Black, Asian, and ethnic minority groups experiences of health and social services and the role of the CQC

Insights and case studies

March 2022

Introduction

This report profiles five people from Black, Asian, and Minority Ethnic backgrounds and their experience of using services. These five case studies present a range of different situations, experiences, and suggestions. For each, we explain their journey is using services through their own words and in telling them they show the complexity of using services: getting the support and care they need and understanding the processes of challenging service when things do not go well or questioning how decisions were made. While in some cases the excerpts are detailed, this is to illustrate the context of people and shows why it may be difficult for them to access support from the Care Quality Commission or even have the confidence to complain. For each we provide some key findings and some suggestion for improvement. Many of these may with within the remit of the Care Quality Commission, but may rely on stronger partnerships with other organisations.

Background

Healthwatch Croydon was awarded funding from the Care Quality Commission derive some case studies of patients and service users from Black, Asian, and Minority Ethnic backgrounds. During the summer of 2021, Healthwatch Croydon arranged some case study interviews and a focus group. We also received a letter also fitted the demographic and the relevancy of the remit.

Objective of project

- Create 2 portraits/case studies that represent 2 of your local seldom heard communities/communities with Protected characteristics that have barriers to engaging with services and CQC

Your portrait/case study should include:

- A good depiction of the seldom heard group they represent
- What services they are likely to use and how frequently
- Challenges they face in engaging with services and CQC; this could be language barriers, digital barriers, concerns with what happens to their feedback e.g. concerns of repercussions etc
- Their hopes and fears for health and social care
- What they would like to see change in the health and social care system.

In addition, the CQC wanted: The write ups of each engagement, with some direct quotes from people you have engaged

- Any previous reports you have written on these specific groups
- Recommendations to CQC on how we can empower these communities to engage with us in ways suitable to them.
- We would like Healthwatch to make recommendations and detail how HW could work with CQC to facilitate these recommendations – including recommendations specifically to the Public Insight team at CQC.

Case studies

1) Asian Mauritian woman, 24 years old, with long-term condition

What services they are likely to use and how frequently:
GP services mainly, or referral to other relevant support services which needs to come via GP.

Challenges they face in engaging with services and CQC; this could be language barriers, digital barriers, concerns with what happens to their feedback e.g. concerns of repercussions etc:

The main problem is that her long-term illness was not diagnosed early enough. She has had symptoms when she was aged 11 and thirteen years on, she now feels that she is being listened to, when she finally got the pain management services that she needed.

A lack of knowledge and understanding by the GP is the key issue for her. As is it rare illness for someone for her age, it usually affects older people, she was ignored or dismissed by a series of GPs to the extent that she describes this as an ‘invisible illness’. Invisible in that GP don’t recognise it. So the barriers we mainly around being believed at all. She feels support services beyond GPs have helped her with the pain management and cognitive-behavioural therapy to help with the psychological distress of not just the illness, but years of being ignored and dismissed:

> “It has been a really hard journey for me to get the help that I need.”
>
> “I think invisible illnesses are not really known to GPs in depth, so even if I did go to my GP I'd feel a bit anxious doing that. Even though, on my notes, I am diagnosed with a number of things, it's still hard for the GPs to understand, because they don't have an in-depth knowledge about invisible

> illnesses, and I'm hoping now there's more awareness than there was thirteen years ago when my illness did start. But I wouldn't feel confident in going to a GP, or even seeking help or referrals from the GP. But I would be more open to using services like pain management programmes and chronic pain programmes that are available in, like, (redaction 01.59) Hospital or (redaction 02.00), which I did, when I was a child, go to. So, I'm more open to those ones where fibromyalgia, or chronic pain, or any of those invisible illnesses are more known."

She had no knowledge of the CQC and, so she never knew this could be a place to go to if she wanted to raise an issue. If she had known of it before, it may have been one of the places she would have gone to. When she was younger, she was listening much to the GPs. This meant she was convinced that there was something wrong psychologically with her rather than physical and that it was not a real illness. Then, later on, she was persuaded so much that she could live it with it, and not do anything about it. Therefore, she did not have the confidence to speak out to people like the CQC:

> "I think at first, so the first, probably, five years, probably up to the age of about sixteen, I wouldn't have because I was very much listening to what the GPs had to say and I was very convinced that maybe, like, there's something wrong with me and it's not real. But because I was persuaded so much that, like, I can live with it and not do anything about it, I don't think I would have then. But when I did really get the confidence to, you know, speak out about it to other people, I think I would have reached out to CQC, because I knew that it would help other people in my position."

This suggests that to contact the CQC to start any complaint you need to have the necessary inner confidence. This confidence came later on through making connections with those in similar situations on social media and becoming part of a community who shared similar conditions:

> "It was through social media, so there's a good fibro community and invisible illness community on like, Instagram and Twitter, where loads of people are now starting to speak out, which is really, like, empowering for everyone. Because I think, the more people speak up, the more awareness there is, and now there's such a good community where you can relate to other people, and just talk to them about your experience, and they share their experience. And, you don't feel so alone. So, I think if I knew I could have made a difference two years ago through the CQC, then I would have had the confidence to do that."

The experience of being recognised made all the difference in being more confident and then able to complain about the service to the CQC. Here is always the concern that there may be repercussions, but through her online community she now feels she has the confidence to complain:

> **“Yes, I think that I always will have that fear, because you don't really want to-, with me, I just hate stepping on people's toes but then, at the same time, it has to be done because if there's another eleven-year-old person going to their GP today, the same GP and they're saying the same thing. And, it's like, 'Oh, but you'll live.' Or, 'Just take some pain killers, just go and do some exercise.' Like, I know how they would feel, so that's what pushes me to do it. But of course, I still have that worry of, 'Oh, if I complain then will it come back to me?' Or, you know, this GP again, but I feel confident enough to-, because it's for the better of other people, I don't want people to go through the same thing I did.”**

Her hopes and fears for health and social care:

Her hope is that it her, and people with similar conditions to her, are listened to and recognised by clinicians and her concerns validated. Her fear is that it will still be dismissed by some medical professionals, particularly for others with perceived ‘invisible illnesses’. Listening is very important:

> **“I think I fear that it will never be an illness that's, kind of, validated. I feel like even now, it's still, like, is it real? Is it all in your head? Like, it can't be that bad. I think there's always that notion around it, and I think I fear that it will always be like that and people are going to have to deal with this for a very long time. And you can push awareness as much as possible, and all of us fibro-fighters and invisible illness fighters, kind of like, push it, push it, push it. But I'm just fearful that if medical professionals don't really push it themselves, then it's not really going to ever be something that's, kind of, a top priority. Because I think so many people suffer from it, and there are probably millions that suffer from it, but it's the fear that people have of speaking out, and I don't think that everyone will speak out until there's, kind of, a validation from medical professionals.”**

What would she like to see change in the health and social care system:

Recognition that when someone says they are unwell that they are. There needs to be more ways of getting support. She has benefitted from support from those in similar situation and this gives her help. Bring people together with similar conditions, like expert patient and support programmes can help prevent isolation. These need to be effectively supported, promoted, and advised and it increases confidence and hope:

> **"I think the other day actually, I did go and see my, was it the GP? Yes, and I think it's just the thing of, 'Oh, yes, you've had it for so long, poor you, there's nothing you can really do about it, it's fibro.' Like, I think the thing is, being told, 'Oh yes, it's just fibro, like, there's nothing you can do.' I think it's heart breaking, and it's heart breaking for a lot of people that haven't had it and dealt with it for so long like me. Because I've, kind of, spoken out about it and I've had that confidence to speak about it and helping other people, I think I'm in a better position now than I was at the beginning. But it's just so heart breaking to be told, 'Yes, there's nothing that can be done.' So, I think, I don't know.**
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> **"Yes, I want to do one myself, like, put my own support group out there, and I try to support people as much as possible through social media. But that's the only thing I have power to do right now. And there's the charity as well, but I just would rather in the system, I would hope that there'd be more things advertised, more support groups advertised, just fibro advertised in general. Because even seeing a leaflet in a doctor's surgery about fibro, your eyes would light up because you're like, 'Oh, it's recognised, like, I have that and this is going to help me.' So, I think with the GPs especially, if there was some way that GPs could have, like, a training session on fibro or something like that, so they know a bit more about it, so they could be more helpful to first-time visits, I think."**

Listening and understanding is so important is giving people time, particular GPs as they are gateway to other support.

> **"I think first, take more time to listen to the person that has fibro. So, not just shut them down straight away and be like, 'Oh yes, I can give you this' or, 'I can do this' or, 'I can refer you to this.' But I think most people want to be listened to and want to be believed. So, I think that that's the first step, to listen and just, kind of, not shut them off or be negative about it. I think, listen to them, tell them, 'Okay, well I understand, it must be hard for you to go through all that pain, let's see what we can do.' Like, kind of, explain that you understand, because I think if you go to a GP and they don't know anything about it, or they're just really brief with it, then the person's going to be like, 'Oh, well, I have no hope then.' But if they know a bit more about it they can, kind of, talk about it more, maybe spend a bit more time than five minutes in the appointment. I know it's hard, GP appointments are very short and there's a lot of things you have to fit in, but yes, I think listening and just being understanding, and letting that person know that you believe them, I think that's a main thing."**

Key issues:

- Not being listened to or believed. This has affected referral and support.
- If the people who are dismissing and ignoring you are also the ones you first need to complain to, what confidence is there that you will be heard when you make a complaint?
- No knowledge of CQC and their role.
- Patients need a level of personal confidence to complain – if they are less confident this is less likely to happen.
- Support networks are sometimes found online – need to go where the support networks are.

Recommendations for CQC:

- Increase promotion, understanding and knowledge of the complaints process including the role of the CQC within this.
- Consider how the CQC can support people at the earliest stages of their concerns, not after they have already made an official complaint.
- A level of personal confidence is required by the patients to complain, what can the CQC do to increase confidence to complain?
- Dedicating resources to advocacy support from day one, and promoting this, so that patients know they can get that support from the moment that they first want to complain would be very helpful
- CQC needs to raise its profile at the grassroots level such social media support groups and actively engage with these groups to remind patients of their right to feedback – it need not always be negative feedback either.

How Healthwatch can help:

- Healthwatch could help with a number of these recommendations around raising awareness and advocacy but would need to be resourced to do this effectively. The variability of commissioning of Healthwatch means that some do these roles, and some do not.
- Healthwatch could also help connect with grassroots and start conversations and well as supporting patients to have the confidence to feedback whether positive or negative.

2) Refugee mother from Sienna Leone, 40s, with autistic child.

What services they are likely to use and how frequently:
Occupational therapist, speech and language therapies, GP, social services, housing.

Challenges they face in engaging with services and CQC; this could be language barriers, digital barriers, concerns with what happens to their feedback e.g. concerns of repercussions etc:

She uses many services - some are adequate but others inadequate. She feels he needs for something joined up with services listening to each other. She has an autistic son, and currently lives in accommodation not suitable for her son. She is waiting for a letter from the occupational therapist to make the case for more suitable accommodation from the housing department. The advice she gets in the meantime does not help. She feels autism is not given the priority it deserves and is not considered by services as a disability like some other disabilities:

> “I use a lot of other services. All of them have their, you know, affect, or they have their different way of helping. Sometimes it is adequate and sometimes it is inadequate. But one thing I remember that pains me so much is when I was asking the occupational therapist to, you know, have a written letter done for me, for her to send it to housing so that I can have a proper environment, housing for my child. What happened is the occupational, by then, told me that I should-, don't worry about the windows, I should close all the windows, my son can stay in, there is not much housing for people. If I want a house, she doesn't think they will give me right now because, for example, you know, disability like autism, which they class as hidden disability, they don't do much to help with housing. The only people, for example, with disability, including autism but the person might have, like, cerebral palsy where they have, you know, a problem with their legs or other severe type of disability, which was wrong.”

The experience of looking after her son in her current environment is producing many challenges:

> "My son was in that flat, going-, I can put it like this-, mad, because I closed the windows. He wants to climb on them. You know, put him inside the house, it's another problem. If you take him in the park where there are lots of people, he will cry, he will scream because, you know-, the way he thinks, it's different from other people. He will just think something else is coming around him. So, I was fighting so hard for me and my son, especially for my son, to have a house with a garden where I can put, you know, lots of things out there for him to play with, if he don't want to go to the garden because I can't-, sorry. In the park, I can't force him, you know. I was refused help. Nobody helped me."

English is not her first language and so she tries to speak in way they can understand, but senses this may be a barrier. There is a sense that services are listening, but they do not help find solutions. They come back to the one suggestion that does not work and increases the problems. The unsuitability of her residential location is causing challenges:

> "They do listen. I know English is not my first language, but I speak to them the way they can understand, or they can understood what I was saying by then. I explained to them that my son is getting more stressed, even though by then he cannot put words together. He is stressing up, and we need changing of our house. We need, you know, not a flat, but a house, where he can go around, explore things around, having the garden at the back, maybe I can put trampoline there for him to jump and (mw 03.50) his energy. But they never listen to me. They just pin a point that, 'Oh, there is not enough housing, I should close the window.' Close the window? What a child needs? No, you can't close the window. Even when I close the window sometimes, I need to breathe. And he has asthma, so sometimes we need fresh air to come in, so the few minutes I will open that window, my son will come there and climb. And half of his body will go outside."

She has complained, written letters about her situation and to the council and even her MP but the overall response has not been supportive. They do not see severe disability in her child and therefore will not relocate her. This has had a negative toll on her mental health. She is in new temporary accommodation but there is uncertainty for the future. The GP did help but other services did not support her well. She feels other services have not done their jobs well with a negative impact for her and her son.

> “The only way I start asking for help through the council, they asked me to go through housing (mw 05.20), they asked me to do housing transfer, it did not work. People are looking for houses, as well, they are looking for houses not flats. And I spoke to the MP by then, I think it was (redaction 05.35), and she started talking to (redaction 05.39) council, they said I have to get a letter from my GP, which my GP did. Wrote them a letter, several letters and tell them that, you know, 'My patient, she's suffering from depression already and the son is autistic, he was diagnosed, and in need, you know, a proper house, where she and her son will have peace of mind.' And what happened is, (redaction 06.12) council, the head of the department for housing wrote me a letter to say that I am not qualified for a house. In that note, they did not see the severe disability (ph 06.25) on my son for him to have an house under that situation. So, I sat down and cried. And my MP had to look for another scheme, which was done in (redaction 06.46) council, I think they called it Croylease, it's another scheme in (redaction 06.52) council where they can help you with housing, but it's, like, private housing accommodation, so you will not be in any-, how do they call it?
>
> “So, for example, where I am now, when the landlord wants to take his house back, I have to leave. They have to look for me for another place. So, it's not permanent housing. It's just temporary accommodation, but it's under (redaction 07.20) council, they call it (redaction 07.20). So, this is the way sometimes the occupational therapies, the speech and language therapies, some of them you can work with. But some of them, they are not doing their job, what we call it-, they have to push all these things so that service users like us-, or people like us, that have children with needs, can access, you know, proper accommodation or services. So that our child can have the required help they needed, but they don't.”

The impact of benefits and allowances and accessing these has also had an impact. She feels she needs support, both in respite care, and financial. As a student she had an allowance, but that stopped and Universal Credit also stopped payments which caused more problems and concerns. There are also basic challenges like having the right code to access the payments:

> “I need, like, to access something they call respite care, which I'm not having. Sometimes I want them to give me respite care for a weekend, maybe they will take him out for a few hours, maybe four or five hours, you know, so I can do my house chores without his-, because sometimes he has his own ritual. He talks, you know, I can't stop him. Right now, he's upstairs talking, you know, I can't stop him from that. You know, I don't have respite care. They need to give me my own little support some time. If you look, how they call this thing they are giving us? Carer's allowance. It's just a little money, it doesn't go anywhere. At the moment, I'm struggling, because I am a student. Whence the payments stopped, the last semester, it stopped June, up until now, Universal Credit did not pay my money in. For two months, I don't have nothing. I'm struggling. I've called them and

they knew that session has finished, they should take up the payment session now, but they are not doing it. Instead, they told me I owe this, I owe that, which I was not aware of. As I'm talking now, they still have not paid me. All these things are so highly depressing. I'm not having respite care. They are giving us sick care allowance. It's so small. It's not doing us any good. It's just depressing. Student Finance is asking me to find somebody at the college who looks after children. I needed a code, but they forgot that not everybody can have a code. So, if you don't have the code, they will not put the money in your account. Some people don't have the code.

“With these challenges, had she considered engaging with CQC in complaining about the issues that she has had with social care and services. She had not heard of the CQC or know about what it could do until she started her university course (which is on public health and social care). She would not think of using it though because she would need someone to help her with it. There are concerns that if she did not do it properly it would be ignored.

“I never did because I don't know how to go about it. The CQC did not come to my mind, or I did not hear about it. When I was in level three, at College, then I heard about the CQC. So, I did not have awareness of the CQC earlier on. So, on that note, I did not talk about it. Now, of course, I'm having the idea about the CQC, that you can make a complaint, and everything.

“I would not because I would need somebody to help me out, to go about it. Sometimes, if you do not go about it properly, they will tend to ignore you as well. That's what I think. So, if you have somebody that can direct you how to go about it, take you through it, it would be easier for me to do it because I know it will go to the right place and they will listen to me.”

Their hopes and fears for health and social care:

She hopes that health and social care can be improved more. Key to this is listening to the service user. She fears that a lack of listening and real support is going to cause a lot of mental health problems, on top of the issues that parents and vulnerable people must deal with. In her case, when she does not get the support she needs, it causes her stress which in turn causes a stressful reaction from her son. With adequate support to develop, she feels those with autism and make a positive impact to society. But failure to support can cause them to have several issues, particularly mental health ones which, she fears, could have long-term impact for them and for society. She also feels that racism plays in part in who gets which services:

> "Okay. I just wish that health and social care will be improved more, and listen to people, especially parents, vulnerable people. If we don't have the adequate support towards people, service users, who are trying to access this help, a lot of people get mental issues, to be honest. That's what creates the mental issues as well. For example, I am a parent. If I'm not getting the adequate help, I'm not getting the assistance or the support from the health and social care services, it puts a toll on me. I get stressed. My son gets stressed. Sometimes you feel like you're giving up your own child, just because you are not getting the support you should be getting. So, let the social service-, let them put more money into the social services, and let them know that autism is a big deal. I mean, if they support the parents more, and they support the children with autism more, with sufficient support, I believe these children will make an impact in society, because they have-, I mean, these children are very unique, and they have a lot of things to give to society, once you develop them well. When they don't have proper development, they tend to deviate out of society. They become, you know-, I don't know the word to use, irrelevant in society, thinking that their best fit is to end up in some mental institution, which is wrong. The government should give hope to social services, and be able to receive the help, not to talk about it, not to give the help and some people cannot access it. What they tend to do is-, sometimes I just think they marginalise some certain race, if I can put it that way. They should give support to people who need it. People should access it. Trust me, if they do that, they will see-, lots of good things will come out of people with needs. They're special."

What they would like to see change in the health and social care system:

Good communication, tailored to the service users' needs is very important and needs to be prioritised. This can include ensure interpreters are available for those who need them. The use of email and text message is a barrier as not everyone can read or write properly or understand English as it is not their first language. There is a need to bring back the phone calls, so that people can be listened to effectively. This could help people navigate through the processes effectively and get the support they need:

> "Yes. Another thing is not everybody can speak or understand some certain high-level of terms (ph 20.10) they can use in most of the health and social care services. On that note, they should still bring an interpreter to help people. What I find, again, with the health and social care service, is everything that you're doing is either via email or via text message. Not everybody can read and write properly. Maybe I am lucky enough to push myself to have a better education so that I am able to do things without the help of the government. However, not all of us can do that. I am still learning, and trying to acquire a better education. Not everything I will understand. Some of the times, we need help. On that note, please, they should bring back the phone calls, and people should be there to pick up that phone call and listen to us. So, if I cannot understand how to go about certain things, or to fill in certain forms, or maybe I am a bit skeptical how to go about it, I can have help. If I'm going to the office, somebody will be there to take me though it.!"

Not the phone talking to you. It's not easy. Let me give you an example. Every year, my son should have a transport relocated for him, so that he will be picked up from home and dropped at school, and vice versa, two ways. So, I did not receive any letter from the council, because they have to send me a letter to say that, 'We have transferred your son to another, new transport system. A new driver will start picking up (redaction 22.19) up. This is the name. This is the cab driver's license plate number.' So, I started calling the council about a week ago. In fact, when you call the council-, before, when you called the council, you have automated-, it will take you through the educational department. Now, when you call the council, it will only talk about housing. The system that is talking to you will not talk about the educational department. So, I got confused. What has changed? I called the other number. It's the same thing. So, I go through the housing department, and said, 'Can you please put me through to the educational department. My son has a statement, which (inaudible 23.15), so I want to know what they have put in place with the transport station, because nobody gets back to me. Nobody's calling me, nobody wrote me a letter, or anything.' They said, 'You have to go through the automation system. It should have taken you to the educational department.’ “I said, 'No, it's not there. I think you have to come off, and listen to the system, and then you'll know what I'm talking about.' They put me through. What did they tell me? They said, 'Now, if you are trying to access the educational department for special needs children, you will not get through. You have to send an email. They have different numbers, mobile numbers.' I called those numbers. Nobody was picking it up. It would forward it to something else, and it would tell you it was the wrong number, that the numbers weren't working. I was patient enough. Yesterday, I got them, and I said, 'What is going on? Nobody texts me. Nobody-, I've sent them an email, through the old email. Nobody replied back. I don't know when or who is going to pick up my son. What is going on here?' That's when the Supporting Voices (ph 24.31) said, 'Yes, sometimes we are not on the phone.' I said, 'This is wrong. You guys have changed your system. You did not write any letter to me, for me to understand that, now, this is the new system.' Remember, not everybody can read and write.”

“Communication has to be done properly.”

Key issues:

- There are many complex processes for her to navigate get the care and support she needs. Some of these processes are also changing, particularly shifting to digital means such as text and email, which are not easily accessible to all. This mean sources of verbal advice and support seem to be lacking.

- While GP and occupational health have been helpful, the lack of integration between different departments at local authority level: education, housing, social care, and benefits impacts the client and service users significantly.
- The lack of reliable and effective support and advice causes considerable stress for the parent and for her child.
- Knowledge of CQC is low, but even when it is known, there is a need the support to make the complaint effectively and challenge the system appropriately. This is additional work to do when so much effort is needed just to access the support and services they need.

Recommendations for CQC:

- There is a role for the CQC in ensuring there a procedures in place to help people navigate the system to ensure people get the service they need. As it is independent of service organisations, it might be best placed to provide this navigation service, and as a result increase engagement with service users.
- Providing verbal support at the end of the phone and helpful independent advice when different departments are not responding could help people access the services they need.
- Supporting people in making the complaint in the right way and empowering them. This enables them to have the confidence to do so. This again makes the case a role for a direct advocacy service from the CQC.

How Healthwatch can help:

- Healthwatch could be funded to provide community navigators to help people through the complex system of social care again specific funding would be needed to cover this.
- With training, Healthwatch could also help provide independent advice although there are other voluntary organisations such as Citizens' Advice and other specific support organisations such as Age UK and Carers Sypport who do this already so the CQC would need to ensure there is not replication of roles.
- Healthwatch already has a good track record in empowering volunteers, they may be well placed to train and support the public to have the confidence to share their experiences more effectively.

3) Southern European parent with son with disabilities in resident care facilities

This case study was derived from a received letter from a resident. It was compelling feedback that we believed it was relevant for this report and therefore shared their experience with anonymity with the CQC. Unlike the other case studies that were interviews where we had received their permission to publicly publish their story. We have not been able to contact them to get approval to publish the letter, so we cannot use direct quotes. However, through our description you will see the relevancy of the case study and some suggestions on how the CQC could improve communication.

What services they are likely to use and how frequently:
Her focus is on the resident care service her son is residing within. He has been there for 17 years using the service daily.

Challenges they face in engaging with services and CQC; this could be language barriers, digital barriers, concerns with what happens to their feedback e.g. concerns of repercussions etc:

This is more unusual in the case studies as this is someone very aware of the CQC and the work they do. Indeed, their response is a critique of the residential care home process. The parent raises several questions about the process, transparency, and communication of inspections, as well as the impact if the closure of the facility, which may be beyond the remit of the CQC. We only have the service user's close relative as a perspective, an appreciate this may not be the full story, but they have put forward some issues which could hope overall engagement, not with raising concerns, but with the inspection process.

As a result of a recent inspection by the CQC, there has been a decision to close the facility. This raises several concerns for the parent. Firstly, her son has been happy in this establishment, and from her perspective the facility has been doing a good job in looking after her son. There seems to be a communications gap between the experience she is seeing in the facility and what is being observed by the CQC on the many occasions they have visited.

<Quote provided>

She believes the impact of this closure will mean he will be placed further away from Croydon, which goes against CQC policy:

<Quote provided>

She believes the process by which the decision was made, was not open or transparent. That considerations of the impact the closure of this facility will have on her son, have not been fully considered. She feels the standards applied have set the bar too high when she believes they are providing a good service.

She senses that many of the aspirations in the CQC Strategy around care could not apply to her son, particularly around work and independence. His disabilities are too complex for this to be a possibility:

<Quote provided>

She is also concerned at the way the process was managed and the transparency around decision-making.

<Quote provided>

She feels that those who use the services and close friends and family who have significant interest in the care of the service user have not been involved:

<Quote provided>

She is concerned that issues of impartiality have been compromised and that the process does not have enough effective checks and balances:

<Quote provided>

She is concerned that the closure of this facility will mean there will not be a suitable location in Croydon for her son and that the rehoming will cause significant challenges. She also feels that the CQC idea of care does not relate to someone with the level of disability that her son has:

<Quote provided>

Their hopes and fears for health and social care:

Her fear that there will not be a suitable service for her son, at a location where she can visit easily. She feels the process by which this decision has been made did not consider her son's specific situation. She wants to understand how the CQC is assessed in the work they do.

A more transparent process on how facilities are assessed in CQC reports with a consideration on the impact this will have for service users if the facility closes as a result. That the CQC processes and ways of working are open and transparent and there to be challenged as with any other part of the health and social care system.

<Quote provided>

What they would like to see change in the health and social care system:

She has several questions on how the CQC inspect which she would like clear communication on. These questions help shape the change she would like to see concerning CQC inspections of residential care service:

<Quote provided>

Key issues:

- A close relative of a service user in a residential home that is due to close as a result of a series of CQC reports, questions the process.
- They do not feel they have been asked to contribute at any time in the process, where their perspective could contribute to decision-making.
- They do not think the CQC has considered the impact that their report may have in closing the facility and creating significant uncertainty.
- They have concerns about how a series of inspections were made and how a decision was made, including points of consistency and impartiality.
- They raise further questions on the role of CQC in undertaking inspections.

Recommendations for CQC:

- Explain and communicate the rationale behind residential care inspections in a way that a close relative of a service user would understand.
- Ensure that that the voice of friends and family is communicated effectively and included in any inspection. Show evidence on how their views have been included.
- Clearly communicate the process so that a non-specialist would understand.
- Clearly show the checks and balances to ensure this is completed in line with the CQCs values.
- Explain the decision in way that would be understood with context and consideration that the impact may have on service user and close family.

How Healthwatch can help:

- When inspections take place, support the CQC in engaging with all residents and the family and friends.
- Support the CQC in explaining the inspection process and what happens after a report is made including how many other stakeholders may be involved in the closure of a facility and help explain where the various responsibilities around the closure of a facility lie.
- Advise the CQC on their public guidance materials, so that they make sense to the public

4) Indian woman - age 40s – caring for both parents and sister

What services they are likely to use and how frequently:
Mainly hospital A&E, inpatient services, and GPs.

Challenges they face in engaging with services and CQC; this could be language barriers, digital barriers, concerns with what happens to their feedback e.g. concerns of repercussions etc:

She looks after her two elderly parents both in their 80s, one who has Alzheimer’s. Other than needing respite care on occasions, the services they have received have been good. However, a recent experience concerning her sister who co-cares for her parents raised many challenges:

> **“I always use GP services when it comes to mum and dad. Myself and my sister, we don't because we're hardly ever ill and little things I'm not going to worry about. I can manage and she can manage. Obviously, yes, hospitals is a much. Unfortunate to that, Croydon University Hospital has deteriorated in their services as a recent experience. So, I will consider probably a little bit further out. Epsom or St George's, unfortunate as it is. With St George's, because dad has been a stroke patient several times, TIA, so that's somewhere I'd go predominantly. But, as for general stuff, I'd have to re-route the ambulance as and when to Epsom, East Surrey. But I would not consider Croydon University anymore from what I've experienced.”**

Her sister returned from India with a mystery rash. They called 111 but got switchboard operator, no clinician. They called the GP, but they did not pick and when they did communicate it was over phone. They called 111 again, and this time got helped, the GP asked to see pictures of rash, but patients felt his warranted a physical examination.

> **“The next day we called 111 again and, thankfully, this time this guy was really nice. He asked all the right questions, got in touch with a GP, and he made that phone call to him and saying, 'Look, you've got to see her.' Because, at that point, the GP had only called us at 5:00 that following evening and then prescribed her strong antihistamines after saying, you know, 'Just send me some pictures of what she's got.' No, I'm sorry, you can send all the pictures but unless you assess somebody physically. She's telling you she can't move, every joint hurts, lesions everywhere, red patches, it's constant severe pain and he gives her antihistamines. Now,**

> generally, he's really good when it comes to mum and dad. But this time, for whatever reason, he didn't want to see her even though she told him, 'I've just come from India, literally, a day before. I think you should take my bloods.' He didn't see the need to take the bloods."

GP is usually helpful with her parents, but on this occasion, he did not examine of taking blood tests. She is now in severe pain and lesions and so was very concerned. After the second 111 call, GP finally saw her and suggested she go to Croydon University Hospital, backed with GP letter. Taking her there, she waited seven to eight hours and got to see a nurse, not a doctor. They kept taking blood tests and making the same questions and this happened regularly and kept sending her home. This happened over four days. They did not see a doctor and just kept taking blood samples. By Saturday they finally admitted her and took more blood tests:

> "So, when that second call went from 111 he finally saw her and when he saw her he realised how bad she was. Immediately we took her to the same day emergency clinic at Croydon University Hospital. He wrote a letter. Took her there, I don't know how I managed to get her in and out of the car because she just couldn't move. Waited seven, eight hours at that hospital and all you'd get is a nurse. You'd never get a doctor or a consultant to come and see you and they'd keep taking bloods, same questions over and over again. This happened Wednesday, Thursday, Friday. Finally Saturday, because each day they said, 'Come back the next day, come back the next day."

They did not communicate any idea of what she might had until one person. They stated at one point that she may have specific condition – 'a deranged liver' but did not explain what it was leaving her even more concerned for her sister. They suggested she take paracetamol, but the following day said the advice was wrong because of her suspected liver condition:

> "They said to her she's got deranged liver function so I had asked the one rheumatology lady, I don't think she was a consultant at the same day clinic, one evening before going home. I said, 'Look, when you say deranged, I understand the word deranged but when you put it in terms of liver what do you mean?.' And she looked at me like I was stupid. I said, 'Look, I'm not a medic. So, just tell me what is deranged liver.' She's like, 'It's not abnormal.' I said, 'I get not abnormal but what level am I looking at?.' Nothing. So, she said, 'Oh, just take paracetamols.' Now, the nurse the next day said, 'She shouldn't have said that because she's got issue with liver function. If anything, should have just stuck to codeine.' So, that was an issue."

The experience of being an in-patient, while most nurses are generally good, the night duty nurses completely neglected her, did not listen when one of the drips in her arm was hurting her, and did not help her with her blanket when she could not move. The next morning the nurse ignored her when in need, bearing in mind the patient felt completely paralysed. Patient mentioned all this to sister, but did not want to complain Sister spoke to ward manager and found out this nurse was an agency nurse. Other nurses were not keeping the environment clean:

> “She's like, 'No, I don't want repercussions.' So, I said, 'No, well I'm sorry. You've got to say something here because this person has just breached the NMC code.' Why are you a nurse if you can't be bothered with a patient, and are you favouriting people? So I found the ward manager the next day. Against my sister's wanting because she just thought it would get worse for her. So, you've got to say something. So, I spoke to the ward manager and I gave her the nurse's name and what had happened and she said she's going to deal with her. Apparently this was an agency nurse. Every time a nurse comes-, and I found this, I only took the image once. They'd do stuff and then just leave the bed or the floor untidy. Like, they'd just drop stuff after they've changes something and they've just left it there or they've taken bloods and the used stuff is on the floor. I'm just, like, what is this? You're supposed to look after your environment.”

Her sister got moved to another ward, where she got seen by junior doctor, who asked questions first and then looked at notes. They continued to take bloods up to two to three times a day, but no results. She got a variety of answers of where the bloods had gone but no feedback on what might be wrong:

> “I don't know why some of these are nurses because they don't really do anything.' I used to go every day, twice a day, get the commode, clean her, wash her, do whatever I needed to, then come home, deal with that with my father and my parents, then go back again to deal with her again. Now, I did that until the 23rd when I had had enough because nobody would give us any answers, as to, you're just taking bloods, poking her, and we're getting nowhere. So, I just spoke to the nurse and said, 'Go and speak to doctor. Unless you can tell me that she has some serious issue going on, I'm taking her home. I've had enough because there's no answers. You keep taking bloods. Every day you're taking bloods, two or three times a day you're taking bloods. Not just one bottle, you're taking three or four blood bottles.' Another doctor, a different woman, said they should not be taking bloods every day.”

She eventually discharged her sister and called the hospital to get results and they referred her to the GP. The GP said you need to call the hospital. Finally she spoke to the discharge nurse, who said they will only notify you if it is positive.

While waiting for the results, they have been undertaking self-diagnosis and did their own investigation on whether they had mosquito-related illness called Chikungunya which happens in tropical countries like where her sister visited. So, they are testing for this but the result has not come back:

> **Well, yes. If you look at all the symptoms and then we spoke to my cousin in India, because his wife had it, and then they spoke to their doctors there and said, 'Look, this is all the symptoms she's got,' and they said, 'Well, it's a no-brainer. It shouldn't take anyone this long to come back with any results. This is what she's pretty much got.' So, they were surprised that they haven't diagnosed it yet.”**

There was a further issue in that while as an inpatient, they did not give her a identity wrist band until three days in. They were taking other patients for CT scans in the ward, and were not checking wristbands, what if a mistake could have occurred:

> **“By the way, in the acute medical centre, she didn't get the wristband, the information band, until three days later. They came to do a CT scan on a patient. They referred to that bed as bed six, not by the name. So, they took her on the third day to CT. Left her there for 45 minutes and then realised that that's not the patient they wanted. They wanted the patient triaged in the same bed prior to her attending. Like I say, up until now, I've had no issues, no-one in my family's had issues but this, this was the pits for me.”**

The impact of the way her sister has been cared for has had an impact for her as well. She now needs to care for her sister as well as her mother and father.

In terms of complaining – she wants to wait until they get some results. She is concerned of repercussions while the patient is still in her care. She would probably like to write a formal letter and complain. She feels that due to remote appointments at GP, people do not get the care they need. She is concerned of what might have happened to her sister had she not been able to support her and be there through this:

> “I mean, I would like to wait until they come back with some sort of result as to what she's got. You know when you want to say something, but you think if you say something, nothing will happen and it might go against you. I'd rather wait for them and then do whatever I need to do, so at least I know she's en-route to recovery.”

She has a good understanding of the CQC and what it does. When it comes to complaining - it is not just one thing it was a few things in a space of a few weeks. She doesn’t usually want to complain because it can ruin reputations and it can affect people who are doing well. However, if she feels did not complain, then those delivering the low quality service will continue to do so. She is likely to complain, but she does not like the word. She prefers constructive feedback and resolution. She will send letters both to hospital and GP.

> No, I know that you can complain but obviously, look, like I said, it's my first experience ever to have such a bad one. It was not even just one thing, it was like a few things in a short space of what, three weeks. So, I don't generally want to have to complain because it ruins reputation and it comes down like a tonne of bricks on those who are doing good. On the other side, if I don't say something, then it continues with those bad eggs and so people start slipping through the net. It's just much like any other business, if you don't take control then all sorts of crappy things happen and things get pushed under the rug. Yes, I do know and I will complain but I hate the word, using complain, I will probably give constructive feedback to Croydon Hospital once we have some sort of resolution for her. Obviously, make a strong letter to my GP because he should have picked it up and he should have done the blood tests, simple as. Instead of saying it was urtica, it's not, it wasn't urtica. Turned out to be a bigger thing, an unknown thing, which I think it's likely going to be Chikungunya but like I say, until it comes back in letter form saying, 'Yes, positive,' I can't really do much at this point.”

However, there is a concern she will only get a generic answer, particularly from the GP. She would probably complain online and expect feedback via email. She would be happy to copy in the CQC but would not think about it as the first line of complaint. They are as likely to copy in their MP or ward councillor:

> “No, no, no. I'm quite happy to, when I do these (inaudible 01.04.13) on the email, I'm quite happy to do a copy in CQC. You know what it is, sometimes people think-, it's like when I'm at work, you don't get your results, so I usually people tell, advice people, copy in your MP. Copy your ward counsellor, and suddenly, people start doing things. So if I just do

> them, they might give me a generic, but if I copy the official bodies in, they might give me a bit more of an answer, and so I'd rather be doing that than just doing, you know, an email to that specific person. I'd rather copy the people who need to know as well."

Their hopes and fears for health and social care:

Her hopes for care are that they will not keep people waiting so long. Appointments come sooner, and people get seen quicker. Her fears are around care, she feels things are getting worse and people are slipping through the net and that people end up in a worse situation that they began:

> "Hopes in care, I would say, not to keep people waiting for so long, because obviously this appointment, I've had to chase up a few times. They should have come to see me in July, and unfortunately it's taken this many months. And I can understand, a shortage of staff or whatever has been going on, but they could have told me sooner rather than later. So that would be the hope, that appointments come sooner, faster, people get assessed so they can get the right support at the right time. But in virtual reality, everything happens amazingly, and reality is a different ball game. Fears, I guess care. The way care is being given nowadays, it keeps getting worse, and people keep slipping through the net, and people end up with a lot-, end up in a worse situation than they started off with. Because you (inaudible 01.27.29) hospital, go with one thing and come out with something else. That was the other reason why I took my sister out, because I didn't want her end up in there, and she gets something else through somebody else, so I just thought best to bring her home. So, yes, hopes, that people do get the care they need at the-, in the timeframe."

What they would like to see change in the health and social care system:

Communications are key. Information from GP to hospital, or between wards could be better as well as communication with patients. Digital does not work for everyone, so you need to talk to the patient and communicate to them better:

> "So yes, there's a communication issue, there's training issue, there's the self (inaudible 01.30.26) initiative issue, where you are just not bothered, and if you're not bothered, what are you doing there? I get that you need to pay bills, but you've got somebody's blood on your hands, no acceptable. So, it's just not one thing, it's bits of everything, and I think when you're doing the (inaudible 01.30.48), if something goes wrong along the way, then it falls apart in different departments, as well. So, you've got to work together. And you've got to communicate. Because without that, you've got nothing."

Better training of staff of key communications and people skills not just medical. Real training that is assessed against e-learning which is self-assessed.

> **"In an ideal world, you'd think, get more training in place even if it's role plays. Sometimes that helps. Getting those specialists in to help those who lack in certain trainings. Be that in communication, people skills, not just medical. Medical yes, you're there, but you also need to have bedside manner."**

The CQC needs to be more focused on ensuring the basics have been done, particularly effective communication and good customer service with the patient and basics such as ensuring patient wrist bands are on patients, and that when nurses changeover they communicate to new nurses about the status of patients.

> **"Sitting there and reading a screen is not going to help me a damn thing. It's just going to be words that I need to get through, so that somebody has done a tick box exercise, that yes this person has been trained. Have you really trained them? Or have you just met your own tick box?**
>
> **So, the tick box exercises need to go, I get that there is a clipboard and a pen attached to it and a whole bunch of boxes that need to be ticked off. I get that, but there are bodies for that, like the CQC and all that to say, 'Right has this been done? Has this been done?"**

Key issues:

- This lady experienced a series of problems in getting care for her sister starting with GP, then Urgent Care A&E, and inpatient-ward, showing the complex journey that some people take when trying to get care.
- Communication was a key issue. At no time did they consider the context of where her sister had been and observations of low-quality care particularly with nursing was raised.
- Awareness of CQC was there, particularly around the role of inspection and complaining. However, she was hesitant to officially complain until the care for her sister was completed. She was aware that separate complaints would need to be made to both GP and hospital and expected generic replies. She saw a role for the CQC as well as contacting local politicians. She however was keener to see 'resolution' for her sister rather than complaining.

- She was more interested in seeing improvements in training, particularly communications between staff and with patients and their relatives. She also says a focus on the basics such as clean environment, better customer service and following procedures.

Recommendations for CQC:

- Some patients will use multiple services in one experience, but then have to contact each part to complain separately, could the CQC find a way for them to send a complete complaint and share with all relevant parties automatically.
- While the CQC assessed facilities against several metrics, how much is effective communication assessed. This might be by patient survey or stories.
- There is an emphasis to increase training in basic skills such as communication, can the CQC have role in prioritising this in their assessment of services?
- Sometimes people don't want to complain – they just want to see resolution. Is there some service that the CQC can assess or provide which focused more on resolution and service change as a result rather than a focus on complaints?

How Healthwatch can help:

- Healthwatch is usually the place where people tell their whole story. Healthwatch could be the go-to place for people to register their complaints which are then communicated to each relevant organisation, meaning the patient need only report their concerns only once. They would also have only one once source to reply to.
- Healthwatch could continue to share patient stories or complete regular surveys on key issues such as communication skills in facilities to inform and improve services. This can include positive examples of good communication which could inform training.

5) Asian man 70+ - caring for himself and wife

What services they are likely to use and how frequently:

Pharmacist, GP, Urgent Care, Hospital services

Challenges they face in engaging with services and CQC; this could be language barriers, digital barriers, concerns with what happens to their feedback e.g. concerns of repercussions etc:

Patient had a rash on his back which did not heal. He went to the GP and had to show the receptionist his condition and they could only offer an appointment the following week. So he went to the pharmacist and was given two medications, one of which was not age-appropriate. Yet he was not asked his age. So, as it was getting worse, he decided to Urgent Care at Purley, but they refused to see him as he did not have a prearranged appointment. Eventually he was seen and told that the medication he was given by the pharmacist was wrong, he had shingles and need antibiotics. He contacted his GP by phone, who said he did the right thing, but this would have been unnecessary had the GP seen him.

> “Let me just (mw 35.39) some of the (mw 35.38) my side. This will be about maybe five, six weeks ago, I had some rash on my back. Itching a lot and you try and sort of say, 'Well, let's put this cream on that stops the itching,' but then when the bumps started appearing on my cheek and at the back of the head, I thought, 'That must be something serious in terms of a rash or something.' So, I went to the GP and all I could do at the time is basically talk to the receptionist and I said, 'This is what I have got. Do you know what it is?' And she said, 'No.' And I said, 'Can I then have an appointment with the GP, just so she can have a look at me?' And 'Well, it's busy. I can only make it next week.' Well, fair enough, but she said, 'You might want to go to the pharmacist and talk to him and see what he can prescribe you if it's getting itchy for you.' So, I went to the local pharmacy (inaudible 36.59) and talked to him and he prescribed with two medications. One of them I've looked at the box at the back and it said, 'Should not be taken for anybody that is over 65,' and I'm 72, right?”
>
> “ No, no. They didn't ask me at all. So, I thought, 'No, I need to go to emergency right away, if I can't get this,' because it was getting uncomfortable especially on the back of the head when you sleep on a pillow, it was getting uncomfortable. So, I didn't want to go to Mayday and I totally

> agree with (redaction 37.40) in terms of the quality of service at Mayday, so I went to Purley.
>
> "I waited for an hour, I waited for an hour. I got in and as soon as she saw my face and my back, she said, 'It's shingles,' and she said, 'Well, I don't know why the pharmacy,' I showed the medication I received and she said, 'No, you shouldn't be taking this at all. It's not the right medication, you should have had and I'm glad that you didn't take anything anyway.' For about 24 hours that I was supposed to, before I saw her. She prescribed me antibiotics, I started taking them. Then, I called my GP and said, 'This is what's happened.' And she said, 'Well, you did the right thing.' I said, 'Well, you had the chance to see me before and your receptionist', and I've had issues with the receptionist."

He had issues with the receptionist in the GP being the gatekeeper when they have no right to take a view on his health:

> "Yes. As (redaction 42.25) said, we need to resolve this issue and the issue I'm going to tell you is, first the receptionist try and act as if they are the gatekeeper. They are not the gatekeeper, they have absolutely no right on my health. They're supposed to listen to me and give me the appointment based on how serious it is. They don't want to know that, how serious is not what they want to know. When is the next appointment available with the GP is what they're interested in. There's no how serious is this?"

He found that he had been struck off a GP list. He had been with the surgery 30 years, but suddenly found he needed to reregister, this took time and in that time he could not see the GP over his conditions, so care was delayed. He wrote a letter of complaint, the receptionist was more upset that she would have to respond formally than about the patient's concern at being deregistered. This was not a one off but has happened to others as well.

> "I went abroad, which I did quite a lot before Covid because my grandchildren live in Amsterdam. For some reason, I had to stay longer than I thought I would stay. For whatever reason, when I came back, I had some chest pain and I called up my GP and I told her I've got chest pain so she said, 'I'll see what I can do in terms of the appointment.' Then she called back and she said, 'I can't find your record.' I said, 'What do you mean? I've been there for thirty years and you can't find my record?' She said, 'It looks like you've been struck off.' So, I went, 'What do you mean struck off?' She said, 'Did you miss an appointment or something like that?' I said, 'I can't recall anything. I know I've been abroad, so I don't know if there's anything.' It took me a while to re-register again and then when I went to see the doctor and I said, 'Why was I struck off? Why wasn't I able to get an

> **appointment when I was serious, which is when I registered the appointment? You're saying I can't have it because I'm struck off now.' Nobody has ever explained, I wrote a letter to the GP and she was upset about that letter because she said, 'Now, I have to answer it formally.' Still not received the letter."**

Now whenever he has an appointment, the same GP sends him a text asking them to rate the GP service. He wonders where all this information goes, how are this contributing to the patient journey:

> **"Well, I already called the experience of-, which is, you know, first time I had an issue in terms of not-, when I was told that I was struck off, and I wrote a damning letter, and I went straight to the GP that was given to me on the registration posters. So I thought that she would be understanding, she would be sympathetic, she would in fact, probably accept that that was an error from their side, because that's what I thought it was. But nothing come back, and you think, 'Yes, alright.' But as soon as we make an appointment, either me or my wife at the GP, a text message comes on my (inaudible 01.06.37) and says, 'How do you rate the GP service?' And I'm thinking, 'Where is this information going? How are they putting all those steps together, and are we just becoming one of the statistic in there, rather than, you know.' So, the service that have (ph 01.06.57) now done to tell us, tell people how did you rate your experience or your experience with the GP appointment, what is it for? You begin to question it."**

He also had an issue with his wife. She had a problem with her foot, as a result of an injury 15 years ago. She was referred to physiotherapy, but this did not improve. He had a long battle with the GP to get referred to the hospital and saw the surgeon who had done the first surgery and he stated the need to do second surgery on the same area. The surgery was undertaken, and after three months, to arrange physiotherapy. A week letter, they receive a letter saying she does not need it when she clearly does. She needed to visit another hospital to have the stiches taken out and he ordered patient transport, which did not arrive, so he had to drive her himself and could not stop anywhere near the entrance and had difficulty getting her to her appointment. The patient transport then call asking where they are, when they were supposed to come at 8am and it was now 9pm the time of the appointment. They tried to arrange transport back as it was so difficult for her in the car, but they did not have any drivers. He did complain about this by letter but got no reply. He sensed it is and outsourced organisation providing the transport, and so who manages the standards. Does the CQC see these complaints letters, does it explore the complaints process?

> "I wrote a letter again, as, you know, I don't have a problem in making a complaint or writing official letter or whatever it is, but I wrote it, no reply.
>
> Moderator: And you wrote that to the hospital?
>
> M: To the company that actually is on the NHS website saying, 'If any patients acknowledge hospital is struggling to get to the hospital for appointments, (inaudible 01.15.10).'
>
> Moderator: The patient transport service.
>
> M: Yes, and I know the fact that it is probably an outsourced organisation that they use, and who manages the standards? So the question to you is, when people complain, would you see my letter coming to you, or would you ever check that on your inspection saying, 'What people have complained to you?'"

He feels that people should be given a choice over whether they want a digital remote appointment rather than it being imposed.

Their hopes and fears for health and social care:

Conversation with people is so important and is the skill that is being missed.

He does not see a team effort within the NHS. He is concerned they do not communicate well enough with each other. He is concerned that the training is not good enough, particularly around teamwork. He sees very little evidence of this, it all seems fragmented.

> "That's the skill, conversation with people is the skill that we're missing throughout the whole framework of NHS I think, okay? To make people talk you need to have a skill. You need to get down to the level that they are rather than that level and start a conversation. What is it that they worry about? What are the other things that are going around in your head and so on. That is very important, that is one of the major things that I feel that I don't feel within the NHS. NHS is like a huge juggernaut, it's slow moving, it doesn't know how to turn back because it's so big. It doesn't know what are the parts that make up the wheels to turn? Everything in that juggernaut is completely fragmented if you see what I mean? The whole structure. There is no team effort, I can't see any team effort within NHS in hospital teams and then say, 'Okay we know about wards and work teams and so on, but are they working as a team?
>
> "Are they communicating with each other? Are they talking about the patients that are staying in there? Do they have all the information?' Can they pass the knowledge with the next shift that is still coming in? Now, what they should be taking care of, or is it, 'I'm going home, somebody else comes in.' I don't know, I don't know, these are the fears I have. The fears about training, what sort of training they get, how do they work in a team?

> It's not evident when you work in those institutions, or that's the fear I have. It does not welcome you in that manner. We need to change that and that's what I'm saying, what would you like to see change? That's the change I want to see. To just deploy technology for the sake of deploying it just to say it reduces the pressure on us, is fine. Use the technology, but then the technologies they are also to be putting the infrastructural and say, 'Well, how do we communicate, for example, much better than we're doing it now?' Right across the board, right from the top to the bottom. And with patients as the centre of it, rather than somebody that (inaudible 01.39.57), you have to look after them."

What they would like to see change in the health and social care system:
Use of technology is good but it need to be deployed in the right way, thinking about how we communicate rather than just bringing in the technology because it takes the pressure off the team:

> "To just deploy technology for the sake of deploying it just to say it reduces the pressure on us, is fine. Use the technology, but then the technologies they are also to be putting the infrastructural and say, 'Well, how do we communicate, for example, much better than we're doing it now?' Right across the board, right from the top to the bottom. And with patients as the centre of it, rather than somebody that (inaudible 01.39.57), you have to look after them."

He sees the value in pastoral training, rather than specific courses, about the tick box approach. He would also like to see more diversity, encouraging staff to understand the cultural background of patients. If staff are of the right calibre, the patient will be more comfortable and be more receptive to the service.

Key issues:

- Due to being assessed by the receptionist and not the GP, he had to go to two other places before he got the treatment he needed, and wad misdiagnosed by the pharmacist. This illustrates the importance of patients seeing GPs particularly when they have urgent condition that cannot wait a week.
- GPs are looking to reduce lists by finding ways to deregister people -maybe because they miss an appointment or out of the country for some time. This goes against the Primary Care Contract. There are rare cases which justify deregistration, but there are clear guidelines. How can these be challenged?

- On complaints, he has complained on the deregistration and on patient transport and not got a reply. Where does he go now.
- Communication is key and staff should be trained with these skills foremost as well as effective teamwork. Good regular training, in a pastoral way rather than as a tick box exercise could be more effective.
- Encouraging more diversity and understanding about the background of patients would help better engagement with them and improve patient experience.

Recommendations for CQC:

- Ensure NHS and social care organisations respond to complaint. Emphasise the importance of assessing the complaints process, and nature of complaint as part of any inspection.
- When assessing GPs, the CQC can ensure that they get enough patient experience stories and assess their deregistration numbers and challenge them for the rationale to deregister.
- Emphasise and assess organisations on the good quality training particular about communication and active listening.
- Emphasise evidence of ensuring their organisations reflect the diversity of the community they serve, understanding the patient’s background and adjusting accordingly.

How Healthwatch can help:

- Healthwatch can help in receiving and analysing patient stories including receiving Friends and Family text data and other mandated surveys and provide a service to each facility to support service improvement
- Again, Healthwatch could continue to share patient stories or complete regular surveys on key issues such as communication skills in facilities to inform and improve services. This can include positive examples of good communication which could inform training.
- On diversity, Healthwatch could focus on speaking to underrepresented groups to ensure diversity of feedback, not unlike the work of this report.

Other reports of relevance produced by Healthwatch Croydon

GP access report for Healthy London Partnership (September 2021)

This report looked at barriers to access and use of GP services – several the focus group members were from a Black, Asian and Minority Ethnic background and also included a refugee.

https://www.healthwatchcroydon.co.uk/wp-content/uploads/2021/09/GP-Access-Guide-Focus-Group-September-2021-final.pdf

Care Homes (June 2021)

There are five reports focusing on the experiences of residents, friends and family and staff in Croydon's care homes under COVID. There is an overall report which also has an action plan from Croydon Council. The staff report reflects views of significant number of BME people. The other reports also focus on those seldom heard – particularly residents in care homes.

Overall report: https://www.healthwatchcroydon.co.uk/wp-content/uploads/2021/06/Experiences-of-residents-friends-and-family-and-staff-and-Croydon-Care-Homes-under-COVID19-final-June-2021.pdf

Residents: https://www.healthwatchcroydon.co.uk/wp-content/uploads/2021/06/Residents-Experiences-of-Croydon-Care-Homes-under-COVID19-Healthwatch-Croydon-final-June-2021.pdf

Residents with Learning Disabilities: https://www.healthwatchcroydon.co.uk/wp-content/uploads/2021/06/Residents-with-Learning-Disabilities-Experiences-of-Croydon-Care-Homes-under-COVID19-final-June-2021.pdf

Family and Friends: https://www.healthwatchcroydon.co.uk/wp-content/uploads/2021/06/Family-and-Friends-Experiences-of-Croydon-Care-Homes-under-COVID19-Healthwatch-Croydon-final-June-2021.pdf

Staff: https://www.healthwatchcroydon.co.uk/wp-content/uploads/2021/06/Staff-Experiences-of-Croydon-Care-Homes-under-COVID19-Healthwatch-Croydon-final-June-2021.pdf

The journey of street homeless using Croydon’s health services (July 2020)

Again research before COVID, but with case studies of street homeless with significant insight of their situation and needs and another seldom heard group.

https://www.healthwatchcroydon.co.uk/wp-content/uploads/2020/07/The-Journey-of-Street-Homeless-People-using-Croydon%E2%80%99s-Health-Services-July-2020-final.pdf

Insights from the BME community about wellness and services to support this (September 2019)

This was a report to help scope what needs to go in a new wellness centre for Croydon’s BME community.

https://www.healthwatchcroydon.co.uk/wp-content/uploads/2019/09/Insights-from-the-BME-community-about-wellness-and-services-to-support-this-1-1.pdf

Statement from the Care Quality Commission and action points:

“Healthwatch Croydon were one of seven local Healthwatches commissioned to engage with their local communities on behalf of CQC. The aim of this work was to reach groups of people that might be called seldom-heard. This includes people from Black and Minority Ethnic communities. Healthwatch Croydon helped CQC to gather rich and reliable insights from these communities in accessible formats, which will be valuable in helping to shape CQC's regulatory work.”

Further feedback from the CQC is likely to come later and we will record this in a future impact statement.

Quality assurance

Does the research ask questions that?

Are pertinent? Yes, these were questions requested by the Care Quality Commission and we agreed they were good ones.

Increase knowledge about health and social care service delivery? This research helps those at the Care Quality Commission inform their new engagement strategy

Is the research design appropriate for the question being asked?

a) Proportionate: The specifications suggested 5 case studies. We produced two interviews, two from a focus group and one relevant letter which we felt reflected the scope of the work

b) Appropriate sample size: Has any potential bias been addressed? As above. They were varied in gender, age, ethnicity, and life experience.

Have ethical considerations been assessed and addressed appropriately? The interviews and focus group were recorded, but names of participants would be removed to ensure anonymity. The letter contents are presented but without any name or address. We received permission from interviewers to publish publically but were unable to contact the letter writer. The full transcripts have been removed from the public version but were shared with the CQC.

Has risk been assessed where relevant and does it include?

- a) **Risk to well-being:** None.
- b) **Reputational risk:** That the data published is incorrect and not of a high-quality standard. We publish the full transcript and show where we have made inferences, based on what was said.
- c) **Legal risk:** Have appropriate resources been accessed and used to conduct the research? There was no need to refer to legal resources for this research.

Where relevant have all contractual and funding arrangements been adhered to? This has been funded by a grant from the Care Quality Commission after a competitive bid process. All contractual and funding arrangements have been adhered to. We received £1,676 to complete this work.

Data Collection and Retention

Is the collection, analysis and management of data clearly articulated within the research design? There was a focus group and two interviews which were to be recorded and transcribed.

Has good practice guidance been followed? Yes.

Has data retention and security been addressed appropriately? Yes.

Have the GDPR and FOIA been considered and requirements met? Yes.

Have all relevant legal requirements been adhered to ensure that the well-being of participants has been accounted for? ie the Mental Capacity Act. None required for this research.

Has appropriate care and consideration been given to the dignity, rights, and safety of participants? Yes. Participants were recruited and supported throughout the process, including access to the guide and preparation and support from Volunteer Lead and Manager to ensure that they could participate fully in discussions. The letter was received in the time period, and while we have not had further contact, the fact it was sent mean that the sender wanted us to respond in some way and this was the most appropriate place to raise its contents

Were participants clearly informed of how their information would be used and assurances made regarding confidentiality/anonymity? These were made clear throughout the process.

Collaborative Working

Where work is being undertaken in collaboration with other organisations have protocols and policies been clearly understood and agreed, including the development of a clear contractual agreement prior to commencement? There was a clear contractual agreement with the Care Quality Commission on what was expected and when.

Have any potential issues or risks that could arise been mitigated? These are shown below:

Risk factors	Level of risk	Contingency
Cannot get enough participants	Medium	Look to recruit more – 5 was minimum required by contract
Question set does not work with group	Low	Questions and themes were set by CQC
Data is seen as being out of date	Low	Report to be completed within two months of insight undertaken.

Has Healthwatch independence been maintained? Yes, this research is shared with the Care Quality Commission before publication for their comment, but only factual inaccuracy would be reviewed. This does not affect the comments of experiences we receive.

Quality Controls

Has a quality assurance process been incorporated into the design? This was a simpler process, running online meetings and interviews and producing a report, but necessary quality assurance as described above was included.

Has quality assurance occurred prior to publication? Data collection was checked and re-checked.

Has peer review been undertaken? No peer review was undertaken. It was not required for this research project.

Conflicts of Interest

Have any conflicts of interest been accounted for? This project was an agreement between Healthwatch Croydon and the Care Quality Commission

Does the research consider intellectual property rights, authorship, and acknowledgements as per organisational requirements? The research is owned by Healthwatch Croydon, who are managed by Help and Care.

Intellectual Property and Publication

Does the research consider intellectual property rights, authorship and acknowledgements as per organisational requirements? Yes this is owned by Healthwatch Croydon, who are managed by Help and Care

Is the research accessible to the public? Yes this will be published on the Healthwatch Croydon website on 17 March 2022.

Are the research findings clearly articulated and accurate? Yes.

Evaluation and Impact

Have recommendations been made for improving the service? Recommendations have been included within this report for consideration.

Has the service provider taken action based upon the recommendations? The CQC are considering our comments and will be feeding back in due course. This was one of seven of submissions from Healthwatch across England which is informing the CQCs new Engagement Strategy.

Is there a plan in place to evaluate the changes made by the service provider? Healthwatch Croydon are regularly in touch with the Care Quality Commission and will track how the impact of the case studies is influencing the development of the new strategy.