Community Engagement Report

NCL Eye Surgery Proposal

October 2023

healthwatch
Enfield

Contents

Acknowledgements

We sincerely thank Chase Farm Hospital, Whittington Hospital, East Asian Women Association, Edmonton Green Library, and our many community partners for their invaluable assistance in this project. A heartfelt thanks to the numerous individuals and communities who took the time to share their experiences, thereby enriching our findings and shaping the services we strive to improve.

We extend our sincere gratitude to all the volunteers and staff of Healthwatch Enfield who dedicated their time and effort to deliver this project. Their dedication and hard work were key to our success, and we're thankful for their valuable contribution.

About Us

Healthwatch Enfield serves as an independent champion for local people who use health and social care services; we lend our ears to the Enfield community and represent their voice. We team up with multiple community organisations and statutory institutions to share information and gather insights in the aim to help improve the quality of health and social care services in the borough. We share information and advice with residents to ensure they get the support they need, acting as a health and social care champion.

We gather feedback through projects, experiences shared by residents and community groups and social listening to share with public health and social care leaders and local decision-makers to help guide local policies and strategies.

Healthwatch is for everyone that uses all health and social care services, ranging from GPs to care homes, hospitals to pharmacies.

Introduction

In August 2023, Healthwatch Enfield was commissioned by NHS North Central London Integrated Care Board (NCL ICB) to gather feedback on their proposal to make changes to the configuration of eye (ophthalmology) surgery services. The proposal has the potential to facilitate an additional 3,000 eye surgery procedures annually and significantly reduce waiting times for certain sight-saving surgeries by up to four weeks.

From 4 September to 16 October 2023, we proactively gathered feedback from patients and the wider public who uses ophthalmological surgery services in North Central London. Our goal was to collect their opinions on the proposal, focusing specifically on identifying any potential limitations, barriers, or incentives that could arise if the changes were to be implemented

We engaged face-to-face with 107 people, of which 85 participated in the survey. Through our own digital platforms, including Facebook, Twitter, Instagram, and the Healthwatch Enfield website, we reached an audience of 7,421 people. Additionally, our presence in community newsletters throughout the borough allowed us to connect with an impressive 14,770 individuals.

What are the proposed changes?

In order to facilitate an additional 3,000 eye surgery procedures annually and significantly reduce waiting times for certain sight-saving surgeries by up to four weeks, two changes were proposed:

1. To create a hub for ophthalmology surgery at Edgware Community Hospital which provides surgery for adults for common, usually straightforward (low complexity) conditions like cataracts. This would bring together all eye surgery currently provided at Whittington Hospital and some activity from Royal Free Hospital and Chase Farm Hospital into one site at Edgware Community Hospital where a higher number of surgical procedures can be done.

2. A small number of complex eye surgeries and procedures that need to co-locate with other specialties will remain at both Chase Farm Hospital and Royal Free Hospital.

Patients would continue to attend their local or preferred hospital for tests and outpatient appointments and could continue to choose which NHS provider they are referred to for care.

Existing planned eye surgery services would continue at North Middlesex University Hospital, Moorfields sites (City Road Campus, St Ann's Hospital and Potters Bar Community Hospital) and independent sector providers contracted to provide services for the NHS.

Methodology

We adopted qualitative approaches in our methodology as it involved a series of collecting first-hand experiences from service users and their chaperones. To enhance inclusivity and reach, our surveys were disseminated in both digital format and as physical handouts in our visits. In addition, we facilitated targeted group discussions to capture diverse perspectives from the broader public.

These discussions served as a means to gain qualitative insights from participants experiences and collected views. They helped us uncover challenges and provided detailed accounts of their perspectives.
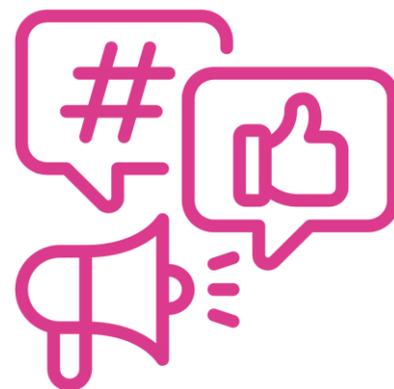
How did we conduct the engagement?

- We made visits to hospitals, community organisations, and represented at events to encourage survey participation, offering both paper and online formats.

- The survey was actively promoted and shared through various digital channels such as social media, email, and other online platforms. Our primary audience was community leaders, volunteers, and voluntary sector organisations (VCS).

- We organised face-to-face focus groups to discuss the proposed eye surgery with specific community groups and members.

- Social media played a pivotal role in raising awareness of the NCL eye surgery proposal and collecting community feedback. We created posts encouraging individuals to share their experiences and opinions, utilising hashtags to amplify our message. This approach acknowledged that those able to access the service would be most impacted by the proposed changes.

- We actively participated in community events to gather feedback on the proposal. During these events, we distributed surveys, engaged with community members, and collected information about the challenges and incentives they perceived in relation to the proposal.

Organisations we reached out to
Age UK Enfield
Caribbean & African Health Network (CAHN)
Chase Farm Hospital
Diversity Living
East Asian Women's Association (EAWA)
Edmonton Green Library
Enfield Caribbean Association
Enfield Councils Community development Team
Enfield Councils Faith Forum
Enfield Vision
Enfield Women's Centre
Love your doorstep
Mind in Enfield and Barnet
Palmers Green Community Newsletter
The Shane project
The over 50's forum
Whittington Hospital

Travel and Transport

Traveling to Edgware Community Hospital presents a myriad of challenges for participants. Financial burdens, distance, and time are primary concerns. Many grapple with the complexities of relying on others, while specific groups, like the elderly, people with disabilities, or those lacking support networks, face unique difficulties. Added to this, technological barriers and unfamiliarity with Edgware's services exacerbate the travel woes. This overview delves into these pressing issues faced by individuals journeying to the new specialist unit.

- Most cited concerns are financial costs, distance, time, and reliance on chaperone.

- Traveling to Edgware presents a financial burden for many participants. The cost of travel is a significant concern, with some patients even facing hefty expenses like £80 for cab fare.

- The physical distance to Edgware was cited as a major obstacle. This concern is exacerbated by the time it takes to travel and potential delays or cancellations.

- Participants have cited that longer travel distances not only increase financial costs but also pose a risk for delays or transport cancellations.

- The unfamiliarity with Edgware and potentially its hospital services pose a challenge for participants, especially for those traveling without a chaperone.

- There are participants who travel on their own, that have disability, impairments, and/or of old age, expressed inconvenience travelling to a new specialist unit.

Post-Surgery Travel: Between Dependence and Expense

"If you don't drive, then you rely on people. How do people get home after surgery? Some rely on kids, but they don't always have the time. There used to be a service for disabled people, done by GP's. If yes, they can't bring anyone with them. Hospital usually says no to this, and taxis are expensive!"

Focus Group participant

- Digital exclusion or visual impairments make it harder for some individuals to check updates on their phones or seek assistance from transport staff.

- Aside from the direct concerns of traveling to Edgware, there's a broader issue of the lack of adequate information or assistance for travellers. For instance, not many can check updates or inquire with the transportation staff.

- A specific segment of the participants depends on their children or grandchildren for transportation, making it especially challenging for them to travel to Edgware.

"I can't drive and don't have the funds to travel."

- Some participants expressed they were uncomfortable or reluctant to rely on others for transportation. This includes not only a psychological aspect of dependence but logistical issues of coordinating with others.

- There's a segment of participants who, despite the circumstances, can and do travel alone, but have expressed the difficulties and challenges travelling there.

- Traveling during peak hours can be particularly daunting for some individuals, especially on public transport.

- Not all healthcare facilities are conveniently located near public transport stations. The added distance between transportation hubs and hospitals can be a significant barrier for those relying on public transit.

Accessibility

Accessibility to the new specialist hub hinges on clear navigation. Participants strongly advocate for integrated visual aids in communications and larger-font signage within facilities. Additionally, a preference for single-level structures emerges, highlighting concerns about mobility, especially for the elderly and those with disabilities. The barriers highlighted in the topic of accessibility frequently touch upon travel and transport issues.

- Participants expressed a desire for visual aids, such as maps and clear directions, to assist with navigation within the healthcare facility.

- There's a clear preference for integrating these visual aids into standard communication methods, such as appointment letters. By doing so, patients can better prepare for their visits and feel more confident upon arrival; navigate to the hospital and inside the building.

- Participants prefer adequate signage with larger fonts for easier visibility. Such enhancements cater to a wide range of patients, including the elderly or visually impaired.

- A preference for facilities on a single level indicates concerns about mobility and the potential challenges of navigating multi-story buildings, especially for the elderly or those with disabilities.

- Participants also recommended the implementation of a guiding green line, akin to the one connecting Old Street station to Moorfields Eye Hospital in the borough of Islington, to facilitate easier navigation for patients.

- Participants have highlighted accessibility barriers in travelling to Edgware, have cited the time to getting there, and difficulties in knowing how to get there.

Communication

Participants voice their need for better awareness regarding their ability to choose healthcare facilities, a desire for clearer information prior to appointments, and a varied preference in how they receive communications and provide feedback. Challenges such as significant waiting times and the particular struggles of ESOL patients also come to the forefront, showcasing the multifaceted nature of communication barriers within the healthcare system.

- A significant number of respondents are unaware that they can choose their preferred NHS trust or hospital upon GP referral.

- Some participants felt that GPs did not give them adequate choices regarding hospital selections for treatments or operations.

- Service-users have a strong desire for more agency in selecting their appointment times and locations.

- The importance of receiving timely and accurate information about appointments, including what to expect, is stressed by participants.

"My daughter must take off work to drive me. If my appointment was cancelled, she has taken a day off for nothing."

- Some participants experienced inconvenience and additional costs, like wasted cab fares, due to a lack of clear instructions about their appointments.

- While preferences varied, older participants favoured receiving appointment notifications via post.

- Visually impaired participant found a combination of phone call reminders and letters to be most useful.

- Some participants also expressed a preference for text message notifications.

A Patient's Journey of Confusion and Financial Loss

"Got letter with an appointment. Didn't know what this is for. Didn't know facility. Got to the hospital by cab but was told by the staff my doctor went to different room and I asked the staff which department to go, I keep going to different ones.
Then I am told I have been late for the appointment, which initially I wasn't. No information – This has caused this issue! If I would have had information [of the correct department to go to in advance], I would have known where to go and I wouldn't be late and need another appointment. This cost me £40, a waste of time and money."
Focus Group participant

- Feedback preferences of service experiences varied. Older individuals preferred traditional paper surveys. The visually impaired leaned towards verbal phone surveys, while a section of participants were more comfortable with modern methods like text messages or emails.

- Several participants cited long waiting times, both in terms of receiving a referral, 3 to 6 months, with some references even dating back to 2021; And during the day of the appointment, 2 to 5 hours wait.

- Extended wait times were noted especially when preceding appointments ran longer than scheduled.

- Patients for whom English is a second or functional language highlighted potential challenges with the proposed changes at Edgware.

- English for Speakers of Other Languages (ESOL) patients stressed the need for clear and easy to understand information.

Support for Vulnerable Patients

Participants express concerns about mental and physical strain, dependency on family or caregivers, and the difficulties of navigating the healthcare system, especially when traveling to unfamiliar locations like Edgware. The discussion highlights the urgent need for a patient-centric approach in healthcare to better support vulnerable populations and ease their healthcare journey.

- There are consistent themes relating to mental and physical health challenges, the exertion on elderly individuals and people with disabilities, and a heavy reliance on family members or carers for support.

- Elderly participants have voiced their concerns about the difficulties faced by older people, especially those who attend appointments independently, highlighting a gap in support for this demographic.

"On public transport, people just push which petrifies me. I just wait until the rush is over."

- There is a notable challenge for individuals who are unable to bring a companion or chaperone with them, making the journey to the hospital and navigating through the healthcare system a daunting task.

- The prospect of travelling to Edgware generates significant anxiety among participants, with some stating that it is outright impossible due to the timings of their medication and the disruption of their routine, particularly for those with disabilities or specific needs.

- Even for those who can manage to travel independently, there is an expressed anxiety about journeying to unfamiliar and distant locations.

- Patients with existing health conditions, such as diabetes, who rely on routine medication are frustrated with the hospital waiting times, indicating a need for better time management and patient care coordination within the hospital.

- While getting to the hospital might be feasible for some patients, the challenge of returning home, particularly after potentially exhausting treatments or procedures, is a significant concern.

Staff Training

Participants rarely discussed the theme of staff training, generally assuming that the team at the new specialist ophthalmology hub would be trained and well-equipped, as is expected. This unspoken expectation underscores the need to uphold high standards of training and equipment in all healthcare settings, ensuring patient trust and confidence

- Patients cited that the staff at Chase Farm are consistent and supportive.

Recommendations

Patient Education Campaign

Develop and launch a patient education campaign to inform patients about their right to choose a trust or hospital for their treatment. This campaign should use clear and accessible language to explain the options available for patients, as it will enable them to have a choice in selecting the hospital or NHS trust for their treatment or operation.

1. **Appointment Discussions:**
   Urge GPs to proactively discuss the available choice options with patients during appointments, particularly when specialist care referrals are made. GPs should ask patients about their preferences and provide guidance accordingly.

2. **Empower patients with information:**
   Actively promote patient choice and autonomy through diverse information materials. Utilise posters, signage, brochures, and leaflets in GP offices to inform and empower patients about their healthcare choices. Ensure all materials are inclusive, providing translations and braille options to accommodate all patients.

3. **Partner with VCS organisations:**
   Signpost to welfare rights, financial assistance or subsidies for patients who face significant travel expenses, especially for those reliant on costly transportation options such as taxis.

Travel and Transport

For improved patient accessibility, explore non-hospital transport options like shuttle services and ensure transparent communication by including travel details, such as maps and directions in appointment letters.

1. **Non-hospital transport options:**
    Explore the possibility of offering alternative transportation options, such as shuttle service (courtesy service) or accessible transport, for patients who have difficulty traveling to the new specialist unit.

2. **Travel Information:**
    Provide clear and comprehensive travel information, including maps and directions, bus routes, nearest train station, and hospital parking facilities to help patients navigate to the hospital. Consider including this information in appointment letters.

Accessibility

Ensure that healthcare facilities are designed to be accessible, with adequate signage, large fonts, and facilities on one level. This is especially important for patients with disabilities and older individuals.

1. **Hospital Green Line:**

   Ensure that a clear green line or easily recognisable path is established from the main entrance of the hospital to the ophthalmology department. This will assist patients in navigating the hospital with ease, particularly those with visual impairments.

2. **Improved Hospital Signage:**

   Install and maintain clear and prominent signage throughout the hospital, including large fronts and braille, directional signs that guide patients to various departments, amenities, and facilities. Ensuring adequate signage will greatly assist patients in finding their way efficiently within the hospital environment.

3. **'Reading Your Name' Audio System:**

   Implement a "Reading Your Name" audio system in waiting areas to specifically assist visually impaired patients. This system will audibly announce patients' names when it's their turn for appointments, significantly enhancing the inclusivity and overall patient experience.

4. **Inclusive Appointment Letter Information:**

   Include detailed maps and instructions on how to get to the hospital, as well as a map of the hospital layout with clear department markers, within appointment letters. Providing this information in advance will assist patients in planning their journeys and navigating the hospital upon arrival.

5. **Accessible Transport Hubs:**

    Ensure that train stations and bus stops near the hospital are equipped with adequate signage, including clear information about their proximity to the hospital and the directions to reach the hospital from these transport hubs. This will facilitate convenient and efficient travel for patients using public transportation.

Communication

Improve communication by offering multiple options for appointment notifications and feedback.

1. **Enhanced Appointment Alerts:**

   Provide appointment and expectation information well in advance to prevent missed appointments and unnecessary expenses. This includes letters, phone call reminders, text message notifications, and emails.

2. **Reduce Waiting Times:**

   Address the issue of long waiting times, which can sometimes extend up to 5 hours. Implement strategies to reduce waiting times, including better scheduling and coordination of appointments.

3. **Referral Times:**

   Work on reducing the long referral times, which can span from 3 to 6 months. Streamline the referral process to ensure timely access to care.

4. **Language Access:**

   For patients with English as a second language, provide clear and understandable information. This may include translated materials and interpreters to assist with communication.

Support for Vulnerable Patients

Develop support programs or services for patients with mental health conditions, physical health limitations, disabilities and impaired condition, caregiving commitments, and those who rely heavily on family or caregivers. Address the specific needs and routines of these vulnerable groups.

1. **Language support:**

   Offer language and translation services for feedback and complaint processes. Recognising the unique challenges faced by these individuals, it's essential to create an environment where they feel heard and understood.

2. **Supporting Individuals Without Networks**

   Provide assistance to people who lack support networks. Recognise the anxiety and discomfort experienced by patients, particularly those who have to travel alone to unfamiliar locations. Offer additional support and information to alleviate these concerns.

3. **Routine Considerations:**

   Take into account the needs of patients who have specific medication timing requirements or routines, especially when proposing changes in healthcare facilities.

4. **Mental Wellbeing:**

   Recognise the anxiety and discomfort experienced by patients, particularly those who have to travel alone to unfamiliar locations. Provide additional support and information to alleviate these concerns, particularly communicate with patients who are neurodiverse and/or have mental health concerns.

Engagement

Healthwatch Enfield advocates for a stronger emphasis on community engagement, heightened awareness, and robust feedback mechanisms to ensure that healthcare decisions are well-informed, inclusive, and reflective of the needs and preferences of service-users, ultimately putting the patient first.

1. **Community Powered Edmonton:**
   To enhance community engagement, gauging nuanced findings, we recommend referring to the 'Community Powered Edmonton' model as a valuable resource. This approach can provide insights into effective community engagement strategies, ultimately contributing to a more inclusive and informed decision-making process.

2. **Raise Awareness of Services Changes:**
   Prior to launching a research study or proposal, proactively engage the public through a consultation process. This should include a widespread awareness campaign to ensure that patients and the community are informed about the upcoming changes or developments to services.

3. **Longer Feedback Window:**
   Provide a substantial feedback window, lasting at least 12 weeks, to allow ample time for meaningful input. Addressing these concerns will not only ensure adequate time for feedback but also help raise awareness of the proposed service transfers among the public.

Healthwatch Enfield's recommendations are designed to elevate patient care in North Central London, prioritising education, accessibility, communication, and support for all. These efforts rooted in community insights, lay the groundwork for ongoing improvements in health and social care, ensuring that service-users' voice remain central to our future endeavours.

Appendix – Selected Quotes

"I never know where to go and why. I would not be able to travel to Edgware, as I have no ability. I can't drive and don't have the funds to travel."

"If you don't drive, then you rely on people. How do people get home after surgery. Some rely on kids, but they don't have all time. There used to be a service for disabled people, done by GP. If yes, they can't bring anyone with them. Hospital usually says no to this, and taxis are expensive!"

"I drive by myself to the hospital. What I am concerned with is that after my treatment, I am not told how long I have to wait before I drive. I drive to the hospital it takes time, then I am waiting longer and sitting again. It's not good for my health."

"Traveling through rush hour is even harder. On public transport, people just push which is petrifies me. I just wait until the rush is over."

"My daughter drives me to the hospital, and she would help me to find the right department".

"Got letter with an appointment. Didn't know what this is for. Didn't know facility. Got to the hospital by cab but was told by the staff my doctor went to different room and I asked the staff which department to go, I keep going to different ones. Then I am told I have been late for the appointment, which initially I wasn't. No information – This has caused this issue! If I would have had information [of the correct department to go to in advance], I would have known where to go and I wouldn't be late and need another appointment. This cost me £40, a waste of time and money."

"I worry that I might not be seen"

"My daughter must take off work to drive me. If my appointment was cancelled, she has taken a day off for nothing."

"I have to rely on others to drive me. There is no way I could get to Edgware."

"I can take public transport to Edgware but would need a family member to drive me home. A shuttle service would help a lot."

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