CLEARVIEW RESEARCH

# Community Diagnostic Centres: Community Engagement

# Contents

# Author & Acknowledgements

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# About Us

ClearView Research (ClearView/CVR) is an audience insight and strategy agency. We are specialists in research, evaluation and engagement projects with young people, minority ethnic groups, culturally diverse communities, people with protected characteristics and those who often go unheard. We are committed to ensuring that our work is inclusive and equitable. We strive to ensure that our participants enjoy the research process and find it accessible, engaging, and empowering. We ensure that their voices are central in the materials (e.g., reports and frameworks) that we produce. We work best with organisations who give a damn and want to make a genuine impact. We are an MRS company partner, and we uphold and act in a manner compliant with the strict ethical and rigorous rules contained in the MRS Code of Conduct.

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# About the NHS in South West London

NHS South West London Clinical Commissioning Group (CCG) is responsible for planning, commissioning and buying health services for people living and working in South West London.

As a CCG, we're a membership organisation made up of over 180 GP practices within South West London. We serve just under 1.5 million people across our six diverse boroughs:

- Croydon
- Kingston
- Merton
- Richmond
- Sutton
- Wandsworth

We were formed on 1 April 2020 through the merger of these six borough CCGs. We manage local healthcare budgets of over £2.3 billion and commission a range of health services on behalf of our residents. The services that we're responsible for include primary care, hospital treatment, rehabilitation services, urgent and emergency care, community health services, mental health and learning disability services

# Introduction

The purpose of this project was to explore the experiences of the local community in six London boroughs (Wandsworth, Merton, Kingston, Richmond, Sutton and Croydon) to capture a wide range of views on the proposals and concept of a community diagnostic centre (CDC), as well as understand the general experiences of people seeking health/diagnostic services, such as blood tests, urine tests, imaging, endoscopy and pathology.

This community engagement project sought to engage a diverse set of people to understand their needs and experiences of the diagnostic pathway, as well as how the centres could be best designed to align with these needs. We were particularly interested in engaging people from marginalised communities who experience health inequalities to ensure the centres are set up in as accessible ways as possible, as well as those who have long term conditions (LTC) as people who may use the services a lot.

**The key objectives of the project included:**

- To understand the existing experience of people seeking and receiving health and diagnostic services, all along the diagnostic pathway including waiting for diagnostic appointments, receiving diagnostic tests, waiting for results, receiving, and interpreting results, and accessing any necessary interventions.
- Capture a wide range of views on the proposed designs and concept for the CDCs
- Identify any additional services or other ways to access services that might better meet people's needs
- Discuss and identify important factors to consider when assessing the location of mobile satellite site

## What is a community diagnostic centre?

NHS England is launching 40 "one-stop shop" diagnostic centres across England, which will carry out a wide range of health checks after people receive referrals from GPs. The centres will be staffed by teams of professionals including nurses and radiographers and will be open seven days a week.

While some diagnostic testing has returned to levels seen before March 2020, the idea behind the centres is to help tackle the backlog that built up during the pandemic.

It is also hoped that the centres will:

- Support doctors to make **earlier diagnoses** for patients by providing **more direct access** to a full range of diagnostic tests,
- Reduce hospital visits and therefore the risk of Covid transmission,
- Cut down waiting times, and
- Help meet emissions targets by providing multiple tests at one visit thereby reducing the number of journeys patients have to make.

## What do we mean by a diagnostic pathway?

The diagnostic pathway experience is broadly defined as a patient's interactions along the diagnostic pathway. A diagnostic pathway route includes an initial GP appointment, a GP referral to a test, receiving diagnostic tests, results, a possible consultant appointment and further treatment if needed. The pathway also includes variables such as communication, waiting times, receiving and interpreting results and scheduling appointments.

A joined-up diagnostic pathway is central to someone's positive healthcare experience. Poor standards of care and long waiting times during any part of the diagnostic process pushes the people who can afford it to seek alternative options, such as private healthcare. Unfortunately, the majority of those we spoke to in this project are not in a position to be able to do this.

## What work does this research project feed into?

The NHS in South West London has already engaged 722 people through a survey of diagnostic testing, in the first phase of community engagement. This survey was designed to provide greater understanding of how three proposed sites (Queen Mary's Hospital, St Hellier, and a site in Croydon) could be best designed to address needs of the local communities in order to develop the business case. Through the survey, the team were able to gain understanding of patient experiences of current diagnostic services, get a feel as to whether local residents viewed CDCs as a good idea, understand what matters most when accessing diagnostic services and compare findings to London-wide insight. The survey was sent to members of the South West London CCG People's Panel, and further disseminated via Healthwatch groups, community voluntary sector groups and other community groups via Borough Engagement Leads.

The results of the survey pointed to the diagnostic pathway requiring improvements around coordination across NHS teams, accessibility of centres, and communication around appointments, results and next steps. Overall, respondents agreed (57%) that a CDC was a good idea. However, it was crucial that the centres would address:

- Shorter waiting times (48% of respondents)
- Quick diagnoses (32%)
- Flexibility around booking appointments (27%)
- Clear communication (27%)

This project, based on qualitative engagement across the six boroughs, seeks to build on some of these findings to understand some of the 'why' questions behind the survey's findings and to ensure the community is at the heart of the design of the centres. It is also to ensure that a diverse set of views are captured.

# Methodology/Approach

## Advisory Group

We worked with the NHS in South West London to establish a diverse group of eight people who live or work across Wandsworth, Merton, Kingston, Richmond, Sutton and Croydon to work alongside us as paid advisors. The group included local community 'influencers', such as local community leaders, nurses, teachers, councillors and some local residents. The group met virtually using Zoom three times in six weeks. Having an advisory group made up of community leaders ensured that lived experience was at the heart of the project. We worked with them to co-design questions for the Exploration Labs and interviews so that we were asking the right questions and in a sensitive way. They also were involved in validating the findings towards the end of the project, to ensure we had properly contextualised the findings, represented them correctly and were framing them as actionable recommendations.

## Community engagement: Exploration Labs and Interviews

We held four in-person Exploration Labs (Merton, Kingston, Sutton and Richmond), six online Exploration Labs and ten online interviews.

Exploration labs are similar to focus groups. They allow participants to share their experiences, views and ideas and incorporate engaging visual and graphic methods where participants can draw and map counter-responses. From our experience and evidence from the literature (Bagnioli, 2009), participatory methods work well, as they break down barriers to engagement in the research process. They work well with young people, seldom heard groups, those for whom English is an additional language, and those who may have special educational needs and/or come from neurodiverse backgrounds.

We were particularly interested in getting the following groups to engage in the research:

- Residents aged 60+
- Residents who have English as an additional language
- Younger residents aged 21 - 30
- People with long term conditions or disabilities
- Carers (unpaid and paid)

We viewed these as important people to include, as those who may be likely to have a variety of experiences of diagnostic testing and as those who are often missed out from research projects.

We were also interested in people who typically may face barriers to engaging with healthcare. This was in order to understand the experiences of people who face health inequalities. Health inequalities refer to the different experiences or health outcomes that occur across groups within society, which are avoidable and unjust. Factors that contribute to these differential experiences and health outcomes can include social-economic status, race, age, gender, disability, religion or belief, sexual orientation, or geographical location. In addition to the list above, we also ensured our sample included a range of demographics to capture these differential experiences.

## Sampling strategy

Participants were recruited through convenience sampling. This is where participants are recruited based on their willingness and availability to participate. This approach enabled us to have flexibility in terms of who attended which Exploration Lab and where.

## Registration form

In order to achieve a diverse sample of participants to take part in interviews and Exploration Labs, the advisory group worked closely with the ClearView Research team to develop a registration form that included questions about long-term health conditions and potential lived experiences or characteristics that could point to health inequalities, such as English as an additional language, standard of living, or lifestyle behaviours. The registration form was shared with existing networks through ClearView, the advisory group and the NHS in South West London. **269** residents from a diverse range of lived experiences successfully registered their interest in taking part in the research and **67** participants were selected on a first come first serve basis (for a breakdown of participant demographics, see Appendix 1).

# Project Limitations

Though the insights in this report reflect the lived experiences and reality of the residents we spoke to, our findings cannot be generalised to represent the wider population of all residents in Wandsworth, Merton, Kingston, Richmond, Sutton and Croydon. We see this project as a helpful way to supplement and complement the broader survey conducted on behalf of the NHS, by asking and building understanding of why people feel as they do.

When conducting this research, we felt a strong sense of community amongst residents. We received a large amount of interest from residents who wanted to have their say and talk about their experiences of the diagnostic pathway. Unfortunately, due to the scope of this project, we were not able to invite them all to take part in Exploration Labs or interviews.

# Key findings

1. **Throughout the research there was consensus amongst patients about the poor communication and lack of coordination along their treatment journey.** This included communication between GP practice and diagnostics teams, diagnostics teams and the patient, and within NHS teams, such as between diagnostics teams and specialist treatment teams.
2. Poor communication and coordination across the diagnostic pathway left many residents feeling like they needed to **upward manage** the system.
3. Although 85% of residents agreed that the system works well in urgent situations, such as potential cancer diagnoses, for seemingly less urgent diagnostic testing, residents across the six boroughs shared a **general lack of faith in the system.**
4. Residents also expressed a **sense of confusion about the diagnostic pathway**, unsure about what the next step in the treatment process will be, where they would be sent or feeling like they were rushed through.
5. Participants identified various **barriers to attending appointments.** These included distance to the appointment, late hospital transport and/or inability to cancel or rearrange an appointment.
6. Inconsistencies and long waiting times across the diagnostic pathway is very distressing for some residents and this can have a devastating impact not only on patients' physical health but also on the **mental health and wellbeing.**
7. Participants, across interviews and labs, showed awareness that many of these concerns were **broader than what could be solved by a local diagnostics centre**. And therefore, participants were unsure of the purpose of a CDC if it did not address some of these systemic issues. However, they were also hopeful that this could represent change, particularly if a CDC would mean greater **continuity of care,** better **patient-centred care** and possible opportunities to **improve relationships** with healthcare professionals.
8. There are some **key practicalities** the CDCs need to address: location, access, accessibility and virtual triage.
9. Overall, residents want **clarity** and a diagnostic process that they can follow, is **reliable** and **effective**.

# People's general experiences of diagnostic testing

## Poor communication and coordination

Throughout the research, there was consensus amongst patients about the poor communication and coordination across the diagnostic pathway. Poor communication and coordination were raised in relation to three main areas: between the GP practice and the diagnostics teams, between the diagnostics teams and the patient, and within NHS teams, such as between diagnostics and specialist treatment teams. The main points along the pathway that were referenced were appointments, referrals and receiving results.

### Communication between and coordination of diagnostics teams and the patient

The main frustrations around patient communication were centred around the inappropriate mode and manner of communication for appointments, next steps, timelines and results. 95% of participants reported that they had never been asked their preferred mode of communication, where *"some centres will text you – which is great and others will just send a letter."* This was particularly emphasised amongst neurodiverse groups, who felt they were classed out from understanding their own healthcare because their communication needs were not considered. One participant with learning difficulties was particularly frustrated because although they were regularly asked by diagnostics teams how she would prefer to receive communications, they would not take this into account in follow-up communications.

> *"If I chose how I wanted to be communicated with, I would be mindful of that method, but when I don't know if I am getting a call, an email or letter, it feels all over the place."*

Many individuals, across ages, referred to the benefit of receiving text reminders ahead of COVID-19 vaccination appointments and suggested the same process should occur for diagnostic testing appointments. Groups who tended to undergo multiple diagnostic tests a month, such as those with long-term conditions, disabilities or carers, felt this would be particularly helpful as it meant they did not have to keep track of multiple letters. For participants over the age of 65, they shared that receiving text messages close to the appointment not only served as a reminder but also enabled them to make the necessary travel or caring arrangements. They also acknowledged how it was helpful to receive both letters and text messages as a means of confirmation. They felt this may prevent postage delays having an impact on their treatment, as it did during COVID-19.

The confusion caused by inappropriate communication around appointments seemed to be compounded for people for whom English is an additional language. Many individuals spoke about knowing people who disengaged from the pathway because they felt overwhelmed or did not understand the process. One individual spoke about how the lack of understanding can cause some people to fear the worst when they are sent for a test. If they are also sent conflicting and confusing communications, this is further reason for them to disengage or not follow up. More work needs to be done to understand the best ways to engage people for whom English is an additional language to ensure they feel informed and involved in the process.

> *"There's also the fear of what you are going to hear. I don't think GPs have time to help you and you may not understand too. The human element of interaction is missing. They only have 10 minutes for you...Whatever the centre there's a need for people who speak the language or the languages that their community speaks most."*

One participant noted, *"Telephone is good because people are conscious and listening. If people don't understand English and they receive a letter in English, then they are not able to read out what the letter says. Same as if people receive a text".*

Patient communication was also raised in relation to poor communication around results. People either felt like they had to chase for results or that they were often left in the dark about what the results meant and what would happen next. 80% of participants had experienced delays in receiving results. All participants showed understanding that their tests may not be urgent or a priority but explained that they would prefer to receive communication updating them on when they might receive results. For many, no matter the urgency, this period of silence left many feeling anxious and concerned they had been forgotten.

In addition, 70% of participants acknowledged that they were not supported to understand what their test results meant in a way that was easy to comprehend. A group of carers who had children with complex needs, including Autism, shared multiple stories of their children sensing their parents' anxieties after receiving results, often leading to the child showing overt signs of distress and dysregulation. Sometimes, results would be shared but explained, for example, where clinicians would say, *"I'm not a X [ neurologist] you need to contact them and ask them what your results mean."* This seemed to cause delays, having to wait for an appointment to get test results explained. This was particularly frustrating if you had a long-term condition, would be receiving multiple tests a month and therefore, would need multiple appointments for results.

> *"Sometimes you spend hours on the phone just to get nowhere and if you have to do that for more than one test that's ridiculous".*

In addition, the MENCAP support group were keen to stress that ringing back with results does not work for them. For such calls, they will have asked their support worker to be around and help them understand the call. However, because many of these calls are late, the support worker often has had to leave and the individual is left by themselves.

> *"It just doesn't work when the hospital says they are going to ring you because they never ring when they say they will. Either by that point, my support worker has had to stay longer than they should or I'm alone and I don't really understand or remember what the doctor says."*

> *"Doctors just seem to wash their hands of you once they've given you results. This is really tough on me and my daughter. I don't know what's going on and she doesn't, but she can sense my stress. We need spoon-feeding to understand these results. We need support."*

### Communication between and coordination of GP practices and diagnostics teams

Residents had mixed experiences of their GP practices, and how their GP practices informed them or supported them on the diagnostic pathway. Typically, the people who had been with their GP for many years or people who would go regularly – such as those with long-term conditions, disabilities or learning difficulties – felt supported by their GP and were confident in the role they played as their advocate.

However, for those who did not have a strong relationship with their GP – because they did not have an allocated GP, they may only see them online or they find it hard to get an appointment – they reported multiple incidents of poor communication with diagnostics teams. These issues would include incorrect referrals by their GP, delayed referrals or not referring at all. Residents shared that they tended to only find this out if they followed up because they had not heard from their GP for a while, or did not hear about a follow-up appointment or test, or received the wrong information in the post. Many residents shared the sentiment that it is only the GPs that go above and beyond that mean you get seen and diagnosed quickly. The default position that the system encourages is that *"GPs make decisions based on value-judgments and cost."* One participant shared that they often try and see locums at their surgery because their decisions seem to be driven less by cost due to fewer ties to that local practice.

*"I am lucky, because I had the time to chase the GP and go down there. But not everyone can do that. What happens if you forget?"*

Residents also shared that sometimes they would be faced by conflicting information from different teams, such as GPs and diagnostics teams. A GP might tell you, you are being referred to one place for tests, but the letter in the post says otherwise. Likewise, residents shared experiences of GPs and diagnostics team explaining the results and possible treatment processes differently.

This links to the final point participants made around feeling brought into the process and feeling informed. Residents of all backgrounds – across ages, ethnicities, health inequalities, healthcare needs and boroughs – shared how they felt uninformed about the diagnostics process. They all demonstrated confusion around who should have what information and how that information was going to be communicated back to them. This led to many residents across the six boroughs feeling they were in a "black hole" about how the diagnostics pathway worked.

> *"In Roehampton, you can be referred to hospitals all over the shop, and that is for me is very confusing. You never know where you're going to be sent next. At the same time, you've got GP practices who are doing much more of their own basic reviews of people. So, confusing is the word."*

> *"I called up the hospital a couple of weeks ago and said, "I had this consultation. What's happening?" I was told my consultant's going to see me later in the year and I'm still kind of waiting. My doctor still hasn't heard nothing. It's absolutely ridiculous. We have to wait for so long just to be seen by somebody just to get an answer to what the hell is going on so I can be treated in the correct way."*

### Communication and coordination within NHS teams

Across the six boroughs, residents felt there was incomplete or no communication between the NHS various departments. For many, this seemed to result in repeated tests and even cancelled operations due to delays in receiving results. Over 70% expressed how they were constantly *"passed from pillar to post"* around NHS staff who could neither answer their questions nor point them in the right direction when ringing to ask for information.

Multiple participants shared how they had been called for an operation – prepared for it, took time off work, attended the appointment – but that it could not go ahead because test results had not arrived at the right place or right time. Others spoke about having to have the same test done twice at two different hospitals because the second hospital did not have their records.

> *"Although you've been diagnosed with something in one hospital, they can't check your scan results from the other hospital, so they have to redo the scans. They can't go to a central system and see what are the things you've had done. They've just got to go with what you're telling them...And I've actually even been for an operation and they didn't have my scan results from the other hospitals, so the whole operation had to be cancelled."*

> *"For myself, they've been very poorly coordinated...There was this ridiculous situation where I was refused an operation because of a certain test result...I'll be there in the hospital, got there at 6:00am, sitting on the bed in the gown, ready to go and they say, no, we can't do it. After this happened once, I said the second time, please run this test in good time and check it before I come through and do this all over again. No, it didn't happen. ...It took four goes. Each time I went through an awful lot of stress, setting up all the arrangements, organising food for my household. It's just a massive amount of preparations.... But the complete lack of joined upness was such a waste of an operation."*

Another participant shared a similar experience:

> *"When the time came, I went in with all the way. Sat there, waiting at 6am, you can't drink, you can't have any food before... Then an hour and a half later somebody came and said, "Oh, I'm sorry, but there was overbooking, and we can't proceed with the procedure right now." And, then, the situation has repeated itself again."*

The participant explained how his surgery got cancelled twice to be rescheduled for October, from July. He shared how this affected his work schedule, taking multiple days off, as well as his mood and anxiety due to the constant *"anticipation of it"*.

> *"I was given a date for my treatment at Chelsea in Westminster but knew that it couldn't be confirmed till they knew what the results of the blood test were. So, you know, I felt I couldn't relax...and if I hadn't checked, then the treatment wouldn't have been able to go ahead."*

> *"My son, a 17-year-old, needed a hernia operation. I was told this is ultra-standard at Kingston, so he was referred into a clinic at Kingston, where they said, "We can't do it because we don't do under 18's. We'll send you to St. George's." Where do they send him at St George's? They sent him to the pregnant lady's ultrasound clinic...They then send him to another incorrect clinic. It's only when I raised a complaint with St George's CEO that they actually got it sorted. But it took eight and a half months to resolve, and you know it cost us £45 each taxi drive."*

### "The system expects us to make managing them a full-time job"

Poor communication and coordination across the diagnostic pathway left many residents feeling like they needed to upward manage the system. Many residents referred to how they used to engage with their GP, where, historically, the GP had been the patient advocate, helping them to navigate the system in liaising with other NHS teams, but that this was no longer the case. Instead, now, without someone advocating for patients or navigating the system on their behalf, patients find themselves being the go-between for different NHS teams, otherwise, they face the black hole of communications and *"risk falling through the gaps"* or being forgotten.

Most worryingly, residents were keen to stress that being this 'go-between' or upward managing the system was not possible for all patients. Residents for whom English was an additional language, those who had learning disabilities, those who were unpaid, full-time carers, and the elderly all found it challenging to self-advocate sufficiently or understand the process. Many residents expressed frustration at how they were meant to access a system with such high barriers to entry, which feels like it is only accessible through high levels of patient self-activation or health literacy. Perhaps in all of this, what was most concerning to hear was how this could mean that some people, often those facing multiple health inequalities, disengaged from the diagnostic pathway, not following up on appointments or results, and being put off from engaging again if there was an issue further down the line.

# Impact of current patient diagnostic pathway

## A general lack of faith in the system

Although 85% of residents agreed that the system works well in urgent situations, such as potential cancer diagnoses, for seemingly less urgent diagnostic testing, residents across the six boroughs shared a general lack of faith in the system in being able to adequately support their needs efficiently and effectively. This lack of trust in the system seemed to create opportunity for inequality as well as worsened the inequalities already faced by some groups.

For example, many patients who had more complex needs, such as mobility issues, learning difficulties or have English as an additional language, felt poorly supported or understood by staff along the pathway. With complex needs, they shared how they really rely on teams working closely and in a joined-up way, but that this seems nearly impossible in the current pathway.

Opportunities for inequality also arose because some people have been able to turn to private healthcare to receive the support they needed. However, this is evidently not possible for everyone – while 98% of participants voiced frustration at the system, only 5% of participants said they had switched to private healthcare. It is worth mentioning that some of the residents included in this 5% did not feel like they could afford private healthcare but were pushed to this point because of delays in receiving diagnostic test dates or results. Some residents had to take on extra hours at work or second jobs to help afford it. Most of these participants had turned to private healthcare because of the time it was taking to receive results which in turn would delay follow-up surgeries.

## Confusion at and disengagement with the diagnostic pathway

Residents also expressed a sense of confusion about the diagnostic pathway, unsure about what the next step in the treatment process will be, where they would be sent or feeling like they were rushed through. This was particularly the case for people who spoke English as a second language. They felt *"there is no real effort made to explain rather we are rushed off with pamphlets".*

> *"I think it's having an idea of how long you might wait because you can get lost in the clouds of time with referrals. I know one elderly lady who was referred to Queen Mary's and she's not heard for 18 months. She actually went up there walking around trying to find somebody to tell her what happened to this referral because she didn't know how else to address it. You may be referred, but you don't know if you're actually just dropped into a great hole somewhere."*

Some residents wanted to know why sometimes they were sent further afield for tests. Some were sceptical and thought it was because of certain contracts a GP might have with a hospital. They stressed the *"importance of knowing what can be done locally"* and therefore, understand why sometimes they needed to be sent elsewhere.

Confusion at the diagnostic pathway – next steps, why there were being sent to different locations – was repeatedly mentioned as a reason why some residents had disengaged from the system. One unpaid carer explained how the person she supports often feels like a burden to her, and therefore, if the process seems too confusing, he will disengage from the support and argue they should not attend. Likewise, other individuals, who shared they had experienced mental health problems in the past, noted how they disengaged from the diagnostic pathway – the test, follow-up appointments, referrals – because it was too complicated to understand during a difficult time for them.

## Barriers to attending appointments

### Distance to appointments

Attending appointments can be a draining and tiring process for many residents especially if they have long-term or multiple health conditions. Many residents in our research spoke of being sent to various hospitals across London for different tests. When discussing barriers to attending appointments, distance to appointments across London was cited as the most popular barrier.

Some residents who took part in our research shared that because they don't drive, they need to rely on family members or public transport to access appointments. This was particularly common for residents who are not able to go by themselves either due to the intensive nature of the test or because of disability. A resident shared how not having access to transport resulted in the test not going ahead.

> *"I live by myself. I went to book for an endoscopy, they [clinicians] say that somebody must come inside to collect you. My children are abroad at the moment so I'm basically on my own. A lot of my friends are like me and have got their own health problems. The clinicians just say sorry there's nothing we can do, just cancel this appointment until somebody can go with you."*

Sometimes, patients may not feel physically up to travelling on public transport and would therefore, need enough time to plan their journey. Residents shared that often, they would receive their letter about the appointment at short notice and this does not give residents enough time to plan their journey to appointments.

> *"I've been expected to get to King's College hospital for early morning appointments at just a few days notice – I've got pancreatic cancer but how do they expect me to get on the train and travel across London early in the rush hour? It's just thoughtless."*

### Hospital transport can be an anxiety-inducing experience for many patients

Some hospitals offer patient hospital transport up to 24 hours in advance. This is designed to enable patients to access their appointments on time. Unfortunately, many residents shared their negative experiences of hospital transport, specifically with regards to King's Hospital transport, because it is regularly late. For many, this meant they ended up missing their appointments. In other instances, residents felt that the journey time had not considered the number of people who had to be picked up on the way to the hospital. This meant that by the time they have arrived at the hospital, the patient had missed the appointment.

Some residents expressed their concern about the safety of the hospital transport in general, where *"some people don't wear masks - it's just not a very comfortable process."*

Many of the residents we spoke to have long term or multiple health conditions and not having access to safe, timely and comfortable transport puts the patient at risk of not being able to attend their future appointments.

### Cancelled appointments is often done at short notice

Consistently across Labs and interviews, residents shared how their appointments regularly would be cancelled. Lack of specialist staff or information getting lost was cited as the most common reasons for clinicians cancelling appointments.

When appointments are cancelled by the clinician, often, residents shared how they were not informed until a couple of days before the appointment was due to take place. In some instances, residents are told on the day or even once they have arrived that their appointment has been cancelled. Residents felt that when appointments are cancelled, this interferes with their planning as some may have taken time off work, organised transport, or arranged for childcare and therefore the "whole day is wasted." Cancelled appointments can also have a negative impact on patients' anxiety where they are left to wonder "how long until the next appointment?" and feel concerned they are pushed back down to the bottom of the list.

### Patient experience of cancelling or changing the date of appointments is "a nightmare"

On the flip side, residents agreed that sometimes there were times that they would not be able to make an appointment because *"life happens"*. However, they showed no lack of willing to try to rearrange or alert the diagnostics team or hospital that they would no longer attend. In these circumstances, many residents shared experiences of finding it nearly impossible to find the right team or to easily be able to cancel or rearrange their appointment.

Illness, caring responsibilities, and departments double booking patients were the most common reasons residents shared for cancelling appointments.

The lack of communication between departments results in patients being double booked for an appointment. Residents shared that when this happens, they are faced with a situation where they have to weigh-up and prioritise which appointment is more important than the other. When this happens, residents felt that having someone who they could contact for guidance would be beneficial in assuring that they are making the right decision; or even to help them negotiate how to best deal with situations like these. They also felt that simply this was not their decision to make and it could have been avoided.

Sometimes, residents need to cancel appointments due to the caring needs of someone who is depending on them, for example, a child with autism might be emotionally dysregulated en route. When this happens, residents feel that there is limited understanding shown when an appointment is missed. Two exploration labs suggested that a *"vulnerability register or a vulnerable / neurodiverse pathway"* within the NHS would be beneficial in understanding why some people might be more prone to missing appointments than others.

Residents who have tried to cancel or change the date of their appointments in advance felt that it's not a *"straightforward process."* When receiving the letter with the date of appointment, residents are given a number to call if they need to cancel or change the appointment date. However, getting through to the relevant department is a challenge – *"you could be ringing and the number is just constantly engaged."* This results in patients being put down as non-attending despite there being an effort to avoid this from happening.

## Long waiting times and lack of communication takes its toll on patients where they feel like a burden on the NHS

Inconsistencies and long waiting times across the diagnostic pathway is very distressing for some residents and this can have a devastating impact not only on patients' physical health but also on the mental health and wellbeing. The overall lack of communication between the NHS and the patient, the long waiting times and having to upward manage was described as *"anxiety-inducing"* and doesn't assure the patient that they are valued.

> *"My appointment has been delayed for 2 years now. At times I've had enough and I don't want to go through with it any more. Just leave me the way I am. You start psyching yourself out. Am I going to start losing my sight? Am I going to see my daughter grow up?"*

There was consensus that the long waiting times and lack of communication makes residents feel like a burden and takes its emotional toll.

Residents shared experiences of receiving diagnostics tests where they would repeatedly be told that the healthcare professionals were concerned about their symptoms. The patients would be told upon receiving the test or their initial appointment with the GP that it was key to get a quick diagnosis because it could be serious. However, they would then be *"left in the dark"* once they had left and would not hear back. They agreed had they not been told their symptoms were serious, they may not have been anxious but this took its emotional toll on them in the weeks after the appointment. Some assumed that it must be that the results were not severe. However, many stated this was a potentially dangerous assumption to make because they felt there was also high chance they had been forgotten.

# What this means for the design of and services offered at CDCs:

Participants, across interviews and labs, showed awareness that many of these concerns were broader than what could be solved by a single, local diagnostics centre. And therefore, participants were unsure of the purpose of a CDC if it did not address some of these systemic issues. One participant described how they perceived a local diagnostics centre to *"just bring some of these issues closer to their doorstep"*. However, they were also hopeful that this could represent change, particularly if a CDC would mean greater continuity of care, better patient-centred care and possible opportunities to improve relationships with healthcare professionals by bringing healthcare into the community.

## Continuity of care and familiar processes

It is clear that familiar processes and consistent, appropriate communication is key for patients to feel like they are at the centre of their treatment. Residents with long-term conditions, neurodiversity, learning difficulties and physical disabilities particularly raised the importance of continuity of care. Participants noted that a local centre for diagnostics tests could be a great opportunity to better facilitate this. Continuity of care was broken down into two areas:

1. Relationship continuity, where patients may be able to develop relationships with clinician(s) so they understand their medical records, healthcare needs and how they can best supported given other needs.
2. Management continuity, where there is continuity and consistency of clinical management and communications, including providing and sharing information and care planning, and any necessary coordination of care required for the patient.

Residents noted this will enable the system to address some of their concerns around coordinating, integrating and developing personalised care to ensure these are delivered to a high quality.

In addition, as mentioned, some residents who had been registered with their GP for seven years or longer spoke highly of their GP because of the familiarity this represented. These residents were adamant that they would not change their GP - even in some instances if they moved home: "*my Dr knows everything about me."*

A resident who suffers from mental health issues described the relationship as:

> *"Having a rapport with someone you trust. I had a GP that I had a good rapport with. Unfortunately he's just retired so now I'm having to go through the process again. If you don't have a rapport with them it can be a very difficult process because they know all about your history. They know your mental state and get to know you on a personal level. You have to open up some personal things to them and get to feel vulnerable and it can be very uncomfortable."*

This suggests that having a GP who is familiar is one of the most important steps along the diagnostic pathway in making someone feel supported and informed. This implies the role of the GP could be a key way to deliver on continuity of care. Some residents even shared they thought it would make most sense for their GP to deliver small tests, such as blood or urine tests, if possible. Many residents were keen for GPs to become the coordinator of care, as they once had been, and suggested perhaps this would be easier if a diagnostics centre was more embedded within the local community. It was agreed that if a CDC were to be built, GPs needed to be built into the design of processes. If this occurred, residents agreed they would feel *"safer"*, *"more relaxed"* and *"more confident"* that they would be treated holistically, given the GP's knowledge of the individual and their medical history.

### Patient-centred care

Residents agreed that CDCs could be a good opportunity to redesign the diagnostic pathway in a patient-centred way. Given the current lack of communication and coordination, and long distances to travel for diagnostic tests, patients agreed that it often felt like *"GPs were making decisions on what is easiest for them rather than what is best for the patient"*. Therefore, if CDCs could be designed in a way that built patients into the decision-making process (where to go for tests, when to receive tests, how to receive results) and consistently communicated with, residents may feel more at ease with the process.

Residents also expressed that patient-centred care included establishing strong and coordinated relationships between the patient, GP and the NHS teams to ensure the patient is treated with dignity and respect, rather than it feeling like a tick box exercise.

> *"I'd like to add that communication between hospital, GP and patients could really do with standardising."*

> *"There should be a slightly different spin on it…Thinking about it from the eyes and experience of the patient rather than the person providing the service. That's quite difficult to do if you're a health professional, but it's essential to think about it from the point of view of the person who's having the test or receiving treatment."*

Some residents were keen to stress the opportunity a CDC could bring by bringing diagnostics testing into the local community. They emphasised that there was huge amount of activity and support going on in local communities around holistic support or health education that could be capitalised on by a CDC to improve engagement with the centre. Likewise, a local centre may be more aware of local signposting opportunities so that they could give options to patients around follow-up care and support, in a way that puts the patient at the heart of their treatment.

> *"But if you are local, you can actually get some great strength from the people that live locally, the voluntary sector, the churches, the local schools – we have everything. And I think that's really important to bear in mind."*

> *"One thing that I'm very keen on is local support for people, for health and social care. I think if you have the local diagnostic centre and the local primary care group centre, I think you could lever in a lot of what is good in the local area. You can look to getting volunteering good organizations that you can support and they support you…All of that sort of thing is diagnostic stuff, early diagnostic stuff."*

## Key practicalities to consider

Overall, residents had mixed responses to the idea of a CDC. They were not averse to the idea or theory behind a CDC, but were generally more cautious about the practicalities of the centre.

> *"Some people might say, "Oh it's a community thing." Just because it has the word community in it, we need to have a better understanding of what it means and how safe you will actually be there."*

### Location (single site or mobile/satellite sites)

There was split in opinions between people who wanted multiple satellite or mobile sites, and those who wanted a single site. These opinions tended to be determined by mobility of the individual, access to the site through parking or public transport, why someone may be getting a test, level of emergency and the type of test.

For people who needed regular non-invasive or less complicated tests, they were keen to consider a mobile or satellite site option. This was also the case for people who may need non-urgent tests such as urine or blood tests. Residents thought satellite or mobile sites were a beneficial idea for initial screening tests such as cervical smears or prostate checks. They agreed they were a good way of making testing more accessible and in many cases, less daunting.

> *"I think local is good. Especially for an area like this, that if you try to get to a hospital from the central Roehampton estate, it is very, very difficult. It's a couple of buses or it's an hour and twenty minutes on the bus. There's no other way of getting there. So the logistics are quite difficult for people."*

However, some participants shared that they would feel more confident in a hospital for more complex tests as they worried about the capabilities of people working in a mobile site. Although many people with long-term conditions spoke of the more approachable set-up and increased proximity of mobile sites, they did express hesitation at how accessible these may be. For example, carers or people with physical disabilities shared negative experiences of using vans in the past for scans. They emphasised these were not disabled friendly, nor did they work for people who may have difficulties controlling body temperature or with difficulties around bladder control. Instead, they shared a preference for satellite sites in community centres for regular testing.

Residents in Richmond were keen to stress that satellite sites would be key if the purpose of the CDC was to be local. They shared that a service at QMH was too far for many and most of the original problems around distance and travel would remain.

### Number of Tests

When asking participants about how they would prefer to receive tests – multiple in one day or spread across days/sites – many argued that it would be most beneficial to have multiple tests in one day as it enabled people to better plan their time. Some said this was beneficial because it meant they only needed to take one day off work and you could *"make a day out of it – take packed lunch etc."*

However, some groups – including, people with long-term conditions, or carers for the elderly – said that having tests all in one day sometimes may not be possible given frailty or the fatigue that would occur. They agreed less invasive tests in one day would work well, if done back-to-back but ones that required fasting or hours waiting around, would not work well. Many residents agreed that given their experiences of the lack of coordination or communication from the NHS, they did not feel hopeful back-to-back tests would be possible. Therefore, they stressed having multiple tests in one day would only be beneficial if it *"speeds things up"* in general and is practical.

## Access and Accessibility

If a CDC, a mobile site or a satellite site are to be set up, residents emphasised the need to take into consideration the importance of parking, transport links and accessibility. Carers and people with physical disabilities shared experiences of being called all across London for tests, to places and sites that were poorly located in terms of transport and were not designed in an accessible way on the inside. They found this particularly distressing because they felt that these centres should be designed with additional needs in mind, given the fact they would be using them the most.

> *"I'm thinking here of my parents and how to get them to places because they couldn't do it by public transport. So, it would have to necessarily have some parking for people with disabilities, particularly around mobility."*

> *"My parents recently, I had to take them to Chelsea and Westminster. My son took my mother in trying to find a wheelchair. One of the volunteers tried to find a wheelchair. There was nothing. So, she had to very slowly, very painfully walk for quite a long distance and by the time she got to the place where she needed her tests, she was beyond over tired. So, it's not just how do you cope when you've got people with disabilities, it's the actual nitty gritty, the nitty gritty of every stage of it."*

## Virtual Triage

People shared the various reasons and times it would feel preferential to receive results virtually, either through text, email or via online consultation:

- If they had a long-term condition that required regular routine tests
- If it meant they would receive results rather than not receiving anything
- If it sped up getting a referral for treatment

For those with long term conditions who received regular routine tests, they agreed they did not need regular in-person appointments, particularly if that meant they would receive results quicker. They shared there could be some way of people voicing a preference for receiving routine test results. Others thought virtual triage was a good way of addressing the fact that sometimes the person giving you the results may not be best placed to interpret them. By using virtual triage, you may be able to miss out the interim appointment where you receive the results and instead go straight to the consultant. Residents agreed that virtual triage was not for everyone, but there needed to be a choice.

# Conclusion

Clear across conversations was the sense that residents want clarity and a diagnostics process that is clear, reliable and effective. One of the most important things that this research tells us is that the patient's diagnostic experience matters and it can have a devastating impact on patients when they are not clear on what is happening next.

This research has identified elements along the diagnostic pathway that can have huge impacts on the patient experience. Based on these residents' experiences of the diagnostic pathway within the NHS, there were mixed views surrounding how a diagnostic centre might alleviate some of these problems.

Currently, the majority of residents are having to plan and travel across boroughs on different days to attend various appointments. This research has found that the planning process for residents is even more challenging and detailed for those who have long-term or multiple health conditions and for those who don't have access to transport.

Having a diagnostic centre set up locally in each of the boroughs would make accessing some tests more accessible and save residents from having to travel on multiple days providing that the centres have transport links, free onsite parking and wheelchair access. Where hospital transport is offered, this should be planned well in advance so that patients are confident that they are travelling in a safe and comfortable manner where they will arrive at their appointments on time.

However, whilst many of the residents who took part in this research welcomed the idea of a community diagnostic centre, others struggled to understand what this will look like in real terms.

Residents who are currently experiencing long waiting times were suspicious of how the community diagnostic centres would help. Their understanding of why they are currently sent to multiple sites is based around the specialisms of the different sites. Their main concern, therefore, was the risk that the diagnostic centres would not be staffed by specialists, having a knock-on impact on the quality of care.

Other concerns raised were about the accountability of the centre and what role the GP would have in the community diagnostic centre and across the diagnostic pathway. Residents were divided if the GP could help to hinder or hamper elements of the diagnostic process.

Residents need clarity from the NHS to understand how a community diagnostic centre will solve the wider issues that patients face along the diagnostic pathway due to poor communication and lack of coordination between NHS departments. The residents we spoke to across the six boroughs are invested in improving the current services and are keen to use CDCs as a way to build a system they would like. If community diagnostic centres were to be introduced across the six boroughs, it is important that community engagement becomes an ongoing process with residents.

# Recommendations

This research has drawn out the real lived experiences of the diagnostic pathway for over 60 residents across the six boroughs. Residents were keen to stress how they had enjoyed the engagement process of this project and demonstrated real appetite to imagine and suggest change in the system.

The NHS in South West London are in a unique position to improve the existing experiences of people who are seeking health and diagnostic services by implementing the recommendations below:

1. **Evaluate how the sites may or may not address the wider issues within the NHS.** There were some key issues raised by residents that the CDCs may address. However, there are also wider systemic issues that came up in conversations. The NHS in South West London needs to manage expectations around what CDCs are there to do by working closely with local residents on an ongoing basis. However, the NHS also has a responsibility to acknowledge these broader conversations, share how they will take these forward and respect residents' appetites and insight into reforming the broader system. Residents showed awareness that the CDC would not solve all their problems, but they also demonstrated frustration at a system not responsive to their need. This project has captured a lot of these frustrations and acts as a good opportunity to build on some of these lessons more broadly.
2. **Encourage health professionals to ask patients about their preferred mode of communication.** The NHS in South West London, where they can, should encourage health professionals to ask patients about their preferred mode of communication and respect this. This mode would be tailored to the individual and their ability. We are confident that this would help to ease patients' negative experiences of communication across elements of the diagnostic pathway.
3. **Develop a clear process mapping of the diagnostic pathway.** The NHS in South West London should develop a clear process mapping of the diagnostic process into the CDC or mobile/satellite sites. GPs and diagnostic teams should be involved in this process mapping to build understanding of available support and design a process that is actionable. With a clear process, patients would develop an understanding of what is going to happen next.
4. **Identify and train up a team of patient advocates that can advocate for a patient and advise them on the pathway.** These could be roles in a local GP practice, such as social prescribers, or it could be community leaders or local organisations that are well-advertised. If patients, for example, do not understand their diagnosis, the patient advocate/designated team would be in a unique position to support them or signpost them to someone who would know more.
5. **Encourage and promote positive patient-staff interaction.** Positive patient-staff interaction requires staff and receptionist training on soft skills and awareness of neurodiversity to ensure that conversations around the process and particularly, results are conducted in a compassionate and accessible way. This could include basic training on local support available for patients to access further support about their diagnosis, such as patient advocate teams.

6. **Workshops with local residents to work through solutions for the communications process**. There are some key communication issues along the diagnostic pathway that require solutions – these should be co-designed with local residents to ensure they are fit for purpose. These key issues include communications to confirm appointments, to receive results, to understand next steps, and to track referrals. Areas that need addressing include tone, mode of communication, and regularity of communication.
7. **Work closely with Sexual Health London** – an online diagnostic service that has clear communication, efficient testing and results timelines, and effective use of digital. Multiple residents spoke about the positive experience they had with Sexual Health London. Although they were aware this may serve a smaller population, they suggested there was clear learning to be had from its user interface, ability to coordinate to ensure efficient turnarounds and clear communications.
8. **Further work needs to be done to address pathways into finding mental health support.** Multiple participants were keen to understand if mental health diagnostics were included in this project. Many felt that a specialised centre, with specialist staff trained in mental health and psychology, was an important addition in the current system. Some felt that the current set-up, where the GP is the entry point to the mental health system, does not work as it requires a certain level of expertise on behalf of the GP, which many do not have. They wanted to see specialist and more accessible mental health diagnostic provision in the area.

# Appendix 1: Participant Demographics

| Age | Labs | Interviews |
|---|---|---|
| -20 | 1 | 0 |
| 21-24 | 0 | 1 |
| 25-30 | 5 | 0 |
| 31-35 | 6 | 1 |
| 36-40 | 8 | 2 |
| 41-45 | 7 | 2 |
| 46-50 | 11 | 0 |
| 51-55 | 6 | 0 |
| 56-60 | 5 | 0 |
| 61+ | 13 | 4 |
| **Total** | **36** | **10** |

Table 1: Age split of participants

| Borough | Labs | Interviews |
|---|---|---|
| Merton | 10 | 2 |
| Sutton | 7 | 1 |
| Croydon | 9 | 1 |
| Richmond | 11 | 2 |
| Kingston | 15 | 1 |
| Wandsworth | 10 | 3 |
| **Total** | **62** | **10** |

Table 2: Borough split of participants

| Gender | Labs | Interviews |
|---|---|---|
| Man | 22 | 3 |
| Woman | 40 | 7 |
| **Total** | **62** | **10** |

Table 3: Gender split of participants

| Ethnicity | Labs | Interviews |
|---|---|---|
| Black – African | 9 | 1 |
| Black – Caribbean | 2 | 0 |
| Mixed – Black and Asian | 0 | 0 |
| Mixed – Black and Arab/Middle Eastern | 0 | 0 |
| Mixed – Black Caribbean and African | 1 | 0 |
| Any other Black background | 0 | 0 |
| Mixed – White and Black Caribbean | 0 | 0 |
| Mixed – White and Black African | 1 | 1 |
| Mixed – White and Asian | 0 | 1 |
| Any other Mixed background | 2 | 1 |
| Asian – Indian | 5 | 1 |
| Asian – Pakistani | 2 | 1 |
| Asian – Bangladeshi | 0 | 0 |
| Asian – Chinese | 1 | 1 |
| Asian – South East Asian | 0 | 0 |
| Any other Asian background | 3 | 2 |
| Latin or South American | 0 | 0 |
| Arab | 0 | 0 |
| White – English/Welsh/Scottish/Northern Irish/British | 27 | 1 |
| White – Irish | 0 | 0 |
| White – Gypsy or Irish Traveller | 0 | 0 |
| White – European | 8 | 1 |
| Roma | 0 | 0 |
| Any other White background | 0 | 0 |
| Any other ethnic group (please specify) | 0 | 0 |

Table 4: Ethnicity breakdown of participants

| Disability? | Labs | Interviews |
|---|---|---|
| Yes | 15 | 3 |
| No | 46 | 7 |
| **Total** | **62** | **10** |

**Table 5: Do you identify as disabled?**

| | Labs | Interviews |
|---|---|---|
| Yes | 40 | 7 |
| No | 22 | 3 |
| **Total** | **62** | **10** |

**Table 6: Do you have any physical or mental health conditions or illnesses lasting or expected to last 12 months or more?**

| Long-term? | Labs | Interviews |
|---|---|---|
| Yes, a lot | 15 | 3 |
| Yes, a little | 24 | 6 |
| No, not at all | 23 | 1 |
| **Total** | **62** | **10** |

**Table 7: Do you have conditions or illnesses that impact your ability to carry out day to day activities?**

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