London get the support and services they need.

Sight Action also works closely with the Thomas Pocklington Trust. Sight Action has a wealth of experience and knowledge and works closely with the RNIB to achieve the best possible standards of care for residents in the borough.

Email enquiries@sightactionhavering.org.uk

✓ **Partially Sighted (Havering) - voluntary organisation based at Yew Tree Lodge**

Partially Sighted Society Havering is a voluntary organisation, also based at Yew Tree Resource Centre. The Society pays London Borough of Havering for the use of Yew Tree Resource Centre to run a Monday evening social group, and also runs a Drop-In group every Tuesday afternoon.

The Society's meetings give opportunity for residents to meet in the evening, once a month, and provide a much-valued social outing and emotional support. It also provides weekend events such as barbeques where other family members can join in. The Society is well networked into the borough and provides members with information, contacts, advice and transport help to attend the meetings and events. Users were extremely positive about the "club". The service meets on 3rd Monday of each month between 8pm and 10pm. Transport can be provided.

The Drop-In Group service aims to offer advice and information; and to provide opportunities for visually impaired people to socialise with other visually impaired people, and to share hints and advice on how to get around everyday problems they encounter. In addition, the Society's volunteers demonstrate specialist equipment and how they can be used, thus encouraging independent living.

The Drop-In group meets every Tuesday between 12:30pm and 3pm at Yew Tree Resource Centre.

Contacts: Peter Slattery = Peter.Slattery@blueyonder.co.uk and
John Slattery = dapjbs@gmail.com

✓ Royal National Institute for the Blind (RNIB)

This nationally respected organisation has a wealth of information and guidance on their website, as well as interactive and video information and the ability to speak to one of their advisers. It is worth a visit and can be particularly helpful for family and friends in helping to guide people through the myriad of complex issues which arise, from clinical advice, to employment opportunities, training and fitness and wellbeing.

Contact: www.rnib.org.uk or telephone 0303 129 9999

✓ Havering over Fifties Forum (HOFF)

The HOFF is a non-political organisation which offers a platform where the over 50's can find information and raise issues which are of a concern to them.

The forum is open to Havering residents aged over 50. It meets monthly, usually on the second Tuesday of the month, in the Council Chamber at Havering Town Hall

Contact 07541 511973 for general enquiries; 01708 733711 for membership

Website: www.havo50forum.org

Email: contact@havo50forum.org

9 BACKGROUND READING

To support our work, we have sourced the following documents which we hope will provide additional information to the reader.

- 1) The Importance of an Eye Clinic Liaison Officer - the link below takes you to the RNIB site where a detailed paper sets out the economic benefits to having an ECLO as a key member of the service.

<http://www.rnib.org.uk/economic-impact-eclo>

- 2) The Royal College of Ophthalmologists provide as part of its professional resources advice on the CVI

www.rcophth.ac.uk/professional-resources/certificate-of-vision-impairment/

It has also produced two videos of interest:

<http://youtu.be/yk0sFBtKNf8> for professionals

http://youtu.be/4iX_0_SlLOE for patients

- 3) Certificate of Visual Impairment

www.gov.uk/government/publications/guidance-published-on-registering-a-vision-impairment-as-a-disability

- 4) Information available from RNIB

www.rnib.org.uk/eye-health/registering-your-sight-loss

- 5) DVLA guidance and RNIB guidance for drivers

patient.info/doctor/visual-disorders-dvla-guide

www.rnib.org.uk/information-everyday-living-getting-around/driving

- 6) LBH advice services
www.havering.gov.uk/accessibility
www.haveringcarepoint.org/.../2015/06/Visual-Impairment-booklet1.pdf
- 7) The Partially Sighted Group
familyserviceshub.havering.gov.uk/kb5/havering/directory
- 8) The changes to the electoral system
www.gov.uk/government/organisations/department-of-health
- 9) UK Vision Strategy - Seeing It My Way
www.visionuk.org.uk/seeing-it-my-way-the-peoples-voice
- 10) RNIB statistical information
www.rnib.org.uk/.../key-information-and-statistics
- 11) RNIB Accessible Information Standards AIS
www.rnib.org.uk/sites/default/files/RNIB-FAQLeaflet-GP-Practice-Manager-for-1605-implementation-Oct2016_0.pdf

KAREN'S SUGGESTIONS - *Following from her Prologue on page 4*

EMPLOYMENT

Getting, and keeping, a job is particularly difficult when you have impaired vision. In fact the shocking fact is that only 27% of those of us of working age are in employment. Luckily though there is some support available.

Blind In Business -

<http://www.blindinbusiness.org.uk/>

This organisation, set up by three blind graduates, provides training & advice for sight impaired people hoping to find work or education opportunities. They sent me on helpful workshops & gave me loads of personal guidance when I was looking for my first full-time job.

RNIB -

<https://www.rnib.org.uk/information-everyday-living/work-and-employment>

The RNIB provides an absolute wealth of information and advice about how to choose, find and keep a job. For a young person unsure of how to embark on their career, the Trainee Grade Scheme (<https://www.rnib.org.uk/information-everyday-living-work-and-employment-practical-support/trainee-grade-scheme>) is probably of most interest. This provides a year of paid work in one of many areas of employment - a fantastic way to learn key skills & decide what's right for you.

Access to Work -

<https://www.gov.uk/access-to-work>

This government scheme provides support if you already have or are about to start paid employment. In my case, I was able to get a voice recorder and a hand-held video magnifier, both of which have been a huge help at work.

Blind Person's Tax Allowance -

<https://www.gov.uk/blind-persons-allowance>

This allowance means that you can earn an extra couple of thousand pounds before you start having to pay income tax. It's free money, and is automatically added each year, without you having to reapply.

EDUCATION

There is a range of help available for sight impaired people who want to learn & develop their skills.

Disabled Student's Allowance -

<https://www.gov.uk/disabled-students-allowances-dsas>

While studying, this fund provided me with various pieces of IT equipment plus an assistant for note-taking & other tasks.

Special Examination Arrangements

Wherever you're studying - further or higher education, or gaining a professional qualification - you should request help with materials & exams. I have been able to get electronic versions of printed course materials emailed to me in advance, and had extra time given to me during exams. The format of exams could also be changed to suit your needs. Contact your institution of provider for details.

BENEFITS

You may not think that your sight impairment costs you money, but I can almost guarantee that it does. From paying for taxis that other people wouldn't need, to buying magnifiers & other visual aids, to replacing the bottle of wine that you knocked onto the floor. You're entitled to benefits, so don't shy away from claiming them.

Personal Independence Payments (PIP) -

<https://www.gov.uk/pip>

Previously known as Disability Living Allowance, this benefit can be paid to you regardless of your income or employment status. The amount depends on how your disability affects your daily life. Contact the RNIB before applying - they can give you essential guidance on how to fill in the forms.

Working Tax Credits -

<https://www.gov.uk/working-tax-credit>

If you're working more than 16 hours a week, you can claim this benefit and there is extra money available for those with a CVI.

General benefits advice -

<https://www.rnib.org.uk/benefits-and-support>

The RNIB, as you'd expect, has a wealth of information available on this subject. Note especially that they provide a 'benefits calculator' that will check what and how much you should be entitled to.

TRAVEL

I believe travel is the area of my life which is most affected by my sight loss. Accessing the services below has made an enormous difference to my ability to travel and consequently to my sense of independence.

Freedom Pass -

<https://www.londoncouncils.gov.uk/services/freedom-pass>

This is the single most beneficial thing that my CVI has given me. It is a card which gives me free travel across London and free bus journeys nationally. I use it on trains, tubes and buses every day. It is only available to residents of London boroughs.

Blue Badge -

<https://www.gov.uk/government/collections/blue-badge-scheme>

Most people think of the blue badge as being associated with a particular car, but people with a CVI can get a 'mobile' blue badge which they can use in any vehicle in which they're a passenger. Blue badge holders sometimes get free parking or discounts/exemptions on things like the Congestion Charge, so it is well worth having.

Disabled Persons' Railcard -

<https://www.disabledpersons-railcard.co.uk/>

With this card you can get 1/3 off rail fares on all networks, for yourself and for your companion if you're not travelling alone.

Other rail concessions -

http://www.nationalrail.co.uk/stations_destinations/44965.aspx

Even if you don't buy a railcard, you can use your CVI registration card to get discounts of up to 50% for both of you as long as you are travelling with a companion.

ENTERTAINMENT

It is always worth mentioning your sight impairment when booking tickets for the theatre, comedy clubs etc, and when arriving at an attraction such as a museum or theme park. Frequently you will get a complimentary ticket for your companion, but there are other benefits on offer such as the ability to 'queue jump' at certain theme parks.

CEA Cinema Card -

<https://www.ceacard.co.uk/>

This card is accepted in many cinemas across the country, and allows your companion to get a free ticket.

TV licence -

<http://www.tvlicensing.co.uk/check-if-you-need-one/for-your-home/blindseverely-sight-impaired-aud5>

The discount given to blind (severely sight impaired) TV licence holders is a whopping 50%.

The things I've mentioned here are just the tip of the iceberg, but I hope they'll prove useful to anyone considering getting a CVI, or who's not sure what they can do with the one they already have. I recommend doing some Google research, perhaps about your own eye condition, or about how sight impaired people pursue the pastimes you're interested in. It can be a huge relief just to discover that you are not alone, that there are people experiencing similar things to you, and that there are solutions out there which can make your life easier & richer.

Karen

10 TABLE OF ABBREVIATIONS

A&E (Department)	Accident and Emergency Department
BHRUT	Barking Havering and Redbridge University Trust
CCG	Clinical Commissioning Group
CVI	Certificate of Visual Impairment
DVLA	Driver and Vehicle Licensing Authority
ECLO	Eye Clinic Liaison Officer
FOI	Freedom of Information
GP	General Practitioner
HOFF	Havering Over Fifties Forum
LBH	London Borough of Havering
Moorfields	Moorfields Eye Hospital
NHS	National Health Service
RNIB	Royal National Institute of Blind People
Royal College	Royal College of Ophthalmologists
RVI	Referral of Vision Impairment
SLA	Service Level Agreement

Healthwatch Havering thanks all service users, staff and other participants who have contributed to this review for their help and co-operation, which is much appreciated.

Disclaimer

This review is representative only of those service users, staff and other contributors who participated. It does not seek to be representative of all service users and/or staff.

Participation in Healthwatch Havering

Local people who have time to spare are welcome to join us as volunteers. We need both people who work in health or social care services, and those who are simply interested in getting the best possible health and social care services for the people of Havering.

Our aim is to develop wide, comprehensive and inclusive involvement in Healthwatch Havering, to allow every individual and organisation of the Havering Community to have a role and a voice at a level they feel appropriate to their personal circumstances.

We are looking for:

Members

This is the key working role. For some, this role will provide an opportunity to help improve an area of health and social care where they, their families or friends have experienced problems or difficulties. Very often a life experience has encouraged people to think about giving something back to the local community or simply personal circumstances now allow individuals to have time to develop themselves. This role will enable people to extend their networks, and can help prepare for college, university or a change in the working life. There is no need for any prior experience in health or social care for this role.

The role provides the face to face contact with the community, listening, helping, signposting, providing advice. It also is part of ensuring the most isolated people within our community have a voice.

Some Members may wish to become **Specialists**, developing and using expertise in a particular area of social care or health services.

Supporters

Participation as a Supporter is open to every citizen and organisation that lives or operates within the London Borough of Havering. Supporters ensure that Healthwatch is rooted in the community and acts with a view to ensure that Healthwatch Havering represents and promotes community involvement in the commissioning, provision and scrutiny of health and social services.

Interested? Want to know more?



Call us on **01708 303 300**

email

enquiries@healthwatchhavering.co.uk

Find us on Twitter at **@HWHavering**



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