

**Proposed move of Moorfields Eye Hospital’s City Road services**

**Consultation with people with protected characteristics and rare conditions**

**(December 2018 – October 2019)**

Monday 13 January 2020

**Introduction**

An independent evaluation of all feedback from a consultation on the proposed move of Moorfields’ City Road services, which took place between 24 May and 16 September 2019, is published and available from [www.oriel-london.org.uk/consultation-documents/](http://www.oriel-london.org.uk/consultation-documents/).

This supplementary report summarises the specific findings from consultation with people with protected characteristics and rare conditions, which took place over 43 meetings and conversations between December 2018 and October 2019.

For further information on the consultation and a more detailed integrated health inequalities and equality impact assessment (IIA), please visit [www.oriel-london.org.uk](http://www.oriel-london.org.uk)

**Background**

We have taken two main routes to reach people and gather views that are relevant to our consideration of equalities concerning the proposed move:

* 1. **Listening to diverse and mixed audiences who took part in the main consultation activities**
	Engagement activities between December 2018 and April 2019, followed by a consultation between 24 May and 16 September 2019 attracted over 1,700 responses in the first phase and around 4,600 contributions in the second. Both phases collected general views from surveys, meetings and discussions, including views on how the proposal might affect those with specific and complex needs.
	2. **Proactive consultation with targeted groups**
	In addition to the main engagement and consultation activities, we contacted some 65 organisations and groups who could help us to reach people with protected characteristics and rare conditions. From this we collected feedback from 43 meetings and conversations.

	Appendix 1 provides a table of the groups we have listened to and the characteristics they cover.

**Reaching the target groups**

As a guide for our search for target groups, we used the nine main characteristics protected by the Equality Act 2010, which are:

* Disability
* Age
* Gender reassignment
* Sexual orientation
* Pregnancy and maternity
* Race
* Religion or belief
* Sex
* Marriage and civil partnership

We gathered feedback from children and young people, older people, people with learning disabilities, mental health problems, physical disabilities, multiple disabilities, sensory impairment, people from LGBTQ+ and BAME groups, including people with these characteristics and sight loss.

We listened to representatives of people who may be disadvantaged by low income, homelessness and social isolation.

Some people were representative of national networks, while others spoke as individuals and local representatives who would travel to Moorfields Eye Hospital from across London and other areas, such as Buckinghamshire, Cornwall, Essex, Hertfordshire, Kent, Manchester, Norfolk, Suffolk, and Worcestershire.

Given the demographic data for patients who use services at City Road, we prioritised groups based in east London that represent people living in deprived areas and communities with a high proportion of people from Black, Asian and minority ethnic backgrounds.

To inform specialised commissioning, we contacted groups and networks of people with eye cancer and other rare conditions. Feedback from the following provided insights into the experiences of people with complex needs and rare conditions:

* Sense (Deaf blind)
* Action on Hearing Loss (Deaf community, some users with multiple sensory loss)
* Hearing Loss (Deaf blind in Cornwall)
* Esme’s Umbrella (Charles Bonnet Syndrome)
* OcuMelUK (Ocular melanoma, form of eye cancer)
* Seeability (physical disabilities, learning disabilities, autism with sight loss.)
* Visually Impaired Children Taking Action (VICTA) (children with sight loss and other conditions)

Most of the people and groups that we have consulted represent issues relevant to several protected characteristics. The table in appendix 1 indicates the range of characteristics covered by each group. The protected characteristic of “disability” covers sensory impairment, physical disabilities, learning disabilities and mental health problems.

**How we consulted**

**Aims of engagement with people with protected characteristics**

* To identify potential issues of equality associated with our proposed service change.
* To further inform the integrated health inequalities and equality impact assessment (IIA) and highlight potential issues for the consideration of decision-makers.

As a minimum, we aimed to listen to feedback from 20-25 meetings with people with protected characteristics. In the event, we heard from 43 meetings and conversations.

Several groups, including RNIB, MoorPride, Transpire, OcuMelUK, New College Worcester and MENCAP, said how impressed they were with the efforts to include minority groups and were keen to be involved in continuing work. We fully expect to build on these relationships so that future developments will benefit from this specialist knowledge.

**Method to reach people with protected characteristics**

In addition to the main channels of feedback to the consultation (survey, written feedback, meetings and discussions), we met people face-to-face in targeted small groups and one-to-one meetings. Some people chose to visit us at Moorfields, but for most discussions, members of the consultation team travelled to networking events and regular meeting places to gain full appreciation of the needs of the target group. In some cases, the discussion was over the phone.

We asked people about:

* Any current inequalities that people experience when accessing health services in general, and at Moorfields Eye Hospital’s City Road services.
* Views on the proposed new centre and the preferred location at St Pancras.
* How the proposal might improve or create further inequalities, and ideas for addressing these issues.

Notes from every conversation are filed and logged in a confidential engagement log, in line with the General Data Protection Regulation. These detailed notes are shared in confidence with programme board members for consideration alongside this report, as part of the final decision-making process on the proposed move. Ideas for improving services will be extracted from the notes and shared with operational and design teams for future planning purposes.

**Findings to date**

**Overview of the risk of inequality for people with protected characteristics**

Our discussions have made clear that for many people who use the services of Moorfields Eye Hospital, their relationship with City Road services is a critical part of their lives.

Many people are regular visitors to the hospital and have been for decades. All of our patients have one or more protected characteristics in terms of age, ethnicity, sensory impairment, disabilities and long term conditions.

A recurring theme in feedback is that, despite the Moorfields reputation for clinical excellence, patients frequently experience stress and anxiety associated with a visit to the hospital. For people with protected characteristics, there is a risk that this may be compounded by communications barriers, physical access difficulties and a perceived lack of awareness among staff concerning sight loss and other characteristics.

It is within Moorfields’ objectives to match exceptional clinical outcomes with an excellent experience for all patients. From our audience point of view, the frequent suggestion during consultation was that the proposed new centre is our opportunity to be the national exemplar of inclusivity and accessibility for people with sight loss.

**Addressing a range of issues**

**We must consider that any change to services could have greater potential impact on people with protected characteristics – both positively and negatively.**

Across the groups and interests, we heard about many particular issues. While details may differ, there were clear, common themes in relation to equality of access, which are described below.

It is likely that current services are already aware of and taking measures to address these issues, but it is important, as part of the consultation process, to review the proposed future service in this context of equalities.

**Common themes from feedback**

**Please note:** Detailed notes from each discussion with people with protected characteristics are shared with lead decision-makers and operational teams.

**Make it possible for people to be independent – an overarching principle**

The importance of independence for people accessing care was a major theme, suggesting that this should be a driving principle of design and service planning.

When services are difficult to access, people need more support from carers and staff, which is not always the best answer. With the right applications of design, information and technology, people can choose to do things for themselves.

**Quote from feedback:**

**“I am 50 years old. I shouldn’t always have to ask my mother to take me to my appointment.”**

It was suggested that people who are well informed and able to understand their care are better able to work with their clinicians and take responsibility for self-care. Where patients are confident and easily able to navigate services for themselves, this contributes to efficiency as well as a good patient experience.

**Reducing anxiety, offering control**

Anxiety is one of the most common challenges we have heard about from people with protected characteristics. Patients’ anxiety affects patient experience and potentially the efficiency and effectiveness of clinical services. For example, people talk about patients not being able to hear or take in what is being said during their consultation. In some situations, patients may not turn up for appointments and carers may be reluctant to take them, if they perceive it to be a bad experience.

For some people with protected characteristics, their anxiety may be exacerbated by the journey to their appointment. They may even face harassment or other negative experiences on public transport. Even before they arrive for their appointment, they may be feeling vulnerable and under pressure.

**Quote from feedback:**

**“People in a state of anxiety, fear, nervousness and isolation expect and anticipate rudeness. They expect systems and technology not to work and this becomes self-fulfilling.”**

Entering a place of care may be a critical moment that sets the tone for the care pathway, calming or otherwise. The following are examples of suggestions that we have heard during the consultation:

* Provide as much information as possible and in accessible formats before an appointment to explain what to expect. For example, some services are gaining benefits from providing virtual tours of their facility for people who can access the internet.
* Make the main entrance welcoming and friendly, with immediate clarity about where to go. Considering St Pancras as the preferred location for the proposed new centre, some suggested a “meet and greet” at King’s Cross and St Pancras to signpost, guide or possibly transport people to the proposed new centre.
* Reception staff (not necessarily confined to a desk) should be highly skilled in helping people and making them feel reassured.
* Both design and people should be able to ensure a smooth transfer from front door to clinic.
* Provide clear information at every stage of the process, so that patients know what is going to happen next and when.

**Quote from feedback:**

**“The proposal is very exciting. A new start is always an opportunity for new practices.”**

Suggestions for action:

* The Trust should continually improve and develop patient information in multi formats, with advice and in partnership with patient representatives.
* Consultation feedback should inform developments in patient liaison and support, staff training and design of the proposed new centre.

**Buildings should be easy to navigate**

Many respondents suggested that by meeting the needs of people with complex disabilities and conditions, we would improve the experience for all patients.

Examples of principles for wayfinding:

* Consistency of design style and layout, making it easy to learn patterns e.g. toilets with the same layout, consistent signage.
* Straight lines are easier to navigate, curved or circular pathways are more difficult and disorientating for people with sight loss and in some cases autism.
* Consistent and even lighting throughout all common areas.
* Colour coding to designate different clinics and areas.
* Contrasting colours to delineate walls, ceilings, floors and doorways.
* Information in multiple formats.
* People to help with navigation.

**Quote from feedback:**

**“A new build is a great opportunity to work with new technology. We would expect nothing less; but personal contact will always be important to be fully inclusive.”**

Suggestions for action:

Co-production between design teams and patient representatives should be embedded within the development of the proposed new centre.

**Good communication**

Most of the people we listened to described similar communications barriers when interacting with health services e.g.:

* Not having enough time to explain things or not enough time to understand things.
* Staff not listening or unable to understand the situation.
* Staff ignoring the patient and talking only to carers or interpreters.
* Having to repeat explanations about important issues and aspects of a condition every time a new member of staff involved; or important things being missed through inconsistency.

It may not be possible to be aware of or plan for every possible need, but patients have expertise that can help to close the gaps. All staff who are in contact with patients and public should have awareness training, including advanced skills in listening to people.

**Quote from feedback:**

**“What would help the most? Longer appointments with more time and simpler explanations. ”**

The voluntary sector has considerable knowledge and expertise to help public sector organisations with policies and plans for improving communications for people with protected characteristics. Sense, for example has undertaken several studies and produced guidelines on equal access to healthcare. RNIB and Guide Dogs provide visual awareness training for all patient-facing staff. Charities for rare syndromes are able to offer a body of knowledge to support clinical practice.

Suggestions for action:

Moorfields Eye Hospital is already improving awareness and communications with support from voluntary sector partners and this should be explicit in the development of the proposed new centre.

There are already support services in place and longer appointment times for those who need it. We should review the availability and communications about support.

**Understanding “hidden disability”**

Some people with sensory impairment talked about “hidden disabilities” where even clinicians seem unaware of the extent of their needs.

It is also common for people to feel ashamed of their differences or to deny or hide problems that may be significant in getting good clinical outcomes.

These scenarios require awareness and skill to build trust. There are examples of discrete forms of communication to help staff to understand the particular needs of the person they are meeting, including safe words for people who need discrete help.

Privacy may be important in clinical areas, such as consultation rooms; and in basic services, such as toilets and adult changing facilities.

**Quote from feedback:**

**“I have helped older people for whom English is not their first language who were waiting for a long time without a drink or a visit to the toilet, because they were worried about missing their appointment.”**

Suggestions for action:

* Improving awareness and communications with people with protected characteristics should be included in an accessibility plan as part of the development of the proposed new centre.
* Consultation feedback should inform continuing improvements in patient experience.

**Managing transition for existing patients**

A change in services and location may or may not create an impact for future patients, but we cannot under-estimate the challenge of change for existing patients, particularly those with protected characteristics.

Comments stressed the importance of timely and effective communications in accessible formats to help manage transition.

Feedback from people with learning disabilities suggests that people with this and other protected characteristics find it difficult to cope with change. They need time, information and other support. It was suggested, for example, that there could be open day type visits to the proposed new centre, before and after opening. This would offer time to “learn” the new service, without the anxiety of attending for an appointment.

Suggestions for action:

* A comprehensive communications campaign should be part of the plan for change, should the proposed move go ahead.

**Issues specific to the proposed move of services**

**Potential positive impacts on equalities for people with protected characteristics**

In general, people are supportive towards a proposed new centre for Moorfields Eye Hospital. Many envisage an opportunity to improve accessibility and services for people with protected characteristics.

The main examples of potential gains are:

* Improvements in accessibility through a new building design e.g.
	+ More space for wheelchair access
	+ Better signage
	+ More lifts
	+ More disabled toilets
	+ Contrasting colours to help navigation, delineate walls, floors, pillars and pathways
	+ Design that avoids large noisy spaces that are difficult for people with sensory impairment to navigate
* Improvements in efficiency and access to services within the proposed new hospital, which would help and support people with protected characteristics e.g.
	+ Shorter waiting times and simpler journeys within the hospital
	+ More accessible technology and procedures for check-in
	+ Better information and clarity of the appointment system and call to appointments
	+ More accessible information
	+ Better use of hearing loops and other assistive technology
* Improvements in care and respect for different needs e.g.
	+ More space and better design for privacy during consultations
	+ More comfortable accommodation and climate control
	+ Better use of lighting for different needs of visual impairment
	+ Better facilities to support people with food and drink
	+ More space to offer information, support and counselling
* Improvement in access from transport to the hospital e.g.
	+ Step free access from transport to hospital front door
	+ Better access by motor vehicles with space for drop off and pick up

**Potential negative impacts on equalities for people with protected characteristics**

* Use of technology versus personal interaction

People with protected characteristics have spoken about the need for flexibility and a range of communications to meet different needs and abilities. Many acknowledge the potential advantages of new technology, which could improve access for some people, but that there is a risk of excluding some minority groups for whom technology could prove a barrier. Even those who are keen supporters of new technology place a high value on personal support being available to meet the diverse needs of patients and carers, particularly children, frail older people, people with multiple disabilities and people who do not have English as their first language.

In a new centre that is designed to offer leading edge services, the potential inequality could be a greater issue than it is now with the current service.
* Journey times

Feedback suggests that there could be different and longer journeys to the proposed new centre for those who live to the east and north east of London, which could, for example, incur higher costs.

This is borne out by our travel times analysis, which identifies an increase in journey times for communities in east London, north east London and the east of England. For areas across the rest of London and the UK, the travel times analysis shows a decrease in journey times.
* Getting to the hospital from transport hubs

Travel times are frequently considered (by people with sensory impairment and disabilities) less important than the journey from transport hubs and bus stops to the front door of the proposed new centre. Old Street tube station to Moorfields Eye Hospital is a relatively short and simple route. For some people with protected characteristics, King’s Cross, St Pancras or Mornington Crescent to the proposed new site remains a high priority for consideration of the following:
	+ Large and complex stations with several exits
	+ Road crossings
	+ Cycle lanes
	+ Cluttered or uneven pavements
	+ Vulnerability to street crime and harassment
* Equality of access across the health and care system

During the consultation, people frequently raised the broader strategic issue of developing care closer to where people live. By maximising the benefits of technology and improving access to care in more local settings, there is the potential to improve health inequalities.

Some suggested that the proposed investment in a new centre could have a negative impact on resources available to maintain and develop network clinics and other community-based services. This will be addressed in decision-making documents.

**Appendix 1: Table of groups and protected characteristics**

Please note that the characteristics highlighted in the table below represent the more prominent concerns of the listed groups.

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Organisation providing contact** | **Age** | **Disability** (inc. sensory loss, LD, mental health) | **Gender reassignment** | **Sexual orientation** | **Pregnancy and maternity** | **Race** | **Religion or belief** | **Homeless** | **Poverty** | **Marriage / partnership** |
| Action on Hearing Loss | x | x |  |  |  |  |  |  |  |  |
| Age UK (Milton Keynes) | x |  |  |  |  |  |  |  |  |  |
| BeMoor |  |  |  |  |  | x | x |  |  |  |
| Beyond Sight Loss |  | x |  |  |  | x | x |  | x |  |
| The Big Issue (North) |  |  |  |  |  |  |  | x | x |  |
| Blind Mums Connect |  | x |  |  | x |  |  |  |  |  |
| Bucks Vision |  | x |  |  |  |  |  |  |  |  |
| Cardboard Citizens |  |  |  |  |  |  |  | x | x |  |
| City and Hackney Older People's Reference Group (Age UK) | x | x |  |  |  |  |  |  |  |  |
| Esme's Umbrella (Charles Bonnet Syndrome) |  | x |  |  |  |  |  |  |  |  |
| Faiths Forum for London |  |  |  |  |  |  | x |  |  |  |
| Guide Dogs |  | x |  |  |  |  |  |  |  |  |
| Hackney Informed Voices Enterprise (HIVE) (Learning disabilities) |  | x |  |  |  |  |  |  |  |  |
| Hearing Loss (Cornwall) |  | x |  |  |  |  |  |  |  |  |
| International Glaucoma Association |  | x |  |  |  |  |  |  |  |  |
| LGBT Foundation |  |  | x | x |  |  |  |  |  |  |
| MENCAP |  | x |  |  |  |  |  |  |  |  |
| MoorAbility  |  | x |  |  |  |  |  |  |  |  |
| MoorPride |  |  | x | x |  |  |  |  |  |  |
| National Federation of the Blind |  | x |  |  |  |  |  |  |  |  |
| Newham Co-production Forum (multiagency) | x | x |  |  |  | x | x |  | x |  |
| Newham Older People's Reference Group (Age UK) | x | x |  |  |  | x | x |  | x |  |
| New College Worcester (young people) | x | x |  |  |  |  |  |  |  |  |
| OcuMelUK (eye cancer) |  | x |  |  |  |  |  |  |  |  |
| Organisation for Blind Africans and Caribbean (OBAC) |  | x |  |  |  | x | x |  |  |  |
| Richard Desmond Children's Eye Centre | x | x |  |  | x |  |  |  |  | x |
| RNIB |  | x |  |  |  |  |  |  |  |  |
| Royal Society for Blind Children | x | x |  |  |  |  |  |  |  |  |
| Seeability (physical disabilities, learning disabilities and autism) |  | x |  |  |  |  |  |  |  |  |
| Sense (Deafblind) |  | x |  |  |  |  |  |  |  |  |
| Standing Together (Domestic abuse) |  |  |  |  |  |  |  |  |  | x |
| Stonewall (LGBT) |  |  | x | x |  |  |  |  |  |  |
| Tower Hamlets Older People's Forum (Age UK) | x | x |  |  |  | x | x |  | x |  |
| Tower Hamlets Commissioning Panel |  |  |  |  | x | x | x |  |  |  |
| Transpire (south Essex transgender network) |  |  | x | x |  |  |  |  |  |  |
| Visually Impaired in Camden | x | x |  |  |  |  |  |  |  |  |
| Visually Impaired Children Taking Action (VICTA) | x | x |  |  |  |  |  |  |  |  |
| We are Ageing Well in Camden | x | x |  |  |  |  |  |  |  |  |