

September 2021 Feedback Report



# The feedback presented in this report represents 751 responses from the following sources:

- Calls and emails to Healthwatch Greenwich from Greenwich residents and service users
- Meetings between Healthwatch Greenwich and groups of Greenwich service users
- Community conversations as seen on digital platforms
- Online reviews of services

## **COVID-19 vaccination**

As booster doses are being rolled out communication has been inconsistent. Many service users are still unsure of basic information, in particular:

- where to find trusted and reliable information about booster doses
- how to book booster doses
- choice of vaccine for booster doses
- if a booster dose can be taken with the flu vaccine
- those vaccinated but without an NHS number worry they won't get access to a booster dose or a COVID pass for travel.



The impact of combining vaccines is a worry for some.

"I a little bit worried-my stepdad had the Oxford jab few months ago his booster is the Pfizer. I don't want him being a guinea pig-he is 70 years old"

"I wouldn't want two different vaccines"

#### **GP** services

While both national and local data demonstrate GPs are delivering more appointments than ever before and more than pre-pandemic levels, access to GP services continues to be the most common issue we hear about. While many enjoy access via digital platforms and rapid telephone consultations, others - particularly those who struggle with digital platforms and those who want face-to face appointments - find it increasingly difficult. Even those comfortable with and happy to use digital platforms, are increasingly telling us that GP websites and online platforms are down or not working for days at a time.

While service users recognise the huge pressure GP services are under, they don't understand - now most people are vaccinated and shops, clubs, pubs, and even international travel is open - why things have not gone back to 'normal' (i.e. relatively easy access to face-to-face appointments without the need to use digital forms) at their local practice.

Some service users tell us they feel their 'right' to access GP services has been removed. Leaving some feeling desperate and abandoned by the NHS. Some tell us it is so difficult to access GP services that they are turning to Dr Google, ordering medication (often unverified medication) from the internet, and or self-medicating by increasing the dosage on both prescribed and unprescribed medication. Others tell us they feel they have no choice but to pay to see a private practitioner. Those who cannot afford to pay say they are scared and frightened.

#### "...[my] negativity is out of fear. I genuinely do not know what I would do if I needed to see a GP. I've already looked into going private... but I need to save up for that.

I really liked my GP pre pandemic but post pandemic, I fear for my health as I don't think anyone would help me.

I needed help with hay fever over the summer. I just ended up giving up & upping the dosage [beyond the recommended dosage] on over-the-counter antihistamines as I had no other option.

I'm sorry but people are genuinely frustrated & worried that they cannot access a GP."

*"It's a reflection of the system. A few years ago, it was quite straight forward. You make one call and got an appointment within a few days. These* 



days, no one answers the phone and the online thing is hit and miss"

"In this day and age they don't have a decent booking system and Covid can't be the excuse any more. Something is drastically wrong with our practices. I reckon it's going to drive a lot of us to go private"

"I've already made the decision to go private. I tried to get help over the summer and it was clear the GP surgery did not care. I could not even book a telephone appointment as the receptionist claimed the online system was broken. Three days on the run"

## **Econsult**

Feedback on econsult continues to be mixed. While digitally equipped service users like the convenience and ease of access - the form can be completed wherever you are, others find the process long-winded and tedious. Service users with limited dexterity in their fingers find typing challenging, those who don't use keyboards regularly or who are slow typists also report difficulty and are most likely to say - for them - the econsult form is not "fit for purpose".

We continue to hear from service users reporting delays receiving call backs after completing the econsult form.

I have been with them over 40 years and now I'm getting fed up with econsult forms, which can't even be filled in accurately about your illnesses, doesn't ask the right questions, nowhere to write how you are really feeling. Then you have to wait over a week for a doctor to ring you, having to have your mobile glued to your body in case you miss their call as you don't get a [call back] time

It's fairly common for mobile phone users to set up their phone to block calls from 'unknown numbers' - indeed - many consumer sites recommend this approach to reduce nuisance calls and potential financial fraud. If the practice number is not saved in a user's phone - the number is not recognised and the call-back is missed. Alternatively - if a call-back is made from an alternative number - not the same number as the practice - again, the number is not be recognised - and the call is missed.

"I've been trying to get an appointment by using econsult, but every time they arrange to call me the call just goes straight through to my voicemail without ringing or registering on my call history. This has happened about 4 times now"

"I do actually quite like econsult and I do get a prompt email response... but just can't seem to get any further. Do the doctors call from the main number or do they have a different line?"



"GP says the phone just rings but my parents don't get a call"

Missing a call-back necessitates service users following-up, which can be time consuming.

"Someone should have called me for an econsult [call] on Monday- no one called and I spent an hour and forty minutes trying to call them back . The whole thing is very frustrating I should have another econsult [call] next week I'm not holding my breath it will work out"

While most service users report a quick and timely response from econsult, a minority have long delays.

"Don't bother trying to do an online enquiry my son sent a request over 3 weeks ago and only got a reply yesterday"

"I sent an enquiry a few months back still haven't heard from them"

"Put a request in two weeks ago still haven't heard back from them"

## Face to Face appointments

Practices are working at unprecedented levels with limited resources. Workforce recruitment is challenging, and many GPs work excessive hours to meet the needs of the service. Both nationally and locally we are at risk of not having enough GPs and other practice staff to comfortably meet the demands of the service.

Telephone triage - a way of assessing which healthcare professional can best meet the needs of the caller - is used to ensure those who need to see a GP (have a clinical need to see a GP) do so. Those whose needs can be accommodated by telephone or digital consultations are offered this.

Many service users prefer the convenience of telephone or digital appointments. Those who find it difficult to take time away from work for in-person medical appointments and those with busy domestic schedules welcome digital and telephone consultations.

While the overall number of appointments delivered by GPs is significantly up compared to pre-pandemic levels, the number of face-to-face appointments has reduced.

For some, access to face-to-face appointments as a service-user choice is a significant grievance. Many service users feel their choice of appointment is a right that has been removed without discussion or consultation. A proportion of elderly service users - those not comfortable with technology - familiar with meeting GPs in consultation rooms - are finding it difficult to explain concerns over the telephone. Those who do not speak English fluently tell us interpreters are not



always offered or arranged.

Others tell us they are concerned that telephone consultations are offered as a blanket approach, and fear symptoms will be missed. Some don't have confidence that prescriptions are issued with rigorous consideration, that it's counter-intuitive (to them) that medication can be dispensed safely without a thorough examination of patients.

"The elderly have grown used to being seen by their community doctor, when they needed to seen. How many possible critical illnesses go undiagnosed by doing e consultations or telephone conversations. It's sometimes difficult to put into words when something 'just doesn't feel right'"

"I think all these new apps are great (when they work) but I can't help to feel sorry for the generations who were not brought up with computers and mobiles. I have elderly relatives at the moment, frustrated, angry and tearful trying to get someone to explain to them what stage 4 cancer means. Yes, we have put them in touch with Elena nurses, but it needed us to do it as they couldn't get through to their GP and I'm guessing they have slipped through the system at the hospital"

"Doctors never used to give you antibiotics and over the phone but now you can ring up and get your medication straight away whatever you ask for. It's not right"

## **Prescriptions**

Delays in receiving medication can create stress, exacerbate conditions, and adversely affect health. Some service users report delays in receiving prescriptions and repeated chasing to expedite the process.

"I spent 40 minutes in a queue on the telephone to the doctors who told me that both mine and my husband's [prescription] certificates are sitting in a very big pile waiting to be collected, so now, one week later I am having to collect the prescription from the doctors.

They won't release prescriptions early and yet we have to put up with this. My husband has enough tablets to last another 2 days. They are just playing with people's lives"

"Consultant sent a letter [to my GP] regarding update on my condition requesting them to prescribe new drugs. 3 months later I had to take in a hard copy [of the consultant's letter] to put on my file. Still took 8 days for the script to arrive at the chemist"



#### "I was stuck without the medicines I need to take daily. My medication prevents asthma and last time I spent a weekend without it I ended up in hospital"

## Accessing patient records

Accessing personal medical information can be difficult, even service-user requests to share information from one medical professional to another.

"Got a text from my GP asking me to book a doctor appointment regarding my recent urine test - so I assume there is some kind of infection. Next appointment is available in five weeks! So, I asked for a copy of the results to take to my private GP. Receptionist refused, said they cannot do it until I discuss the results with the GP. I've had lower abdominal pain and felt generally poorly for two weeks already and hence the test. I don't want to struggle for another 5 weeks"

## Referrals

Service users say the referral process can be frustrating and wait times substantial.

"I had a referral done and waited 14 weeks and no appointment. [Then I found out], the doctor had not actually completed the referral, so I now have to wait a further 16 weeks to be seen"

"Been chasing a referral for my child since June. I've made several calls and now they say they have no record of it whatsoever"

## Increasing use of hospital services

Service users continue to report increased reliance on hospital services because of difficultly accessing GP services. Service users tell us they would much rather see their GP but can't get through on the phone, or can't get a timely appointment, or can't get access to a face-to-face appointment.

#### "I had to call 111 as I had a suspected kidney infection and GP appointments are ridiculously hard to come by.

They arranged an appointment with the Urgent Care at the QE. It was quite a serious kidney infection and the GP at Urgent Care prescribed me antibiotics"

"I've had an ear infection for the past 5 days they [GP practice] told me 3 weeks for an appointment! When I told them it's an infection they said if it's that bad ring 111"



"My daughter ended up in hospital with a severe kidney infection because she was not able to get a GP appointment. I've now got to spend hours up a hospital because they can't see my child who is poorly.
I think it is pretty poor to tell patients to go and sit in A&E for what could possibly be for hours when they could be seen by a doctor locally"

Lewisham and Greenwich Trust

Waiting times at A&E

Service users report extensive delays waiting to be seen at A&E.

"Been referred to A&E since I have been ill for the past month and a half. I have waited for 5 and a half hours... till 2:30 am"

Some fear getting infected with COVID-19 while waiting in crowded hospital areas. We've been told people don't maintain social distancing and mask wearing is not enforced<sup>1</sup>

Cleanliness at A&E

"We saw a woman ring the emergency alarm in A&E toilet for 40 minutes. She dragged herself out of the dirty wee stained toilet after having given birth to a baby that wasn't crying. They then didn't clean the blood. It looked like a crime scene, for an hour and a half.

People in A&E were crying, it was so traumatic"

## Patient facilities at A&E

Visitors to A&E at Queen Elizabeth Hospital say there are very few food, drink, or pharmacy facilities available after hours or at night. Service users spend long hours waiting for treatment and, if alone, don't want to go in search of provisions in case they miss their turn. Being given a prescription at night with nowhere on site to dispense medication adds to service user anxiety and distress.

"What does one do if they want urgent medication at night, as I did then, to deal with a serious eye infection?

It was also plain daft to expect a disabled man of 71 to go home at 5am and then come back again at 9am for his medication"

"There's nowhere after about 8pm when WHSmith closed to get food or drink. The A&E don't seem to give out medication to go home with either and pharmacy is 9-5 only I believe for collecting medication once sent home"

<sup>&</sup>lt;sup>1</sup> See Aaron's story



## **Blood tests**

While service users are aware the process has changed, and they need to prebook blood tests by calling or using an online form to book a call back, many report waiting over an hour to get through on the line.

"Most times when I've called there are 40/50 in the queue. I tend to just wait... I have been cut off a couple of times in the past - once when I got to no 1 in a queue of 80+!!!

"Still haven't been able to book. It's been 3 weeks since the doctor requested the tests. I tried calling three times and was 60+ in line. Then requested a call back twice and not had one"

Others report not receiving a call after filling in the call-back form.

"I filled out the form 6 days ago and still haven't heard anything from them and my blood test was marked <u>urgent</u>"

"I've been waiting for a call back for about 5 weeks now!"

"Been trying to book a blood test for 2 months. What a joke"

Those who successfully receive an appointment tell us they wait weeks to have blood taken and tests done.

"Took me 4 weeks to get an actual blood test"



#### Support for patients with special needs at Queen Elizabeth Hospital

Aaron 18 was taken to A&E at Queen Elizabeth Hospital by ambulance and sent to a busy waiting room. He says every seat was taken, it was difficult to maintain social distancing and hardly anyone was wearing a mask.

On arrival, he explained to hospital staff that he was autistic, would need assistance to understand any diagnosis and treatment, being placed in a busy area made his autism worse, and he needed to wait in a quieter place.

No additional support was offered or provided. No chaperone or assistant was made available. He was not moved to an alternative waiting area. No reasonable adjustments were made despite his disability.

## "At other hospitals, I was given the details for the Learning Disabilities Liaison person and given a hospital passport to fill out. This did not happen at Queen Elizabeth Hospital"

After more than 10 hours waiting in a busy A&E, Aaron was moved to a ward. Even though he told the staff on arrival he was autistic and needed extra support, it took over five days as an in-patient before this was acknowledged and logged in the system/on his records.

Aaron says there was another patient who was autistic on his ward. Both felt their needs were ignored or overlooked causing them significant distress. One experience with a doctor was particularly upsetting.

## "I told him I was autistic and wanted my mum to be aware of anything happening with me. He went on saying it's my fault and "that's your problem then", and that I'm old enough and big enough to make my own decisions without my mum"

On the ward, most of the time - Aaron says the nurses helped him as much as they could. They often spoke to the doctors - making them aware of his condition and they helped Aaron understand what the doctors were saying by putting it into simpler terms.

Aaron says the experience was very bad and he felt discriminated against. He said he made a complaint but is yet to hear the outcome. He is now frightened of using hospital services or getting medical help when unwell.

"I would never use the hospitals services again after this. Autistic or not, I should never have been treated like this".



## Oxleas

Talking therapies are an important component of the treatment plan for those with mental health issues. Service users report long waiting times to access talking therapies.

"I suffer of Bipolar Disorder and I've had to pay for my own therapy the last 6 months because of long waiting time"

## **Community Pharmacy Services**

Service users at the same pharmacy say despite having an exemption from wearing a mask they were denied access.

"I am absolutely disgusted; I just visited the pharmacy for my second vaccine and was refused entry.

I am unable to wear a face mask due to a disability and have proof of this. And was still refused although confirmation clearly states I do not have to wear a mask if I am exempt. This is discrimination!

I am completely unable to wear anything over my face otherwise I would have complied. But the sad fact is, I was wearing a lanyard and I explained that I cannot wear anything and was turned away.

I shouldn't have to defend myself to them in any way but felt like I had to. I was not disclosing in public in front of people what makes me exempt to gain entry and shouldn't have to"

"I went in for a prescription mask-less. Told them I was exempt and had proof. I was told it doesn't matter as their policy states they will only serve those with masks, and insisted I waited at the back of the shop. I felt like a leper and was more angered by the fact that 3 members of public were allowed in with masks pulled under their noses, and the pharmacist himself was mask-less!"

"My son was turned away. They were so rude to him and he has autism and ADHD other people backed us in the fact it was disgusting the way they spoke and treated him but they didn't care.

I said you want people vaccinated but yet turn willing people away due to a disability"



#### Service user role in decision-making about their care

Oliver, who has a Master's degree in engineering, was diagnosed with high functioning Asperger's. He also suffers from chronic fatigue syndrome and arthritis. Oliver was put on the Learning Disability Register (LDR) when he was in his mid-20s without any discussion with him or with his mother, his primary carer. She says:

## "I don't understand why they did this because autism is not a learning disability. Equally if you are making this decision [to put him on the LDR register] the patient should be involved."

Oliver has annual reviews with a Learning Disability Nurse (LDN). Nearly two years ago, Oliver said he wanted support to function more independently outside his home environment. Oliver said his request was ignored, he was "*just shut down*" and spoken to like "*a naughty six-year-old*."

This year, because of COVID restrictions, he was told his annual review with his LDN would take place over the telephone. His mum explained that Oliver's Asperger's means he does not and cannot engage by telephone and an alternative was required.

No alternatives or adjustments were offered or discussed. Oliver's mum said:

"I spoke on his behalf, and I tried to say before the review started that I am not sure this is right for my son, but this was completely, absolutely ignored. The questions were irrelevant because he is an intelligent 30-year-old man.

The next time I went to the GP the receptionist handed over a [completed] health action plan. We had no idea this document existed. If the patient isn't involved in planning the care, what is the purpose of doing it?"

During lockdown and forced isolation Oliver's anxiety worsened. Despite asking for more support 21 months ago, Oliver is still waiting. Oliver's mum says:

"I just want this specialist support to increase his psychosocial training and enable him to function better in the world. I am almost 60 and I am his carer not because of LD but his arthritis and chronic fatigue syndrome.

I have concerns about his future, what if he does not get the support he needs to live the life he lives?

I am not getting any younger. What happens when I am not here to speak for him and help him as much as I can.

It has affected my mental health because of all the barriers that are put in place"

## healthwatch Greenwich

#### Communication between services

Robert, 21 is of mixed ethnicity. He is autistic with Global Developmental Delay. Robert's family say even though he is non-verbal he is very intelligent. Robert thrives on being around people, swimming, assisted cycling, and doing artwork.

Robert has been in supported housing for the past three years. His family say the carers are good and Robert likes his home. Since moving in, Robert's speech has improved, and he is a lot more independent.

Because of his condition, Robert displays challenging behaviour when he is not clear about his routine or is not kept mentally and physically occupied with stimulating activities. His family say his schedule must be communicated to him in advance and disruptions to this routine can trigger violent episodes. In the past, disruptions to his routine have caused violent situations and led to Robert self-harming.

Robert's home has not been registered as a care property. This puts Robert at risk of being moved. His family are concerned that this disruption will put both Robert and his carers at risk. *"The social worker and the authorities say "it's not our problem.*"

This is the team who is supposed to have a duty of care for him. It took a lot of work for him to get here [his current home]. We are worried for his wellbeing"

Robert's care plan - attending an activity centre weekly - is failing. When Robert arrived at the activity centre his carers were told there was no funding for a place for him. His family had not been informed. They say:

"Failings of social services and adult social care means it has made the job of the home more difficult. They have taken his stability away. There was a plan and the plan wasn't put into action.

The activity centre allowed him to stay for a little time so he wouldn't associate it with negative memories.

They [adult social care] have put other service providers and other service users at risk by not putting in place what they said they would do.

It's just unfathomable that you'd take someone somewhere without first putting funding in place. It's like getting onto a train and hoping someone else was arranging a ticket. It's disgusting. Not everyone has someone fighting their corner"

Robert's family say they and Robert have been badly let down.

"The social services and adult social care are probably relying on the CCG [clinical commissioning group] to pay for the funding.

But we don't know how to apply for the funding. The residential house doesn't know how to apply for the funding.

We need some steer from the professionals. This should all have been arranged prior to him doing an assessment to go there."

The instability and disruption creates anguish for Robert and his family. His mother suffers from poor mental health and has chronic health issues. His sibling says

"My mom didn't want him to get into care but it was necessary because she was unable to manage his care at home. At one point she gave up on life because she has to constantly fight for him.

I have two jobs and it has affected my ability to work. I am so frustrated, it's almost like having a full-time job, to constantly chase, attend meetings and then for nothing to happen"



## **Dental Services**

Service users continue to tell us they are unable to access dental services as NHS patients. As people are removed from practices if they don't use services for a year, many service users are having to re-register at new practices and facing further delays.

Next Steps We will follow up on all concerns or issues raised. We will work with commissioners, providers, and service users to understand where services are working well and where further development may be needed.

#### **Contact Us**

For more information on our September feedback report, contact Sue: 'sue@healthwatchgreenwich.co.uk'

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