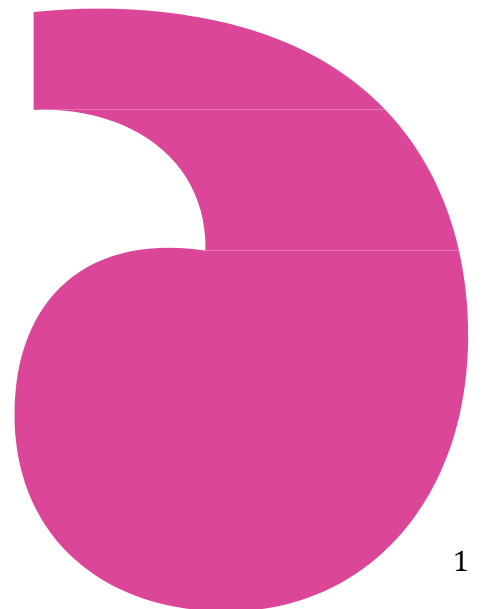




General Focus Group

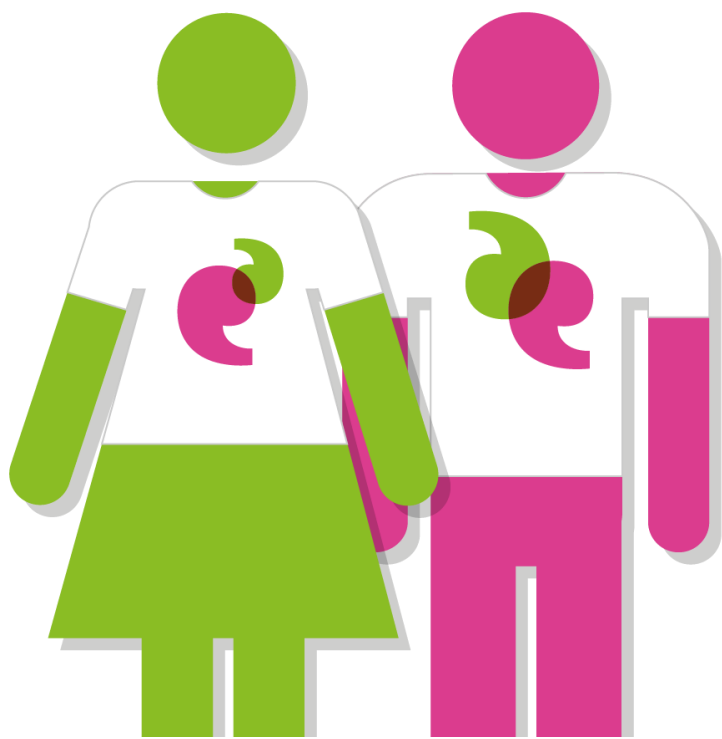
NHS Long-Term Plan

Engagement Report 2019



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Event Details

Date: Wednesday 15th May 2019

Location: Welshore Community Hub, W13 9BP

No. of people in attendance, not including Healthwatch staff: 17

Introduction

As part of the NHS Long Term plan engagement, each Healthwatch was asked to conduct 2 focus groups alongside completing the Long-Term Plan Survey. The purpose of this work was to find out what local people think of their NHS services, in order to feedback to services and inform how the national NHS Long Term Plan is delivered locally. Healthwatch Ealing decided to conduct one of the focus groups on mental health services in Ealing, whilst the other was about NHS services in general. This report outlines the feedback given to Healthwatch Ealing about general health services by local service users, including what works, what does not work, what can be improved, what matters most, and how people want to be engaged. This engagement work resulted in feedback about specific services in the borough and overarching themes, such as 'GP to hospital communication'.

What is the NHS Long Term Plan?

With growing pressure on the NHS - people living longer, more people living with long-term conditions, lifestyle choices affecting people's health - changes are needed to make sure everybody gets the support they need.

The Government is investing an extra £20 billion a year in the NHS. The NHS has produced a 'Long Term Plan' setting out the things it wants health services to do better for people across the country.

This includes making it easier to access support closer to home and via technology, doing more to help people stay well, and providing better support for people with long-term health conditions. There is also a strong focus on children and young people, improving care outside of the hospital, and a commitment to developing 'fully integrated community-based health care'. The clinical priorities outlined in the plan include cancer, cardiovascular disease, maternity, neonatal health, mental health, stroke, diabetes and respiratory care.

Read more about the plan here: <https://www.longtermplan.nhs.uk/>

Summary of themes

- 1) **Restoring Ealing hospital:** Participants agreed that they wanted services to come back into Ealing hospital, citing paediatrics and maternity as their main concerns. They acknowledged that certain things, such as physiotherapy, would be better placed as a community health service. A recurrent theme was accessibility of services, or lack thereof.
- 2) **Admin & referrals:** Participants complained that the entire administration of system in reference to all GP and hospital communications, including referrals, was not efficient. Across the board there were examples of miscommunication, withholding of records, data breaches, and untimeliness.
- 3) **Staff training & support:** There were concerns that staff were not always trained adequately, or that non-clinical staff could be trained further in order to help out GPs and patients equally. People mentioned that staff, nurses particularly, need to be paid and supported properly in order to work effectively.
- 4) **Social isolation:** It was highlighted that one of the biggest challenges people faced was overcoming social isolation, and that combating this was an effective method in preventing ill-health. Participants agreed that the voluntary sector, and accessibility, played a key role and should be funded accordingly.
- 5) **Digitisation:** Participants agreed that there was a role for the digital within the NHS but that this should not replace human contact. However, they did voice concerns about the recent data breaches and the lack of security within the NHS digital systems.

What did people tell Healthwatch?

Here we take a more detailed look at the feedback emerging from discussions.

Section one: Feedback on service providers

When talking to service users they gave feedback on specific services and providers. They discussed what they thought were the problems with those services and what was working well. These issues have been highlighted in this section.

Ealing hospital

There was general consensus from the whole group that they **wanted services to be brought back into Ealing hospital: Eurology, Maternity and Paediatrics**. They said that Maternity and Paediatrics were priorities because if you use Ealing A&E as an adult, you would also like to be able to take your children there, and people would like to be able to give birth to their children in the borough they live in - other hospitals are also quite far to give birth in and for post-natal care. Participants highlighted that before the maternity ward was shut down, a brand-new birthing suite had just been built and that the staff there were exceptional. They also mentioned that the closure of the maternity ward in Ealing would have increased pressure at Queen Charlotte's hospital. Even though the patient to midwife ratio has apparently improved in Ealing, according to the CCG representative, it was mentioned by the participants that there still weren't enough.

Administration

Problems with **admin** were cited often. Letters are being sent to confirm appointments that have already taken place, this has happened to patients at Ealing hospital. Additionally, there have been examples of data breaches whereby letters containing medical information have been sent to the wrong addresses without the patient knowing until they received follow-up letters. People also reported having limited access to their own medical records and one person mentioned that Charing Cross hospital had once

lost their records.

Other concerns

- **Staffing:** It was noted that nurses are filling in and covering shifts due to shortages and too much is asked of them - they will eventually 'burn out'. One participant who delivers food to foodbanks said that they saw nurses relying on foodbanks and living in homeless hostels. How can they provide the best quality care when they are struggling so much themselves?
- **Parking** availability and expense at hospitals is also a concern for patients, especially those with long-term conditions or new mothers.
- **Public transport:** There are poor links to Northwick Park hospital from Ealing borough if you use public transport which is not useful when you are ill/ less-able.
- It was noted that people would like the opportunity to request a **same-sex doctor**, especially for gynaecological exams. There was a report of someone having requested a female gynaecologist but on arrival to the hospital only male doctors were present and she therefore had to restart the whole referral process.
- Lastly, people noted that they wanted a neutral overview of Northwick Park and Ealing hospital instead of the larger hospital making decisions about the smaller one. They would like more of a balance with Northwick Park.

Quotes:

- *"The Maternity and paediatrics wards should be brought back to Ealing hospital, because if you're an adult who uses Ealing A&E then you would want to be able to take your child there too."*
- *"I turned up on time for my appointment and was informed that the doctor had gone as there had been no other patients."*
- *"I had an appointment letter turn up the day after the appointment should have taken place."*
- *"I can't access my own medical records."*
- *"Nurses are always filling in and covering shifts due to shortages. They can only do this for so long before they get fed up. Too much is asked of them."*

What would local people like?

- Eurology, paediatrics and maternity to be brought back to Ealing hospital.
- Decisions about Ealing hospital versus Northwick Park being made in a balanced way and for Ealing residents to have a say.
- More affordable parking.
- For administration to be done in-house, not by a third party, with increased efficiency.
- To have access to their medical records in full.
- For staff to be looked after (including pay and working hours), and to work in an environment conducive of delivering quality care to patients.
- To be able to request a same-sex doctor and have this seen through.

What works?

Within Ealing, specific initiatives in GPs were reported to work well. One of these initiatives is by Florence Road GP who have dedicated hours in the afternoon for urgent cases. This is further facilitated by the receptionist who has medical knowledge and experience and is able to provide an initial assessment when patients with urgent cases show up at the practice. SUs liked the idea of these sorts of drop in sessions. Another initiative which was spoken highly of was the telephone triage used by Waltham Park GP. SUs would phone up the practice, describe their symptoms and would then be advised on whether they needed to come in and see someone or not. However, people did not want telephone triage to become the only option or a way to save money.

Furthermore, SUs have reported that they prefer to see their own doctor as they believe that a good doctor-patient relationship is important for good health management and often are willing to wait longer to see their own doctor. SUs felt that continuously seeing different GPs often leads to poor information sharing and potential misdiagnosis.

CASE: Older patients approved of the idea of a “health passport”. A participant that had been given a health passport by their GP said it made information sharing with other services easier because they could just hand over the passport rather than trying to remember everything about their condition and medications.

What doesn't work?

The **quality of care** was dependent on the GP practice and doctor the SUs were seeing. Many complained about having to see different doctors or wait a long period to see their preferred GP - one SU had to wait 2 months to see their preferred GP. Furthermore, SUs reported issues with **accessibility**. The 8:30am call up process was a difficulty for some due to other commitments, i.e. work or the school-run. Additionally, GPs were often overcrowded. SUs felt not enough GPs and nurses are being trained leading to an inadequate quality of service.

The **referral pathway** was also an issue. There is a binary of 2-week referral for cancer-presenting patients and 3 months for everyone else - many felt 3 months was too long to wait to get referred to a specialist. In addition to that, there were further problems with the cancer referral pathway as those who had not yet been tested, not yet received their results, or were required to provide other information did not seem to get followed up.

In addition, the **lack of follow up** was not unique to cancer referrals. GPs do not follow up with patients in a variety of ways ranging from not communicating test results to not following up on patients after a serious injury.

CASE: one SU who was in their 70s/80s went to the UCC with a fractured elbow in November 2018. Up until May 2019, The GP still had not followed up on their patient despite the fact that injured elderly people are often more likely to need help with day to day life due to increased likelihood of frailty and isolation.

Other concerns:

- People concerned about the **poor diagnosis of dementia**.
- SUs are unable to **access their own medical notes**, they would prefer to be able to access both their digital and physical files and bring them to appointments.
- **Parking** was also an issue at GPs; due to inaccessibility, expenses for less-able patients increase as they have to use taxi-services.

What would local people like?

- Access to their medical notes when they want. Additionally, ‘health passport’-type

documents to be provided by GP's, especially for older patients or those with long-term conditions.

- For GP's to have adequate parking nearby.
- For referral and follow-up pathways to be timely and efficient.
- To be able to see the GP that they want - this is especially a concern of patients with long-term conditions.
- Receptionists to have some general medical knowledge to be able to give advice on whether or not an appointment is necessary - but for caution to be exercised.

Quotes:

- *"Your experiences is very dependent on the doctor you see"*
- *"If you are older or have multiple long-term conditions etc, seeing the same doctor and someone that knows the history well is very important."*
- *"When you don't hear back from the GP regarding test results, it is disconcerting. They tell you if you don't hear everything is ok, but I don't have confidence in the silence"*
- *"I had a test for diabetes in November 2018. The GP has still not followed up (May 2019). No one has got back to me."*
- *"The 'named GP' system does not mean anything in reality. I have never seen them."*

Pharmacist

SUs had positive experiences with pharmacists with one noting that the pharmacist was able to notice that the GP had made a mistake on their prescription and advised them to go back to get it altered. Furthermore, some pharmacies offer "My Medication passport", small booklet which contain medication records and other key information ensuring accurate transfer of information.

However, one participant also had a situation where the pharmacist had given them incorrect medication.

What would local people like?

- Would like a medication passport from pharmacists - this could be incorporated with the idea of the health passports.

Quotes:

- *"The pharmacist was able to pick up on a mistake in my prescription, and told me to go back to the GP to amend it"*

Out of Hospital Services/ Community Health Services (CHS)

A participant suggested that the physiotherapy service should be an out-of-hospital service with local sites available. Many who seek physiotherapy suffer from limited mobility thus having local sites would make it easier for them to get to their appointment. It should be noted the physiotherapy department in Ealing hospital was mentioned as being excellent.

What would local people like?

- Services that need to be immediate and accessible should be made available in the community - there needs to be a re-evaluation about which services need to be provided entirely within the hospital environment.

Quotes:

- *"I asked for physio[therapy] for a broken arm, but the wait was approximately 19 weeks. Physio has to be immediate in order to be effective."*

Care homes/ Domiciliary care

One of the main issues brought up was the lack of clarity regarding **carer** availability post-discharge. People are often discharged not knowing if there will be a carer waiting for them at home. In some cases, due to a lack of carers, people had to be readmitted to the hospital.

Furthermore, the problem of “**15 minute**” **appointments** by carers was also brought up. While the official line from the CCG representative about this was that people would not be given a 15-minute appointment unless it was for something small such as administering pills, other participants had heard “horror stories”.

Sus raised concerns about who was **training carers** as they have witnessed a lack of basic hygiene by some staff. There was an example given of a time a carer was working in the medical surgery (of a care home), wearing gloves, and the person went into the kitchen wearing the same gloves. However, ECIL to do run a 12-week course for carers about medical administration and hygiene etc.

Section two: Overarching themes

General

There were two main areas of concern about the managing bodies of NHS services.

- **LNWT (London North West Trust) TUPE-ing:** The plans are counting on staff TUPE-ing across from LNWT to the West London NHS Trust (WLNHST). Participants were concerned that not all staff may transfer and that there are already staffing issues and vacancies. Most wondered whether there were enough sweeteners to ensure staff can be recruited to the services.¹
- **CCG Merger:** Concerns about the move to a NWL-wide CCG resulting in the reduction of a role for Ealing CCG - that local concerns would be diluted in a CCG that covered a larger area.
- **Personalised care:** Participants said they **wanted a choice of when they get appointments and who they see**, they thought the LTP should involve more personalised care. However, they were concerned that the move into the **personalisation of healthcare could also lead to privatisation**, and whether or not this was a stepping stone to that end result.

Voluntary Sector, other services & social isolation

The role of the **community and voluntary sector is vital for health and wellbeing and supporting communities to stay well**. They can keep people active, sociable and engaged in both their local area and their community with their activities that the sector put on. The community classes, for example, that are put on by voluntary and charity groups are very important.

Combating social isolation and keeping people active is a form of preventative care and they should be supported by the NHS as well as the council as they save healthcare services from having to provide further care. The **Strength and Balance classes** by the council had really positive reviews by service users, when it was first introduced it had a number of free weeks. However, over time the number of free weeks was reduced incrementally to the point where users now have to pay for classes, which resulted in

¹ Healthwatch Ealing has attended community meetings where Ealing Community Partners have addressed the TUPE-ing issue. Dr Hilton stated that the Trust was doing ok on retention, and that not many staff had been lost during the TUPE process. The Trust was ensuring that any leavers went through an exit interview to fully understand their reasons for leaving and take away learning where necessary. ECP should be providing a fuller report on staffing levels and approaches to reduce vacancy.

people not being able to afford it and they had to stop going.

However, charities and Voluntary groups need to be supported. Many of these services provide something for people to do which helps to combat social isolation and keep mental health issues as a result at bay. People are often stuck at home with no reason to leave the house, and these organisations give them something to do, and leave the house. Aging people need a safe space to come out and interact with other people. Mental health services closing down will be detrimental to those who use them. People who are also less-able often access these organisations too. **These spaces need to be encouraged, funded, and supported** by the council instead of constantly being inundated with higher rents and bills. These charities could also be supplied by other services with food etc - such as when supermarkets throw out food, this can be diverted to these spaces instead.

In terms of combating social isolation, initiatives such as a **free travelcard** could help because having a free travelcard would mean that people would not be hindered by financial stress in order to leave the house for outings - it will help to encourage people to get out and see others. Additionally, **libraries** are being shut down by council cuts but they often double up as community centres for groups and social interactions, they also employ local people. Free **gym membership** for certain people could be useful to keep them active and therefore foster good mental and physical health.

What would local people like?

- Community groups, organisations and spaces to be supported and funded instead of being shut down.
- Initiatives to combat social isolation - free travelcards and gym membership.

Hospital & GP communications

Service users across the board had experienced difficulties with communication both between hospitals and GPs, and between hospital departments - predominantly during referral pathways.

A majority of participants complained about the private company that works on behalf of the NHS to communicate between services and patients. Many found that it was inefficient - test results were withheld, and communications regarding referrals were confusing and unnecessarily repetitive.

Participants discussed that GP communication to other services did not always work - if they were referred somewhere for further check-ups, results would not always make it back to their GPs. Patients also found that doctors in different services did not have ready access to patient notes and records, resulting in patients spending time updating doctors on recent treatments. People were concerned that this restricts services being able to provide the best possible care and it could put patients at risk.

Participants complained about the lack of choice in the referrals being made on their behalf. Some said that their GP did not refer them to the place they had requested and others said it was the system that chose for them - that they didn't have any say.

Private companies: A separate issue about outsourcing to private companies came up. Patients had been referred to private services for MRI scans or X-rays, and found that the results could not be shared with their GP. These patients then had to get the tests re-done in an NHS-owned service.

What would local people like?

- Want a choice in where they are referred.
- For records to be shared efficiently between departments.
- For referral information to be shared with them efficiently and directly - this is seen to work better without a private company in the middle.

Quotes:

- *“I asked for referral to another hospital and got the same thing, an appointment letter listing a different hospital. Choice does not exist. The systems automatically decide which hospital you go to.”*
- *“I went to the GP and he gave me a letter to take to A&E. I went to A&E and they triaged me for UCC. The GPs decision should be respected. Differing opinions does not give the patient confidence that their care is being managed appropriately.”*
- *“GP referral didn’t get to the hospital and was intercepted by the private referrals company, wasting resources.”*

CASE: *“I asked my GP for a referral to Guys and St Thomas. I got a letter with an appointment for Charing Cross. I logged on and cancelled it and then received another letter for a new appointment at Charing Cross. I called the number and was told I can’t actually cancel it myself, only they can. Eventually I got my appointment at Guys.”*

CASE: In one example from an appointment in the morning, Drs within Trusts seemingly did not have ready access to patient notes and records. The patient had to spend half the appointment explaining to the doctor what had been happening and what treatment has taken place at another site within the Trust etc. this was Imperial. The doctor eventually found the information, but it was not easily accessible (ie not on the front page). At first she said she had no record.

CASE: *“A Private Company working for the NHS refused to give the test results to my GP or the Consultant at the hospital where the test was done. I went for an MRI at Central Middlesex Hospital requested by a GP at a health Centre. My GP could not get the result. I was then sent to a specialist Consultant at Central Middlesex Hospital. He also could not get the result of the MRI done in his hospital because it had been done by a private company for the NHS. So I had to have another MRI.”*

IT systems & digital communications

People are concerned about their data, especially data concerning their health and wellbeing. Due to the NHS security breach of 2018, trust in the NHS ability to handle their sensitive data is low. Participants, acknowledging the lack of communication between GPs and district nurses, would like their data shared with them to ensure a greater quality of care. However, SUs are concerned that this may expose their sensitive information to private companies who may sell it to 3rd parties for profit. In the light of the Cambridge Analytica scandal, this is not surprising.

Participants believe that digital healthcare, and thus an overhaul of the IT systems in the NHS, have a place in the NHS but fear there has been an overemphasis on digital healthcare. As health is such a personal and sensitive thing, it is important a person-centred approach remains - SUs fear that this may disappear as the NHS moves towards more digital based healthcare. In addition, older participants are wary of the extra passwords they would have to remember.

What would local people like?

- The NHS must ensure that IT systems, new and old, are secure and comply with GDPR regulation to ensure that people’s data are safe and that they can be confident it is.
- To make sure there is still a personal element to NHS services - only digital where necessary.

What matters most?

- Paediatrics and maternity to be restored in Ealing hospital, and for the future of the hospital to become more concrete.
- To re-evaluate which services should be placed within the hospital or as a community service based on accessibility.
- For the private referrals company that worked for the hospitals to be scrapped because it was inefficient, or for it work better. Referrals and all NHS communications need to be timely and appropriate.
- To make sure that NHS systems are secure in order to mitigate further data breaches.
- A 'health passport' to be administered to older people and those with long-term conditions, making information-sharing easier.
- For community voluntary groups to be funded adequately.
- To give those that need it, access to free transportation/exercise.
- To make sure all staff are appropriately trained and well supported.

Moving forward & how do people want to stay engaged?

The participants were interested in remaining engaged throughout the process with opportunities to provide input at various stages. Most importantly they want to see the impact of the suggestions they have made, or at least for their suggestions to be considered and to be told why/why not they have been acted on. They would like to see plans beforehand so that they can comment and test it.

People said that they wanted clarity about what is happening locally, regionally and nationally. They said they would be happy to attend another event to receive feedback.