



Engagement Report

April-June 2019



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Feedback: Themes and Trends

This section will cover a summary of the feedback that we have collected through engagement activities this quarter. This will include feedback from our focus groups - both are covered fully in separate reports which are available on request and online once. Feedback from our engagement with carers at Avenue house and from the Tracker we have kept to document all feedback that we have heard through ad-hoc engagement - this quarter the majority is from outpatients at Ealing hospital.

Mental Health service users focus group

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, which was held at the Solace Centre. Additionally, we collected experiences through one-on-one interviews at CAPE, another mental health service in the borough.

This summary outlines the feedback given to Healthwatch Ealing by local mental health service users about 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 'communication'.

We found that local people consider staff attitude, efficient communication, continuity of care, environment, community services and co-production to be important in current and future services.

- 1) **Staff attitude:** Service users wanted supportive and caring staff in all service areas, from nurses through to management - for people to fight for them, care about them and treat them with respect and humanity. They wanted staff to provide useful, relevant information and help when requested. It was noted that staff, such as GPs, were not knowledgeable enough about mental health and that this needed to change.
- 2) **Communication:** People wanted different services to communicate with each other openly and to share information. They wanted the administration processes to be easier to navigate and for referrals to be followed through in a timely manner. People were particularly concerned with the lack of communication between physical health services, such as GPs and other hospital wards, and psychiatrists - noting that the lack of information-sharing, especially regarding medication, is potentially dangerous.
- 3) **Continuity of care:** Service users wanted to see the same care coordinator, psychiatrist and GP over a long period of time, so that they could build relationships and trust. They wanted an up-to-date care plan. People also discussed how post-acute care was inconsistent.
- 4) **Co-production:** Most people wanted to be involved in the production of their care, from a strategic decision-making level, to being on the boards of services. They wanted to work with a psychiatrist to co-produce their care plans. Overall,

they wanted to make sure they had an influence in how their care was being managed.

- 5) **Community services:** The existence of community services that people could drop-in to and create networks was very important to service users. They noted that it helped them from being isolated and worked as a way to help prevent crisis. Community-based psychotherapy was useful for some whilst on the NHS waiting list.

The complete report is available on request, and can be found on our website.

General service users focus group

This summary 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'.

- 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.

The complete report is available on request, and can be found on our website.

Mental Health Carers Forum

We went to the Mental Health Carer Forum, at Avenue House, and gathered the experiences of services used by carers in relation to their relative with MH diagnoses.

Event details:

No. of people engaged with: ~20-30

Date: 14th May 2019

Communications

Members brought up poor communication between the A&E at Ealing hospitals and GPs, between different hospitals, and between hospitals and the Community Recovery Team. Poor communications having led to delayed appointments, no feedback post-operations, and no help post-discharge.

Quotes:

- “No feedback to GP about/after operation”
- “Discharged from St Bernard’s and nobody informed Community Recovery Team West”
- “Attended Ealing Hospital A&E and was told I needed immediate neurological surgery. We were sent home expecting to hear imminently from Charing Cross Hospital regarding a date for surgery. We then received a letter for an appointment 3 months later. I chased and chased and eventually we had the operation 3 days later.”

Charing Cross hospital

Staff at the hospital were well received and said to be polite, they also had a good attitude towards carers. The post-operative care was “fantastic”. However, one person mentioned there is a delay in follow-ups.

Quotes:

- “Neurological operation went very well and received fantastic post-op care.”
- “Still waiting for results of biopsies 3 months later”

Community Recovery Teams CRT (West and East)

Members said the time between discharge and a follow-up by the CRT is too long.

CASE: A carer’s child, 21 years, used to be under CAMHS which was doing a lot for them and constantly checking in. However, as they grew out of the CAMHS service, they felt as if “there was no gradual transfer, it was like dropping off a cliff.” The parent said that in adult services the child is too quiet and therefore “left alone - there is not enough contact with mental health services”. The child now sees a psychiatrist every 6-8 months, and was offered group therapy but this was not appropriate as they have anxiety. The parent privately pays for therapy but is concerned that it’s disconnected with the rest of the care. Additionally, they have struggled to obtain letters from the CRT for school exam and university application purposes, having to chase up constantly.

St Bernard’s

Members felt supported as a carer at this service.

However, the main issue is that people feel that urgent improvements are required. The wards are not deemed fit for purpose, and this has been highlighted as an issue in the last 2 CQC reports at least.

People would like to know what the plans are for the site, and why there seems to be no plan to improve, rebuild and change. Especially as the transfer from John Donnelly to St Bernard’s was meant to be temporary but has become permanent, there needs to be a plan.

Forensic Services

It was mentioned that there was no patient advocate on site at Derby ward, a medium secure ward. Members found this “appalling”. One person mentioned that their son has

been in the ward since December 2018 and only seen a social worker once as since then he has been 'in-between' social workers. They added that there is no specific/personalised therapy available.

Triangle of care

Carers said that the most staff have never even heard of Triangle of Care, and that it needs to be included in the induction because right now "the reality of triangle of care for carers is nothing, it does not exist".

WLNHS Trust - General

As the trust take on community services, there are concerns that it will lose its mental health focus, that MH services will become the "Cinderella of the Trust".

Most felt as if the attitude towards carers in services was that they're "seen as a problem not a resource".

For those that have used mental health services over a long period, they feel they have witnessed a decline in services, and a decline in the level of expertise.

Carers in crisis service

It was highlighted as a necessity in the service for carers, and that it had been discussed for a number of years but has not gone anywhere. It was felt that "a pilot project would be a good start" at least.

Early Intervention Service EIS

The EIS was said to be a very good service that also practised the Triangle of Care, and the participant felt as if they were involved from the beginning and supported as a carer

Crisis care A&E at Ealing Hospital

A majority of the carers cited that the waiting time for psych liaison at A&E was too long, some quoting 6 hours. They mentioned there is no dedicated doctor for mental health at A&E, but that when psych liaison team do come they are very good and helpful. It was highlighted that there is no safe and secure facility within A&E and that it is inappropriate and uncomfortable for both carer and patient to be in the main waiting area.

Quotes:

- "Our experience at A&E, twice, with my husband was good. We were there a long time - 8 hours - but there is a room we were put into. Two Psych Liaison staff came. The second time we saw one of the same liaison staff and he remembered my husband and that helped too."
- "The crisis team are very very good"
- "We have to wait in the main waiting area and had to wait for 6 hours. It was uncomfortable to the carer and not appropriate for the patient. We had to wait so long for the AMHP team to come for sectioning."

Single Point of Access (SPA)

It was felt that this service was not able to provide useful help during crisis situation as they "did not do anything". However, for one participant the SPA was useful as they sent a crisis team out to their son.

Quotes:

- "I have phoned on five separate occasions for my husband when he's in crisis. They simply can't help you. The response was either take him to A&E or dial 999."

- “SPA played a role for us. I would call them if my son hadn’t gone to school for a few days in a row. They would call him the next day, talk to him for a few minutes. SPA also got crisis to come out and watch my son take his meds. That’s all they did and then left!”

Consultation fatigue

The group felt that they were constantly being asked for their views, insight and to help out but nothing ever changed and there was a lack of follow-up.

Quotes:

- “What difference does it make, we are always being asked for views and nothing changes.”
- “We were asked to get some people together to help with Triangle of Care and now its 6 months later and there has been no contact made.”

Ad-hoc feedback

This section will cover the ad-hoc feedback that we collected as we were conducting the engagement around the NHS Long-term plan. This feedback predominantly stems from visiting Outpatients at Ealing hospital and GP waiting rooms.

Ealing hospital

General

Both patients and staff at Ealing hospital have raised concerns about the future plans of the hospital, they want to know concretely if it will remain open and want more transparency around its future. If it is, then they would like to see the site being invested in. A member of staff told us that when they flag maintenance issues, nothing ever happens. They also pointed out that if Ealing hospital were to close, “Northwick Park wouldn’t be able to handle all the patients coming from Southall”.

A few patients have said that if they could avoid coming to Ealing hospital then they do - preferring Charing Cross or Northwick Park as they were likely to be seen in a timelier manner or in a better environment.

Environment

Both patients and staff have pointed out that the environment of Ealing hospital is not conducive to recovery, especially post-operation. Staff have said that it’s often not a great environment to work in let alone recover in.

In Outpatients, there were people complaining about the hard seating as there are only 2 soft seats. This is particularly difficult for those with long-term conditions, or the elderly, as they often have to wait and sit for long periods of time.

Communication

Patients felt as if communication between them and the hospital was often inadequate, leading to over- and under-communication, and time-delays in appointments and operations.

OPTUM Referral Facilitation Service

Patients complained that the system automatically chooses where you get referred and that they feel as if they don’t have a choice regarding which hospital they want to be seen at, for example one patient wanted to go to St Mary’s but was allocated Northwick Park.

aCASE: Patient said they were sent around 10 follow-up messages and calls in a 2-week period about this one appointment, which according to them was not of high importance, and they found this generally quite distressing and intense. All calls were from differently people - probably outsourced. Felt that follow-up calls should be coordinated or at least properly tracked because this was an overwhelming experience and it felt like there was no communication between the different admin sides of the hospital due to the repetitiveness.

CASE: Patient had an operation scheduled with Ealing hospital which they cancelled without informing the patient - they had to ring to find out. The second time around it got cancelled by the anaesthetist as the patient was going into the operating room because their blood pressure was too high. The third time waited for 6 more months to finally get the operation, only because their GP pushed for it. This was a 2-year process altogether.

Appointments

There is a recurring problem in Outpatients regarding appointment delays, having spent many afternoons in the waiting area we noticed that delays were often up till 2 hours fairly regularly - through the month of May. We also spoke to patients who told us how long they had been waiting and all appointments were delayed to some degree. Patients said that they often had to take half-day or full-days off work in order to accommodate appointments as they were aware that it would likely be delayed. During one instance, an additional cardiologist turned up to help alleviate the delays.

CASE: We observed that one patient - wheelchair bound - had been waiting for nearly 2 hours and re-emerged 5 minutes after being called into the consultation room, and said "well, that was a waste of 2 hours". It is possible that they had been referred wrong/ didn't need to be there or that it was a long wait for something very minor - regardless, there should be better communication about what appointments are actually for/ the reason behind them between doctors and patients.

CASE: Around 6 months ago at Ealing hospital a patient came in with their daughter (who had to take a day off in order to bring patient to appt) for an appt but the staff had left early (at 3.30pm) so they ended coming in for no reason. One of the nurses left managed to get a doctor to come in to the clinics so that they were seen but it was not their regular consultant and therefore it was not a useful appt - he just read the notes. It then took 6 months to get a follow-up appt (what they were there for today) to see their actual doctor so that they could have a useful appt. They wish that they had just been properly informed in advance if their consultant wasn't going to be in - even a text to let them know would have been enough because now they have come all the way in and wasted a lot of people's time in order to have an appt that wasn't useful.

CASE: Urgent care at Ealing hospital (around 2017): Patient had a broken toe and they came in to get it looked at and fixed (essentially all that needed to happen in turns out was to get it put in a splint and then not put weight on it), however it was left untreated by the doctor who initially saw them. They then went through a process of over 2 years of trying to get appts (waiting 6 months for an appt at Charing X only for it to be cancelled, in one case). They ended up getting worse and developing further conditions regarding their veins in their foot and their gait, which the doctors could not do anything about. At one appt with the doctor they were told they'd already had a steroid injection in the foot - which had not actually been performed. It took the 3rd person they had seen about it to actually physically look at their foot - something that should have been done in the first place. In the meantime, their condition has just gotten steadily worse due to misdiagnoses etc. The patient also commented that this

was a waste of NHS time, money and resources when they should be trying to save it and are already stretched thin.

Self-check in & Outpatient's reception

There is a fairly new self-check in system at Ealing hospital Outpatients and no permanent receptionist in the area. After asking the Nurse about the new system, they told us that usage had improved recently as patients have got used to it. Patients who speak English and are comfortable with technology are the happiest to use it, but those with some language barriers find it easier to use if there's a member of staff around to help them. However, people would still like a receptionist so they can have some acknowledgement that they're in the right place/waiting in the right area (there are different waiting sections in Outpatients 2). A patient came to us personally to ask for directions from outpatients 2 to the blood tests waiting area and another patient had to help guide them.

Patients want to feel as if they know the doctor knows that they have arrived - a machine does not provide this reassurance. From observation it looked as if nurses were stuck between doing their job and functioning as a receptionist. As nurses are the people that patients see the most in the waiting area, they are stopped regularly for questions and queries. When there is a delay of waiting times, patients are not told often, a nurse has to come out at some point and announce the delay and what is happening i.e. that an extra cardiologist has come in to help deal with the appointments.

Services

A patient pointed out that some services were no longer available at Ealing hospital, citing Urology as one. They also said that changes often happened without engagement or consultation of local people.

Staff

Patients said that the staff at Ealing hospital were good and they felt looked after post-op. They also said that they would rather see the same specialist for their appointments rather than different people each time. One patient even waited an extra hour so that they could see their normal cardiologist rather than someone else.

Parking

Patients complained that parking was very expensive, especially as appointments are often delayed so they do not know how much it will end up costing them. One patient's parking ticket was about to run out as we spoke to them and they were still waiting for their appointment.

GPs

Referrals

Patients said they had no choice where to be referred, that the GP chose for them. One patient specifically asked the GP to be referred to Guys, but the GP refused, and later relented after the patient pushed for it.

Appointments

A few patients had struggled to get GP appointments, one said that they had previously gone to A&E rather than their GP because they couldn't get an appointment.

Other

- A visit from a nurse or GP may be more appropriate than coming into the clinic for some people as they age.
- **Irrelevant and judgemental comments** from the GP has made one patient refuse to see the particular doctor at all as they comment about them being overweight, when actually the patient has come in for a sore throat. The patient seemed quite distressed and very annoyed by this.
- **Untimely treatments** have worsened the condition of a patient. The patient had been diagnosed abroad with something but the GP here said they wouldn't treat for it - now they have gone through a long process to get it sorted, and in the meantime the condition has become worse.
- Patient thinks that GP partners run like a business, thinks it's a conflict of interest for GP partners (not NHS GPs) to be in the CCG to have a say on how and where money is spent, and do not think that equal services exist across the borough.

Single Point of Access (SPA)

One patient said that they have had no answer from the line before, or has often had to wait 30+ minutes for an answer. They were also concerned that it uses a premium rate telephone number.

111 service

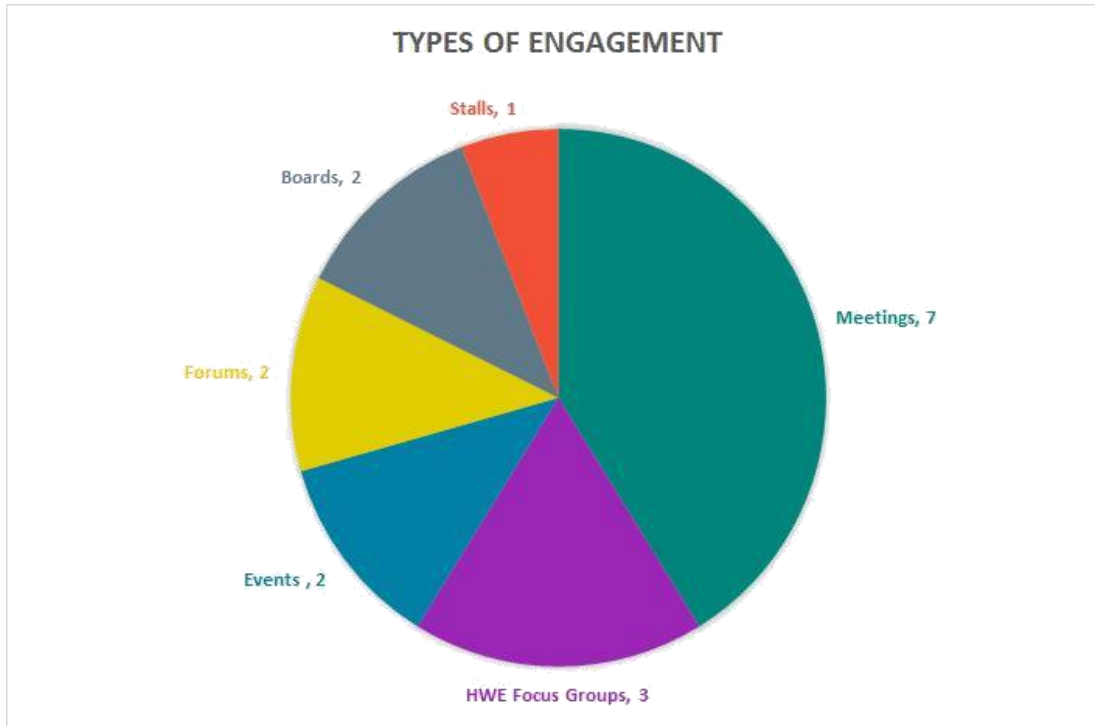
CASE: Patient thought the advice was not helpful. He is semi-disabled and his wife is disabled. When he had a problem and called 111, they told him to just go to the local chemist to get some medication but he was physically unable to.

NHS Long Term Plan

People said that the plan focused too heavily on independence and people looking after themselves, and IT and technological solutions. Additionally, they were concerned about its achievability as it did not address funding issues.

Engagement activities

We have been to 17 engagement meetings and events in this quarter, not including collecting survey responses for the NHS Long-term plan engagement. As a part of the NHS Long Term Plan engagement, we went to Ealing Hospital outpatients most afternoons and to a few of the local surgeries and mental health services in order to fill out the survey, eventually collecting 250+ responses. Additionally, we held 2 focus groups to fulfil the criteria of the engagement, one a general focus group and another specifically about mental health services.



The meetings this quarter were introductory/catch-up and event planning meetings with other organisations, i.e. The Solace Centre, ECVS, ECN and CAPE.

As we had collected service user views during our focus groups in May, we began to feed that back at any opportunity that came up. We attended the NWL Transformation Events that took part in this quarter and contributed the feedback we collected regarding general and mental health NHS services. We also fed back directly to CAPE, Ealing Community Partners (who run the mental health Single Point of Access), and at the Mental Health Partnership board.

Organisation engaged with & events
The Solace Centre
CAPE
NHS LTP general focus group
NHS LTP MH focus group
NWL Transformation Event (General)
MH Carers Group - Avenue house
Southall Community Alliance
Mencap
Acton Community Fair
Ealing CVS meeting
NWL Mental Health & Wellbeing Transformation event
ECN (Ealing Community Network)
ECVS (Ealing Community and Voluntary Service)
Long term conditions & Older people's partnership board
Ealing Community Partners
Mental Health Partnership board

Follow-up activities and next steps

We will continue to feedback on mental health services, particularly focusing on the Mental Health SPA. We have a meeting with one of the Mental Health Transformation Leads to follow-up on the feedback we gave at the event and to make sure that everything is properly passed on, and to see how we can work together as part of the Transformation project.

We will be sending out our finalised Mental Health and General report to all relevant groups and services, including the Mental Health Partnership board. Healthwatch Ealing will be putting together 2 follow-up events for our focus groups. The general follow-up will be held in Southall and the mental health follow-up will once again be held at the Solace Centre. These sessions will be an opportunity to let participants know where their feedback has been heard, to try to bring NHS and CCG staff to the events so service users can speak to them directly, and to collect additional feedback. From attending the Ealing Community Partners event we have spoken to their SPA lead and we will be following up their attendance at our mental health follow-up event.

Our goal around mental health services will be to set up avenues of regular feedback so that we can build a larger evidence-base to go to the relevant bodies with. This will ensure that the issues brought up are not anomalous, thus strengthening the case for change.

Other upcoming activities following up from this quarter includes attending the Mental Health Forum, mid-July, where we will be presenting our report findings, next steps and building relationships with other community organisations. We will have a stall at Mencap's upcoming "Help My Health" event, to collect feedback and hopefully sign people up to come to a future focus group for carers of and people living with learning disabilities. We will also have a stall at Ealing hospital's community open day to increase our profile within the community and collect patient feedback. Healthwatch Ealing also recognises, from doing our general focus group, that we do not engage with the communities in Southall actively enough and therefore the following quarter will be focussed on building relationships in this part of the borough. We will be following the basic structure of the NHS Long Term plan engagement and finding out what these communities think is working well, what isn't and what needs to be improved. We will also be looking at issues of access, referral and other themes that came out during our general focus group.