Waiting for Hospital Treatment

A qualitative report on patient experience in Southwark

Contents

healthwatch
Southwark

Introduction

Waiting is built into the NHS. At any one time, there are people waiting to be seen at an Emergency Department, to have their surgery, for a GP appointment or to start mental health treatment. This is because there are limits on the amount of healthcare that can be provided - limited funding, staffing, resources and building space.

NHS services are monitored by their ability to meet targets on waiting times, but these targets are being missed across the whole system (including in Southwark)[1][2]. This has only been exacerbated by the Covid-19 pandemic.

Research also shows that, particularly for hospital treatment or elective care, the patient experience of waiting extends beyond how the NHS defines and measures it[3] - as a 'clock' that runs from referral to when treatment starts.

We also know from the signposting and feedback queries we receive, especially from older people and people with multiple health conditions, that waiting can be a huge source of distress and worry. Delayed treatments and cancelled appointments were the most common issues we heard about in 2019/20[4].

Overall, we saw this as an opportunity. Waiting may not be able to be eliminated entirely, but if local patient voices and stories are included in service reviews and plans, the waiting experience could be improved.

Executive summary

We carried out 11 in-depth interviews with local people waiting for hospital treatment. We found that while our interviewees experiences of waiting for hospital treatment were generally negative, they were understanding of the pressures on the NHS, appreciative of staff time and any direct communication. A few were adept at managing their health, but there was a general sense of just about managing - 'getting by' one day at a time. Their experiences of waiting had four main aspects:

Uncertainty

Related to lack of communication and a sense of 'not knowing'.

Fighting

Feeling like they alone had to constantly push for things to happen.

Crisis

Uncertainty and exhaustion while waiting contributed to a decline in mental health, physical health, or relationships.

Resignation

People accepted what was happening and felt they couldn't change it or weren't in control.

We also found that the COVID-19 pandemic had exacerbated uncertainty, crisis, and resignation in particular.

Based on our findings, we made seven recommendations:

1. Give more information to patients at set stages of their journey.
2. Include, for example, acknowledgement of anything that has happened, a clear point of contact, and next steps with expected timeframes.
3. Have a process or protocol for waiting patients, where if something is incomplete or hasn't happened, their case is flagged in the system.
4. Ensure experiences of patients with multiple long-term conditions are included in service design and quality monitoring.
5. Provide mental health signposting upon referral.
6. Promote opportunities for positive interactions between staff and patients.
7. Ensure feedback and complaints information is given to waiting patients.

Project background

Most of the existing research on waiting for treatment has focused on the service, and how they can manage waiting times efficiently. There is limited research that puts patient experience at the centre, although it is just as important for quality of care[5].

A study interviewing people waiting in HIV clinics in the US found that acknowledging delays can 'reduce uncertainty and make the patient perceive the wait as something more manageable, and in turn more tolerable'. They concluded that waiting experience is an actionable and feasible focus for improvement[6].

In Australia, researchers have looked at how experiences of waiting for surgery impact patient trust. They found that the lack of contact and isolation is key to negative experiences of waiting and loss of trust. However, they also found that patients were unwilling to criticise or express distrust of public healthcare - which the researchers called a 'don't bite the hand that feeds you' philosophy[7].

In the UK, National Voices recently published a project where they interviewed 15 people waiting for hospital treatment. They found that poorly managed waits had a negative impact on people's physical and mental health, relationships, housing, and employment. There were common experiences of waiting, such a being in an 'information vacuum', being 'bounced between services', constantly 'fighting the system', and the patients and their carer(s) feeling hopeless[8].

National Voices also concluded that the COVID-19 pandemic had not changed these themes, only worsened them[8]. Our Healthwatch Southwark survey on experiences of care during the pandemic also found that lack of communication made people feel uncertain, which had an impact on their mental health[9].

We wanted to build on this work by adding local Southwark voices, particularly exploring the experiences of people waiting with multiple long-term conditions and disabilities, who might have greater barriers to access.

Methodology

We planned to speak to 20-25 people living in Southwark who were waiting for care from Guy's and St Thomas' or King's College Hospital. We targeted people with experience of cancer, orthopedic conditions, and visual impairments.

We were interested in finding out about people's experiences of waiting for hospital treatment, their feelings, attitudes and beliefs about the situation, and what they thought could be improved.

Therefore, we decided to do in-depth phone interviews and small online focus groups, with a topic guide (Appendix 1) that explored the full patient journey of waiting - from the first time they saw a health professional about the issue, to where they were at the time of the interview (whether they had started treatment, were in the middle, or had completed treatment).

Our research questions were:
- How does waiting for hospital treatment impact patients' health and wellbeing?
- How did COVID-19 impact waiting experiences?
- How do people manage their health and wellbeing while they're waiting?
- What could be done to improve patients' experiences of waiting?

We recruited participants mainly through our connections with other community organisations, such as BlindAid, between October-November 2020. Interviews were carried out between November 2020-January 2021.

When we closed recruitment in February 2021, we had spoken to 11 participants (8 by phone interview, 3 by online focus group). Informed consent was obtained over the phone or in writing.

Analysis

The insight we gathered was analysed qualitatively - focusing on what people said, how they described their experiences, and what this revealed about healthcare services.

We recorded all the interviews and took notes while they were happening, before transcribing them.

We looked for important or common themes in these transcripts (thematic analysis) as well as the overall story the patient told us about waiting (narrative analysis). We looked for shared meanings and common themes between the interviewees, as well as places where their stories differed.

We then identified areas that healthcare services could improve on - by looking at what the interviewees told us directly, and what we understood indirectly from their stories.

This report presents these themes and stories, illustrated by quotes from the interviews.
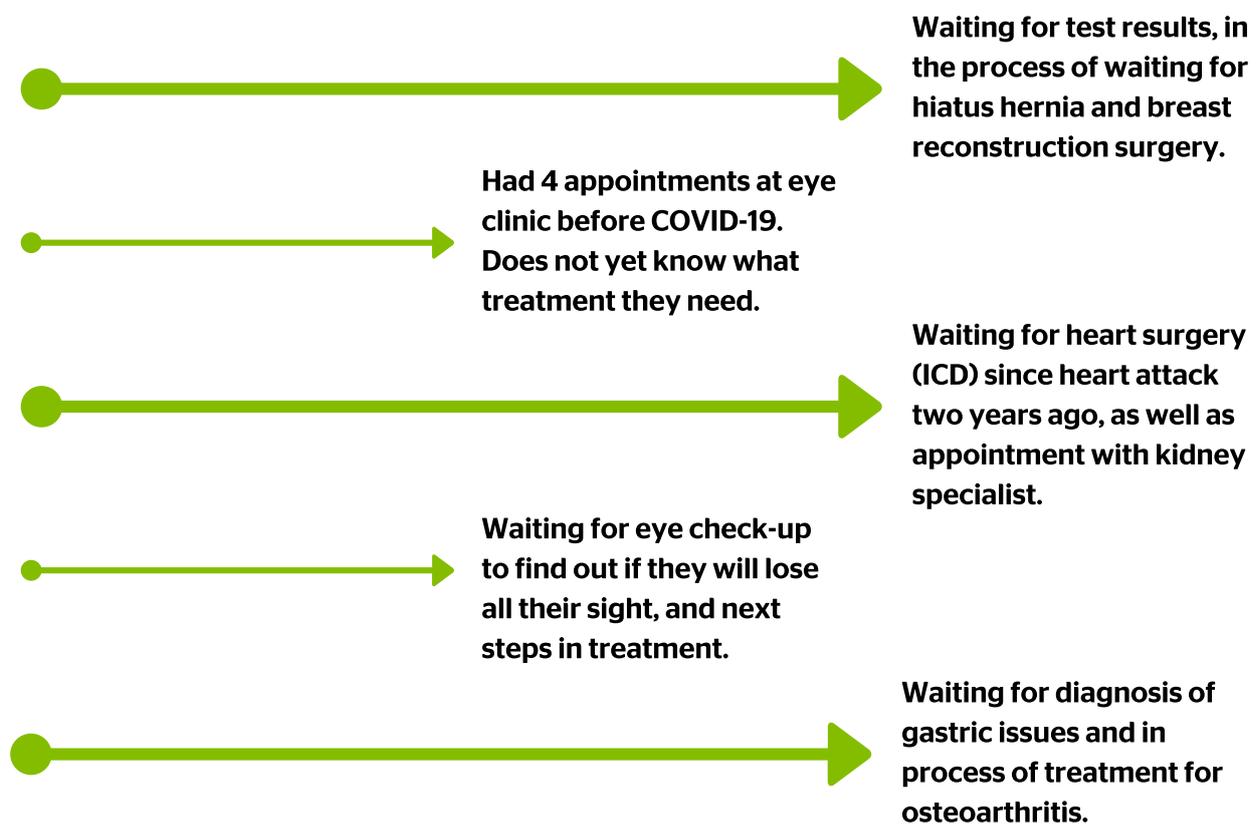
Limitations

The two main limitations of this project are the small number of people we spoke to, and the fact that many were recruited through BlindAid and had the specific experience of having a visual impairment.

However, the project does provide in-depth insight from a seldom-heard group (those with visual impairments, disabilities and multiple long-term conditions) that we feel still has value for informing service improvements, even though it is not representative of all patients in Southwark.

Findings

Of the 11 people we spoke to, four were receiving care from KCH, three from GSTT, and four from both hospital trusts. All of the participants had multiple long-term health conditions, including breast cancer, arthritis, hepatitis, COPD and coronary heart disease. Seven had a visual impairment, ranging from partial to complete blindness (see Appendix for full demographic breakdown). All were at different stages of their journey, which demonstrated how complex and individual the process of waiting could be for patients. For example:

Waiting for test results, in the process of waiting for hiatus hernia and breast reconstruction surgery.

Had 4 appointments at eye clinic before COVID-19. Does not yet know what treatment they need.

Waiting for heart surgery (ICD) since heart attack two years ago, as well as appointment with kidney specialist.

Waiting for eye check-up to find out if they will lose all their sight, and next steps in treatment.

Waiting for diagnosis of gastric issues and in process of treatment for osteoarthritis.

18 weeks is the maximum waiting time for non-urgent, consultant-led treatments (for example most surgeries). The clock starts from when the hospital receives the patient's referral letter. The current target is for 92% of patients to have treatment in 18 weeks.

Our interviewees' experiences of waiting for hospital treatment in the local area could be categorised into four distinct themes. Everyone experienced most of these themes during their waiting journey, to different degrees. There was a common order that the themes occurred in, but our interviewees moved back and forth between them throughout their stories.

Each theme was influenced by external factors where improvements could be targeted, such as the healthcare system, actions of the health service, social support, and self-management. This is where our recommendations will be targeted.
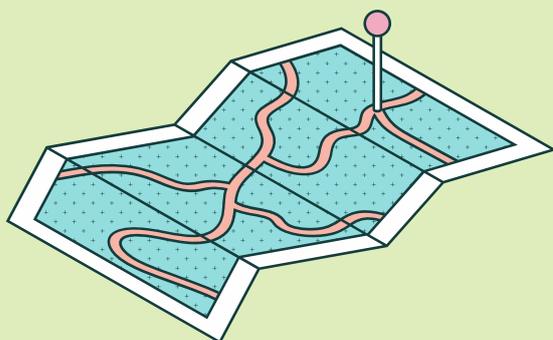
1. **Uncertainty**
2. **Fighting**
3. **Crisis**
4. **Resignation**

Uncertainty

All of the participants started experiencing some level of uncertainty fairly soon after their first contact with the health service about their current health issue. These first points of contact included emergency admissions, check-up appointments for existing conditions, and routine primary care appointments. It is also at this time that the interviewees perceived their wait as starting, which ranged from 7-8 months to 3 or more years ago.

The uncertainty was mainly about their next appointment, what their treatment would be, or the status of their illness. It was caused by:

1. A lack of information about what was supposed to happen next.

'The problem I have is with the eye clinic. It's annoying that I'm not getting an update from them as to my appointment and so forth. It feels like I'm waiting forever.'

'They said you will hear from us again in 6 to 8 weeks, so from January that would have been around the time that lockdown started probably the middle of March. I didn't hear anything from them for I should think at least another 9 months after that. And then I had a telephone call which I wasn't expecting from a different cardiac specialist at King's to essentially just monitor my health and see how I was getting on.'

2. Being told one thing, and then finding out contradictory information later.

'After two weeks of not hearing anything, I contacted them. They said 'Well you didn't contact us', I said 'My GP said you would contact me'. They said 'Ooh no, you've got to contact us'. Oh blimey, it's just like going round in circles'.

'After getting loads of calls from a private number, I got a text from the breast clinic saying 'We're trying to contact you urgently, we need you to come in to do a biopsy'. This was in December 2019, after I had been there in August for a check-up and been told everything was OK. They realised now that they'd messed up and I should have been in there.'

'I went to see a specialist and they said they would give me some special glasses, but I never received the order. I did mention over the phone that I was waiting for the glasses. (I: What did they say?) "We'll chase it up, we'll chase it up" – and then another time they did respond and said they were changing the supply or something. It's really annoying and frustrating but what can I do?'

This uncertainty had the biggest impact on people's mental health and wellbeing, as it caused them anxiety and frustration, and challenged their resilience.

Not knowing makes staying positive a very big challenge because every morning I get up and I haven't been phoned, I say to myself 'don't get annoyed, don't get angry'.

'I would like to get my eyes checked definitely. I would like that because it's more relaxing when you're not frustrated. It's more calming to kind of know what's going on.'

Not having clear information also challenged some interviewee's sense of control over their own health. Enabling people to feel more in control of their own health can help to improve their health - this is one aspect of health promotion, which is key to the NHS Long Term Plan.

> Mentally, it's the not knowing. Am I alright, or not?
>
> Because you're self-medicating, you never really know if you're doing the right thing.

This uncertainty was present for most interviewees before the COVID-19 pandemic happened, but for some it really impacted the level of communication.

> Communication was very good until the corona – number on the letter, everything I need to know, when the next appointment is...this all stopped when the pandemic happened, no one answering the phone number on the letter.

For people with disabilities, like many of our interviewees with visual impairments or mobility issues, this was worsened by not being able to plan for their treatment. Several people relied on patient transport, lifts from friends, and family or neighbours to read all their hospital letters.

> I want to not have [the appointment] just echoing in my head, so I can actually make arrangements...I have to know in advance. So I can rely on friends to take me and pick me up or whatever.

Recommendations: Uncertainty

All of the interviewees felt that more, clear communication would have improved their wait, and was an essential aspect of good healthcare.

> 'A little more in the way of knowing what was happening would certainly have been welcome, even email or something...but I wasn't surprised that people were too busy in the health service.'

> 'They say when you call 'Oh we're very busy' – but they can still communicate with us and let us know what the procedure's going to be.'

This could be achieved by:

Recommendation 1: Giving packages of information to patients at set stages of their waiting journey including: when the referral is received, after every appointment, before and after treatment, if a delay occurs, and upon receipt of information from another service (e.g. test results, records from a different hospital).

Recommendation 2: Including, for example: confirmation of any action that's been taken; next steps with estimated timeframes (even if they are longer than expected); a single point of contact that can view the patient's hospital notes and records; PALS contact details and what it can help with; any information the patient needs to provide and to who; patient transport information.

'I don't even know who to go to access this information. Yeah, "try phone King's", I don't even know which department to ask for. It's not like one person that you can just call up to see everything about you. It could help me because they could look on the system for me and say 'I'll get them, I'll just send an email'

'There's some kind of gap...there isn't somebody that has to contact the patient, it's haphazard. There's a role missing, particularly in the case of co-morbidities, for somebody to know your condition and what's happening.'

It is also important to note that when patients did receive communication from the hospital they were almost unanimously complimentary of the staff. Feeling listened to and taken seriously is so valuable to both the patient's experience and their wider wellbeing. Although our interviews mostly focused on phone communication, perhaps due to their older age and disabilities, we believe this type of communication can be achieved through text and letter too.

'The fact that people are nice to me and patient and understanding and they treat me seriously, and I get these explanations to understand. Those are all vitally important things to do. '
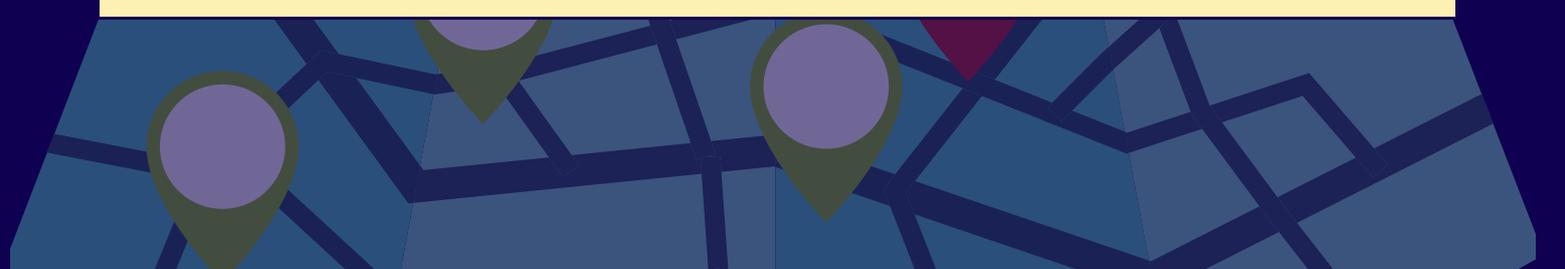
Fighting

Uncertainty often led in to periods of conflict, to some degree, with the hospital. Several interviewees characterised themselves as constantly having to contact, ask, and push the service, which they felt turned them into a difficult patient. This experience was more common in people without a visual impairment, perhaps because of the greater ease of access they have to a service.

'Unless you're in the boxing ring, kind of going at them the whole time, nothing happens. And I'm not really good at that, I've had to learn to be.'

You start to feel you're perceived a certain way...I felt like sometimes staff get fed up when my family came [with me to appointments], one person even said 'Oh you got Sergeant Major with you'.

'Sitting on the phone all day every day, just trying to get through to someone. And of course, you become an annoyance, when you're just trying to solve your problem.'

Those with a visual impairment tended to be more resigned to the situation, and spent more time on day-to-day management. One person summarised this, saying 'my hands are kind of tied. I do what I can...I manage'. This is partly because they had to rely on family, friends or neighbours to help with things like reading letters. Resignation will be explored further in the last section.

What was similar in all participants was their tendency to characterise the service as one large being. This means that what, for the service, is maybe a one-off, inconsequential interaction, is generalised by the patient to their overarching view of the service. This has implications for patient experience, and for whether and how patients seek help from a service.

For a few interviewees that had been waiting for longer, the experience of fighting for information and care had severely impacted both their trust in the hospital and, because it was so exhausting, their mental health.

'If you want anything to happen you've got to push it yourself. But it's very difficult to push, because you don't know what to push, or where, or who to push...It makes you very anxious also, because it goes on for a long time.'

'I just feel really awful....and now I worry myself because because they take long to provide me with information or they don't tell me what's happening properly...I'm kind of scared of them now.'

Recommendations: Fighting

The patient experience of battling with a service is a little more complex to address, as it seems to be an extension of patient's uncertainty that is related not just to communication, but also system-wide issues with integration, information-sharing between services, and care provision for multiple long-term conditions.

One interviewee, who had a very negative experience of fighting for their care during the course of breast cancer and its complications, said there needed to be 'more checks and balances along the way' of waiting.

Recommendation 3: Have a process or protocol for patients waiting for hospital treatment, where certain things need to happen before you can move to the 'next step'. For example, flagging a patient's records as 'incomplete' if they haven't been contacted following a test. Or, if they haven't provided information before a treatment about any other conditions they might have. This could provide an easier way to see when things haven't been done.

'The paperwork has been sent but the doctor hasn't responded. You can't close it down because you haven't written about the biopsy procedure and how it went...You promised me massage [for breast cancer symptoms] but it hasn't been arranged, so it's flagged up.'

Recommendation 4: As integration and 'no wrong door' type approaches develop, factor in how the patient experience of people with multiple long-term conditions might differ. Our interviews show they might have to 'fight' more, so services may need to take extra actions to address this.

Crisis

For all but one of our interviewees, the uncertainty and fighting contributed to some sort of crisis: a time of intense difficulty or a challenging change. These crises could be categorised into three types:

1. Mental health or identity crisis

'Mentally I would say it's kind of changed my personality. I'm not really an aggressive or pugnacious type of person, but I've had to become that...'I also think I've become quite pessimistic and kind of depressed.'

'Yes it really annoys me but...before I was turning to alcohol just to relieve the frustration. And I was literally drinking myself death...It's when I was very depressed... I wanted to just give up...everything.'

2. Health deterioration

'I used to walk, even a little way, but I can't walk anymore. And then of course other things got worse.'

'All between [various breast cancer treatments], I've had DVT, I had blackouts, I had a heart condition. All of these things all stemmed from this thing. Plus I was it emotional wreck anyway. '

3. Feelings of shame and guilt in relationships or friendships

'My sister she does for me a lot. Really, I can't say thanks enough to her because she's doing so much for me. (I: How does that feel for you?). It's really not a good feeling because she does so much, and she has a child, so it has an effect on her. She does so much.'

'I had to keep on top of it and not let people know how bad things are. I didn't want to lose my work. It's also very boring for people, friends and such, to hear constantly that there's no good news! So you have to bottle it up.'

However, we also found that most of the interviewees had come through their crisis at the time of the interviews and were in a state of resigned uncertainty or self-management. It would of course be best to try and prevent patients from reaching crisis point altogether, so it's helpful to explore what has helped them overcome. We found it to be very individual, ranging from meditation and walking, to faith.

> 'It's the little things. If I'm getting all frustrated, I go for a walk. It's only going to be around the block, but the clean air gives me a chance to think.'

> 'It's not really a bad feeling, you know, because at the moment there's people worse. There's people completely blind, for example. When they did the check-up, I have to say thank God because I may still have a little sight.'

A few people, including the interviewee who had not experienced any crisis, found the support from primary care essential.

> I have an excellent GP so that might contribute to the fact I'm not anxious about everything. If something went wrong I would have every confidence in my GP to sort it out. That's why I don't worry as much as some people.'

> 'The only people that have really reached out, is my GP, because obviously they're fully aware of my condition...GP has been very good, as well as the pharmacist. They've all been really really good with me.'

Recommendations: Crisis

We think the recommendations to reduce uncertainty and a sense of fighting the service will help to prevent crisis, and are actionable for hospitals. They could also:

Recommendation 5: Acknowledge that waiting can be challenging at the point of referral and provide some mental health signposting (including to NHS Talking

Therapies or any condition-specific counselling available), as well as information on what to do, or what action the service will take, if the patient's health majorly deteriorates during the wait.

> 'Our issues are real and we still need to be treated like we have issues, we shouldn't be put aside because if all my things were put aside, you can make me become an emergency case.'

> 'We need some personal things, sometimes there's something going on, like somewhere to say that my children are not coping well or whatever it is.'

Resignation

We found that everyone, to some degree, was resigned to their waiting situation, even if it had been really difficult. This was down to two reasons:

1. **'Pragmatic acceptance':** This has been recognised by other researchers as a coping mechanism particularly used by public healthcare patients[7]. They generally excuse faults in the system ('I understand there's a crisis', 'They're doing their best, 'I don't want to add extra burden to the staff') because it is therapeutic and helps reduce anxiety. We observed these kind of comments frequently across our interviews, where patients would pre-empt or follow up any criticism with an apology or expression of understanding of NHS pressures.

> 'It's just like out of your hands'.
>
> 'What can I do?'
>
> 'We have to cope'
>
> 'It's out of my control.'
>
> 'I don't really have a choice!'

2. Giving up: This was much less common, and only part of one patient's story. They had reached a point where they were so exhausted of waiting that they had decided not to seek any further care from the hospital, despite having multiple long-term conditions. This is rare, but it is important to ensure patients do not reach this point.

Recommendations: Resignation

Again, this is a more complex aspect of experience to improve as it is related to the wide public's relationship with the NHS. This is something we also saw in our COVID-19 experiences survey, with many people making comments about avoiding services for fear of being a burden on overstretched staff[8].

It could be addressed by generally cultivating an open, transparent and honest relationship between patients and healthcare providers, which is touched on in our previous recommendations.

Recommendation 6: Continue promoting opportunities for positive interactions with patients through staff training and learning. These interactions are not 'one-off' for a patient who has been waiting, and can build up and positively or negatively impact their trust in the service. For example, we have learnt that patients appreciate open and honest information, including about delays and 'unknowns', as it gives them a greater sense of control.

There are many ways that these interactions could take place, including by email, text, phone, and forums or meetings. First and foremost, it is important to note down any adjustments that need to be made for a patient's disability

Recommendation 8: Provide information on giving feedback, making complaints, and finding advocacy to patients at the point of referral for a treatment or appointment. Patients can also be signposted to Healthwatch for this information.

healthwatch
Southwark

Next steps

This report shares insight from a small group of people with multiple health challenges in Southwark. We hope it can be used for learning, and to inform and shape the improvements our local hospitals (GSTT and KCH) are already working hard on, especially as they recover from the impact of the COVID-19 pandemic.

We will share this project with our partners at GSTT and KCH, discuss the findings, and give them the opportunity to respond.

We are also hoping, as a result of this project, to do some more focused work with Blind Aid to gather feedback about accessing healthcare services with a visual impairment.

Finally, we are also planning on recording an audio version of this report in podcast or video format, that can be shared with our interviewees that are visually impaired.
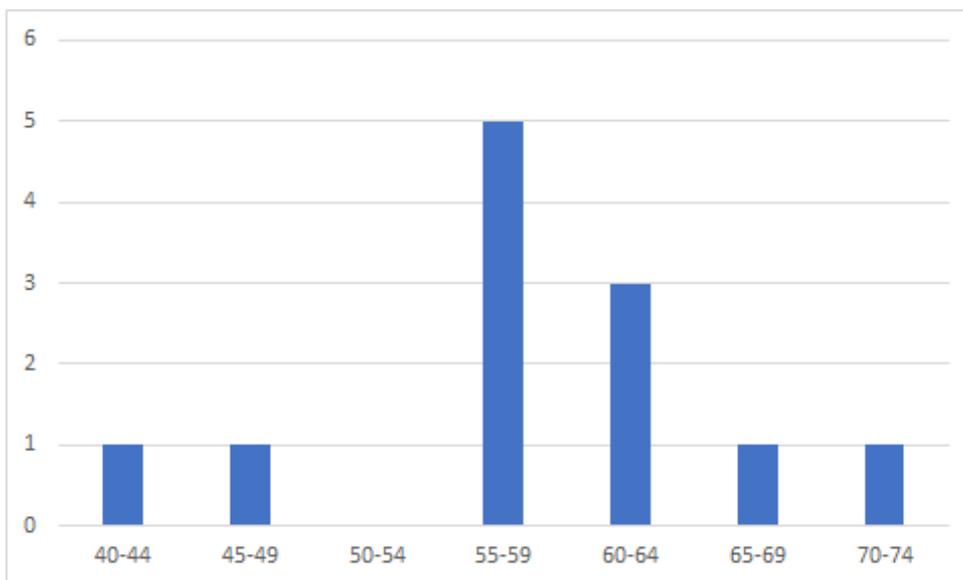
healthw**o**tch
Southwark
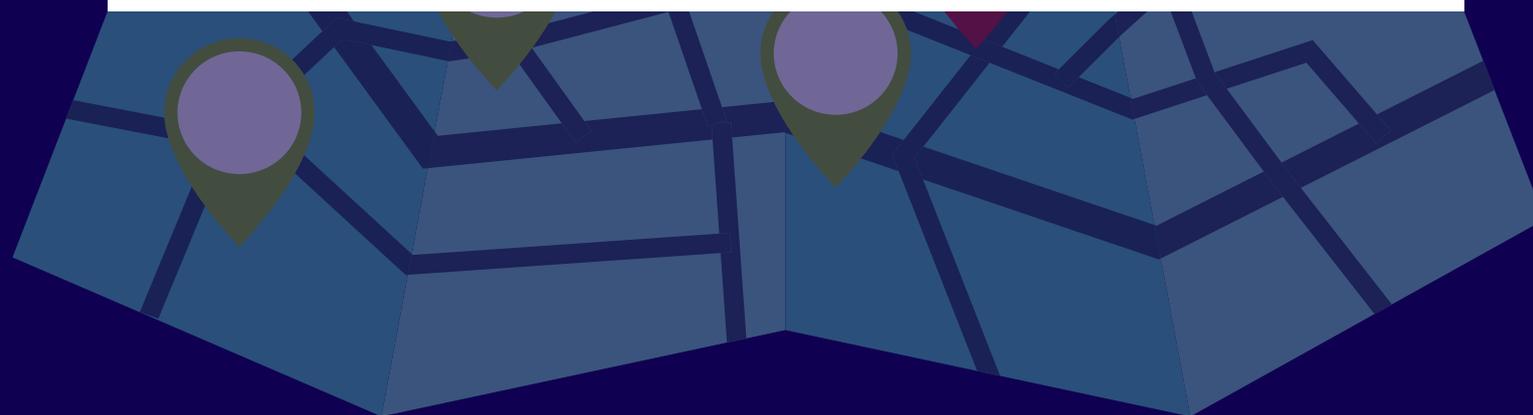
References

1. Appleby J, 2019. What's the point of waiting time targets if they can't be met? BMJ, 364(l845).
2. NHS England & Improvement, 2021. Referral to Treatment Waiting Times ny Hospital Trust Febuary 2021. NHS Statistics: Consultant-led Referral to Treatment Waiting Times.
3. Walter F, Webster A, Scott S & Emery J, 2012. The Andersen Model of Total Patient Delay: a systematic review of its application in cancer diagnosis. J Health Serv Res Policy, 17(2): 110-8.
4. Healthwatch Southwark, 2020. Annual Report 2019/20. Healthwatch Southwark: News and reports.
5. Goode J, 2020. Improving our understanding of the experience of waiting for elective care. National Voices: Publications.
6. Chu H, Westbrook RA, Njue-Marendes S, Giordano TP & Dang BN, 2019. The psychology of the wait time experience – what clinics can do to manage the waiting experience for patients: a longitudinal, qualitative study. BMC Health Services Research 19(459).
7. Ward PR, Rokkas P, Cenko C et al, 2017. 'Waiting for' and 'waiting in' public and private hospitals: a qualitative study of patient trust in South Australia. BMC Health Serv Res 17(333).
8. National Voices, 2020. Patient Noun Adjective: understanding the experience of waiting for care. National Voices: Publications.
9. Healthwatch Southwark, 2020. Experiences of health and social care in Southwark during the COVID-19 pandemic. Healthwatch Southwark: News and reports.
10. Beecher C, Devane D, White M, Greene R & Dowling M, 2019. Women's experiences of their maternity care: A principle- based concept analysis. Women and Birth, 33(5): 419-425.
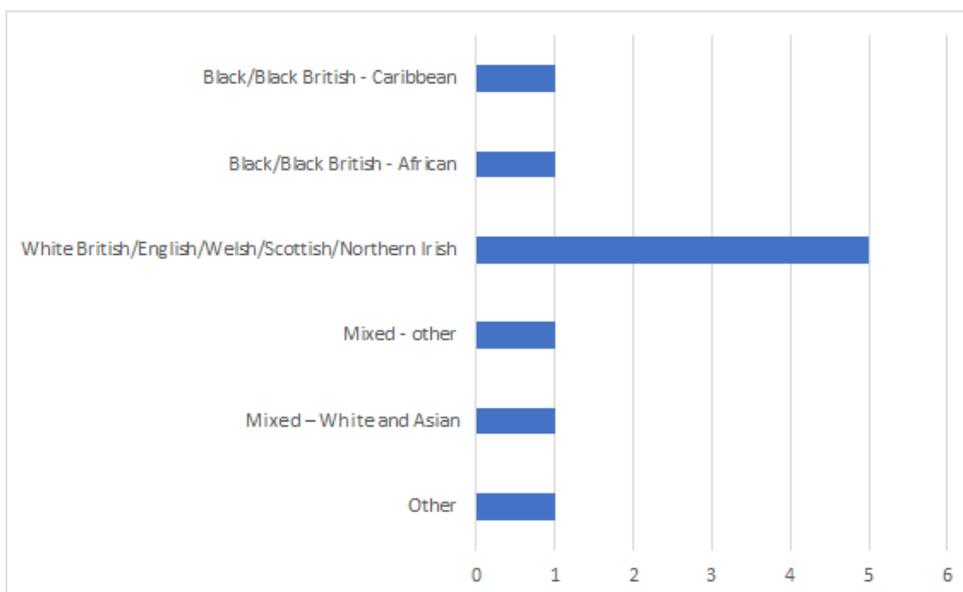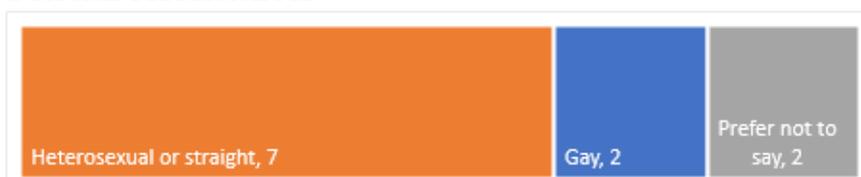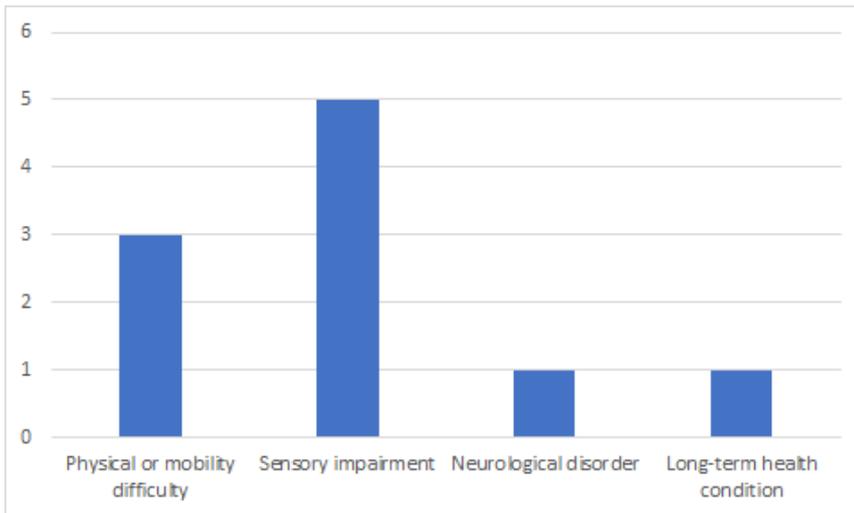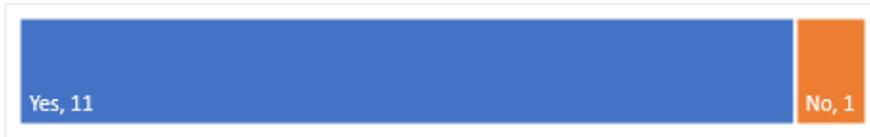
Appendix 1 - Participant demographics

Gender

Male , 6	Female, 5

Age group

Age group	Count
40-44	1
45-49	1
50-54	0
55-59	5
60-64	3
65-69	1
70-74	1

Ethnicity

Ethnicity	Count
Black/Black British - Caribbean	1
Black/Black British - African	1
White British/English/Welsh/Scottish/Northern Irish	5
Mixed - other	1
Mixed – White and Asian	1
Other	1

Sexual orientation

Heterosexual or straight, 7	Gay, 2	Prefer not to say, 2

Do you consider yourself to have a disability?

Yes, 11	No, 1

Religion

Christianity — 4, Islam — 1, No religion — 3, Atheism — 1, Prefer not to say — 1
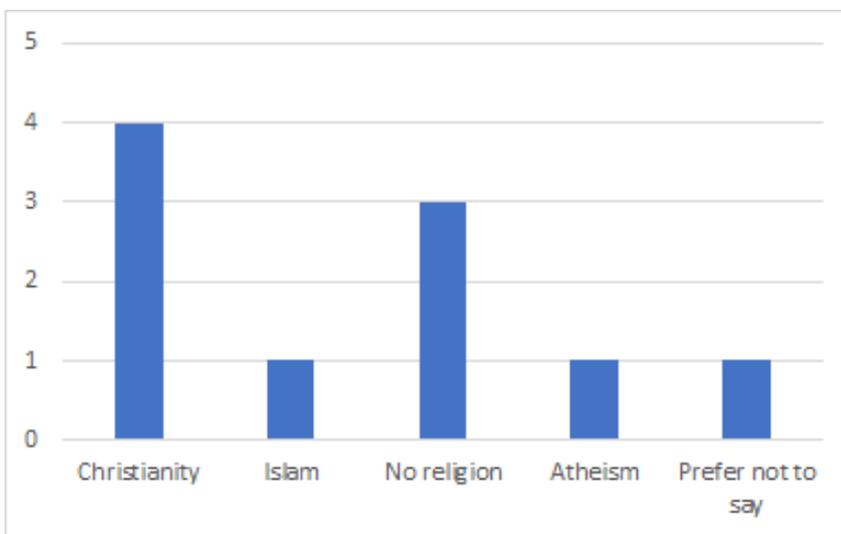
Are you an unpaid carer?

No, 10	Yes, 1
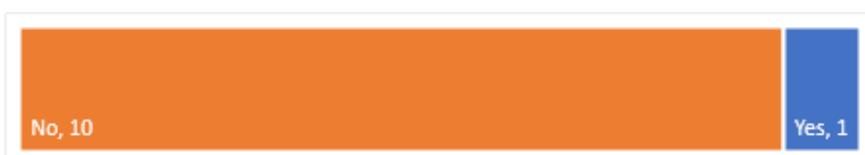
Appendix 2 - Topic guide

Prompts for semi-structured interviews

Introduction
- **Explanation of study aims**
- **Confirming verbal consent**
- **Icebreaker: one word to describe experience of waiting**

Part 1: Mapping your wait
- **Confirm key details: treatment, location, illness**
- **"Tell me about your experience of waiting"**

Part 2: Getting referred
- **Tell me about the first health professional you saw about your illness.**
- **How was your experience of getting diagnosed?**
- **What went well? What could have gone better?**
- **How was your treatment confirmed? Did it work for you?**
- **What information were you given during this process?**
- **Were there any changes due to COVID-19?**

Part 3: Waiting for treatment
- **After your referral, how did you feel while you were waiting for treatment?**
- **How was your health during the time you were waiting?**
- **What was it like trying to look after your health/wellbeing?**
- **Did your normal life change at all? Tell more more...**
- **Did you have any support while you were waiting? Tell me more...**
- **Did you receive any information or updates while you were waiting?**
- **What would have helped you during this time?**

Part 3: Reflecting on the wait (for those that have already had treatment)
- **How was your admission into hospital?**
  - **Ask about impact of COVID if relevant**
- **What went well? Were there any issues?**
- **Is there anything else that you think could have improved your waiting experience?**

Close interview:
- **Demographic questions**
- **Next steps**