

Not the person I used to be

City & Hackney Long COVID

Deep Dive Report



"I'm not the person I used to be..."

-Hackney resident



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Executive Summary

Long COVID refers to the signs and symptoms that persist or develop after an acute COVID-19 infection. This report highlights the impact of Long COVID on individuals' mental and physical health, as well as their ability to work and engage in daily activities.

As of February 2023, it is estimated that 2 million people in the UK have symptoms associated with Long COVID. The City & Hackney CoRe Service offers a multi-disciplinary, community-based rehabilitation service for individuals experiencing Long COVID symptoms.

The service provides various therapies and support, including input from GPs, physiotherapy, occupational therapy, psychological therapy, and speech and language therapy.

The report identifies several of the barriers faced by individuals seeking support for Long COVID. These include a lack of information from trusted sources, isolation, cultural and language barriers, financial challenges, and a feeling of being a burden on resources.

The findings from the report indicate that while most respondents sought help from their GPs, there were challenges in the referral process and accessing appropriate care.

However, GPs were generally praised for their support and proactive approach to treating Long COVID. Peer support and clear communication were also identified as important factors in improving the overall experience for individuals with Long COVID.

Based on the findings, the report proposes a robust set of recommendations devised to enhance support structures for Long COVID patients. The primary focus of these include: Awareness and Education, Enhanced Referral Process and Care Coordination, Support for Self-Management, Collaboration and Partnerships, and Inclusive Support Services.

It is hoped that the implementation of these strategies by the CoRe Service and partner organisations promises to improve care coordination, patient empowerment, and foster stronger collaboration with relevant stakeholders.

Furthermore, our hope is that by implementing these recommendations local and national integrated care partnership organisations will be better able to support individuals living with Long COVID, improve their overall well-being and amplify their voices both locally and nationally, to improve and best shape future services.

Background

Post COVID-19 Syndrome (Long COVID)

Long COVID is commonly used to describe signs and symptoms that continue or develop after acute COVID-19.

As of March 2023, the Office of National Statistics (ONS) estimated that 1.9 million people in the UK had symptoms associated with Post-COVID Syndrome, more commonly known as 'Long COVID' ([ONS, 2023](#)). Long COVID is considered a Long-Term Condition, in keeping with the Department of Health's ([DoH, 2012](#)) definition of '*a condition that cannot, at present, be cured but is controlled by medication and/or other treatment/therapies*'.

This condition significantly impacts a person's mental and physical health, impeding one's ability to maintain employment, self-care, and relationships. The latest ONS report (March, 2023) states that 1.5 million people (78.9%) expressed that Long COVID symptoms had adversely affected their day-to-day activities, with 381,000 (25.4%) reporting being "*limited a lot*".

There is currently no recommended pharmacological treatment or curative intervention for the condition itself, but some symptoms may be managed following existing guidelines specific to those symptoms. The recommended approaches for managing Long COVID include self-management, supported self-management and multidisciplinary rehabilitation ([NICE, 2022](#)).

The mainstay of long-term condition management typically involves self-management strategies, often provided by a multi-disciplinary team. Long COVID significantly impacts mental health, with 67% of patients from the City & Hackney COVID Rehabilitation (CoRe) Service reporting moderate to severe depression.

Most self-reported cases of long COVID fall within the age range of 35-69 years (ONS, 2023). This aligns with the CoRe demographic data, which most frequently

features referrals in the 25–54-year age range, representing a predominantly working-age population.

Case definition, Symptoms & Physiology

Long COVID is commonly used to describe signs and symptoms that continue or develop after an acute COVID-19 infection. Three main categories help define symptoms related to COVID-19 infection (NICE 2020):

Acute COVID-19 Infection:

- Signs and symptoms of COVID-19 from initial infection up to 4 weeks

Ongoing symptomatic COVID-19:

- Signs and symptoms of COVID-19 from 4 to 12 weeks

Post-COVID-19 syndrome:

- Signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 12 weeks and are *not explained by an alternative diagnosis*

Current research data suggests that the risk of Long COVID is mitigated by vaccination. Furthermore, we know that ongoing symptoms from an acute COVID-19 infection bear no relation to the severity of the initial infection itself. The symptoms of Long COVID are very real and often severe, significantly affecting a person's life, arising from a complex interplay between mind and body.

There are over 200 recorded symptoms linked with Long COVID, the most commonly reported being fatigue, breathlessness, 'brain fog', issues with memory and concentration, muscle pain, and chest pain and/or tightness. This list, however, is not exhaustive. Patients have reported a wide range of distressing symptoms that significantly diminish their quality of life.

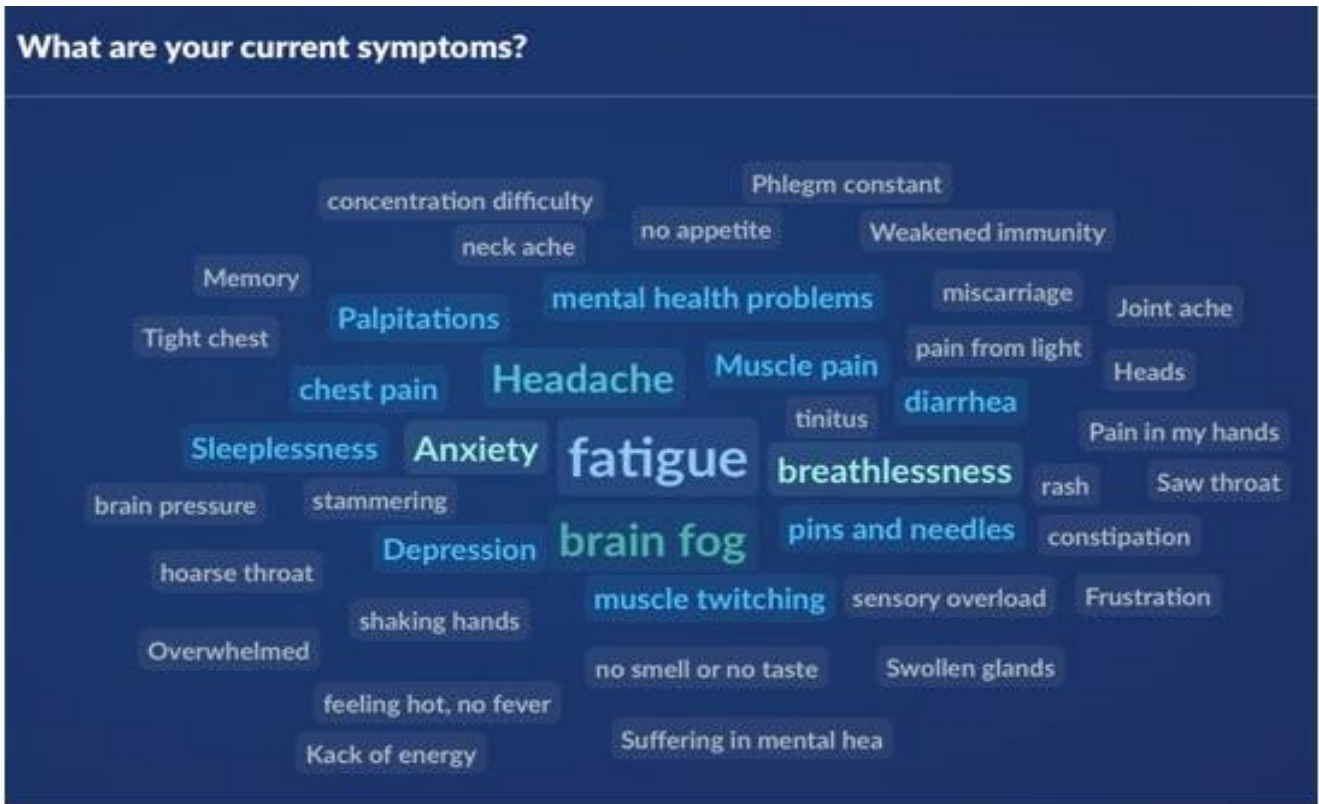


Image: Range of symptoms as described by Long COVID patients at an online introduction to the CoRe service.

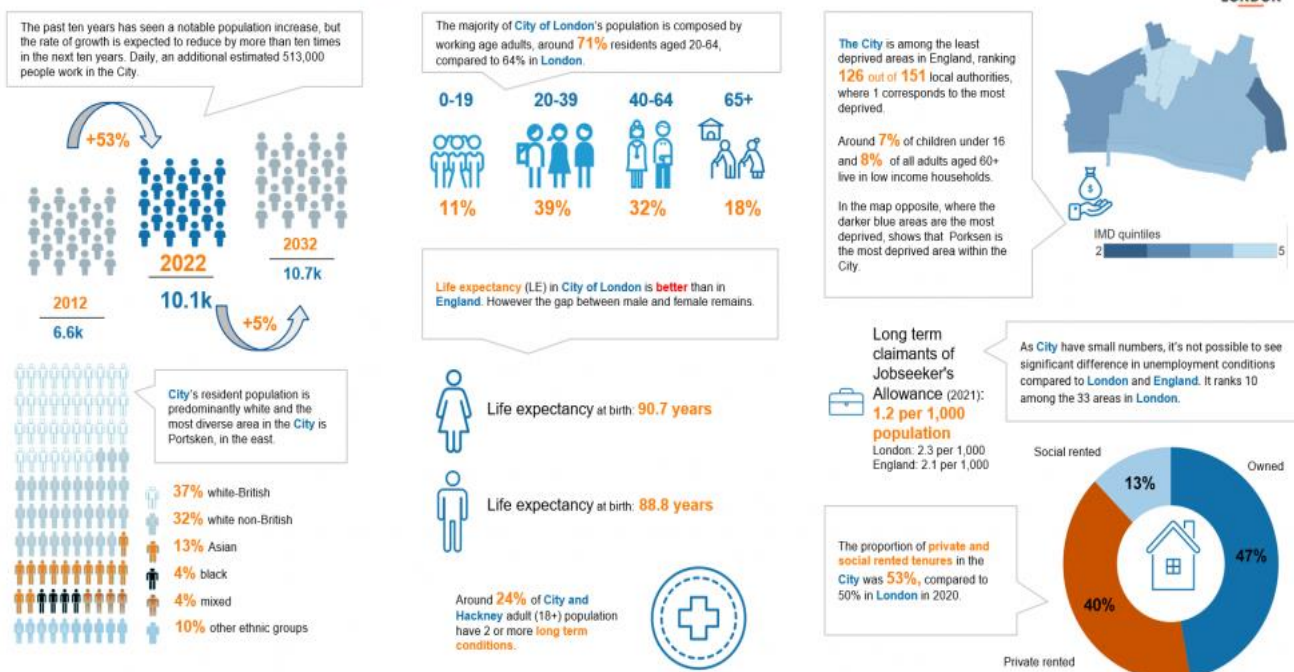
City of London Population Statistics

The City of London is home to approximately 10,000 residents. Of these, 25% are aged 60 years and above. The largest age bracket is the 25–29 years group, with 10% of the population falling into it. The population is nearly evenly split between males and females, with a ratio of 53% males to 47% females.

In terms of ethnicity, around 38% identify as white British, 30% as other white, and 30% as non-white. The non-white breakdown is as follows: 4% black, 7% Arab, 2% Bangladeshi, 2% Chinese, 4% Indian, 1% Pakistani, 5% other Asian, and 5% other ethnicities.

It is estimated that 7% of children under the age of 16 and 8% of adults over the age of 60 reside in low-income households. Approximately 80% of the population are registered with the Neaman Practice, while the remaining 20% access their Primary Care in the neighbouring boroughs of Tower Hamlets and Islington.

Population in City of London



Sources: GLA 2020-based housing led population; GLA 2016-based ethnicity housing led population; City of London website; UKHSA Fingerprints; Ministry of Housing, Communities & Local Government, 2019; Hackney JSNA website; ONS 2020; UKHSA Borough profile 2019.

Hackney Population Statistics

Based on recent growth rates, the estimated population of Hackney in 2023 is estimated to be 261,000. As of mid-2021, Hackney covered an area of 19 square kilometres (7 square miles) and had a population density of 13,647 people per square kilometre (km²), a figure that has increased by 407 people per km² over the past decade.

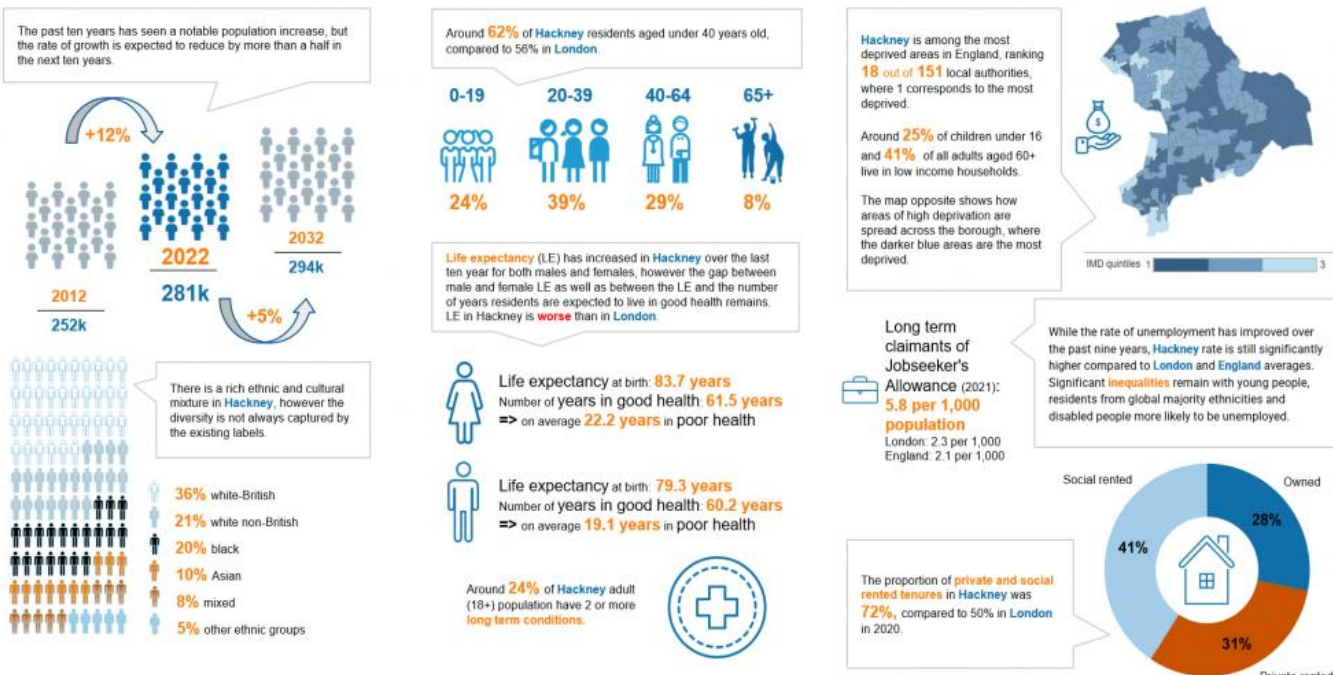
According to [2021 census](#) data, 53.1% of Hackney residents identified their ethnicity within the 'White' category. The proportion of the population who identify as 'White' is largely consistent with London (53.8%) but is far below the average for England as a whole (81%). This is reflective of the relative ethnic diversity of the population of London and Hackney.

The second most common high-level ethnic group in Hackney is 'Black', with 21.1% of Hackney residents identifying in this category. Hackney has a significantly higher proportion of residents who identify as 'Black' than the average for both London and England where the figures are 13.5% and 4.2% respectively.

English is spoken as the main language by 80.1% of people in Hackney and spoken either well or very well by 15% of the population. 4.0% reported having poor English language skills, and the remaining 0.8% spoke no English at all. A diverse range of communities are present in the borough, including the Charedi Orthodox Jewish, Turkish and Kurdish, Irish, Caribbean, Vietnamese, South Asian and African communities.

While Hackney's rich cultural mix brings a lot of positives to community life, poor integration can negatively affect community cohesion, perception of safety, utilisation of local services and, ultimately, physical and mental health outcomes. In addition, a lot of migrant communities are often overrepresented in deprived areas which puts them at an increased risk of poor health and wellbeing ([Diverse communities – cityhackneyhealth.org.uk](#))

Population in Hackney



*Global majority ethnicities refers to people who are black, Asian, brown, dual-heritage, indigenous to the global south, and or have been racialised as 'ethnic minorities' (Rosemary Campbell-Stephens, 2020)
Sources: GLA 2020-based housing led population; GLA 2016-based ethnicity housing led population; UKHSA Fingerprints; Ministry of Housing, Communities & Local Government, 2019; Hackney JSNA website; ONS 2020.

[Population Infographics - City and Hackney Health and Wellbeing Profile \(cityhackneyhealth.org.uk\)](https://cityhackneyhealth.org.uk)

City & Hackney COVID Rehabilitation (CoRe) Service

The City & Hackney COVID Rehabilitation (CoRe) Service provides an established multi-disciplinary, community-based, therapy-led assessment and rehabilitation outpatient service for individuals experiencing the impact of symptoms associated with Post COVID Syndrome/Long COVID (i.e. symptoms persisting beyond 12 weeks from initial infection).

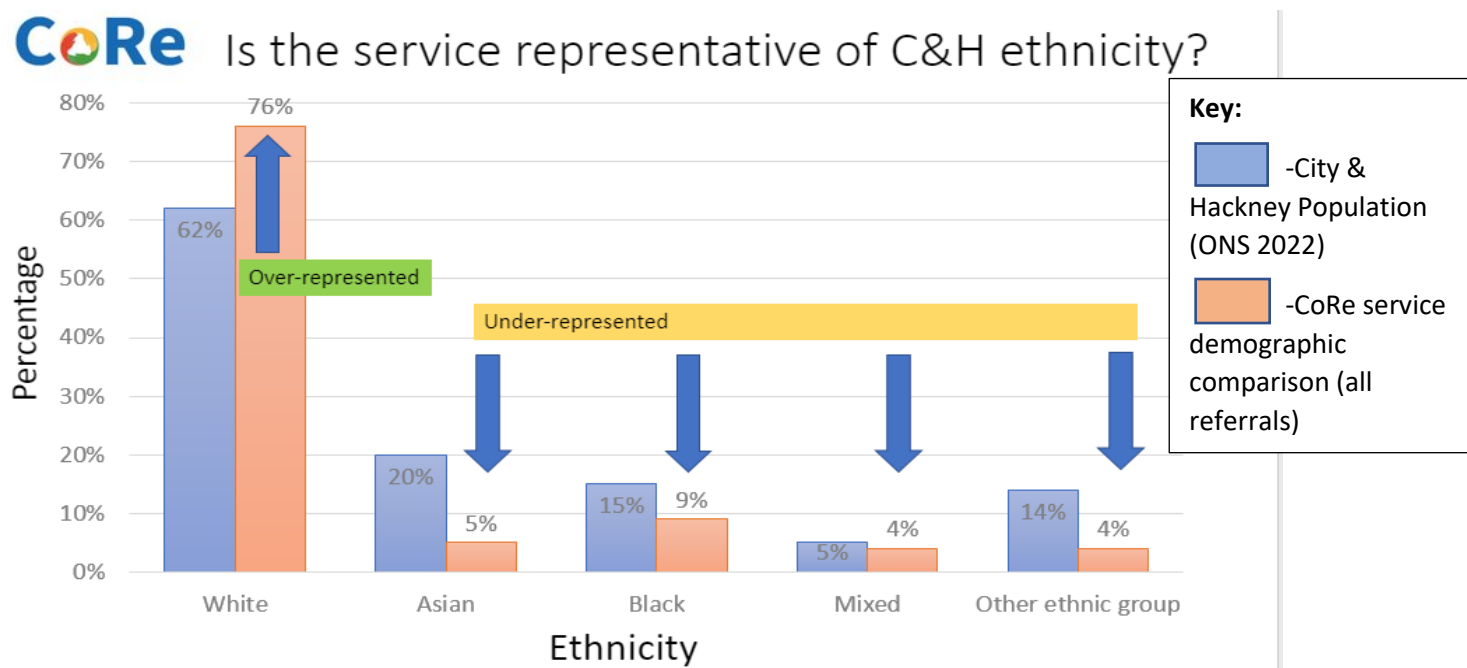
Adults over the age of 18 registered with a City & Hackney GP are eligible to receive the service. A dedicated pan-London service for children and young people is in place, in addition to three other local services supporting North-East London (NEL) residents in Barking, Havering & Redbridge, and Tower Hamlets, Newham, and Waltham Forest.

The service currently offers flexible rehabilitation options in keeping with current NICE guidelines for managing the long-term effects of COVID-19, including input from a GP, physiotherapy, occupational therapy, psychological therapy, and speech and language therapy. These provide continuity of care and a sense of 'safety' under the supervision of a specialist team (a factor frequently praised in patient satisfaction feedback).

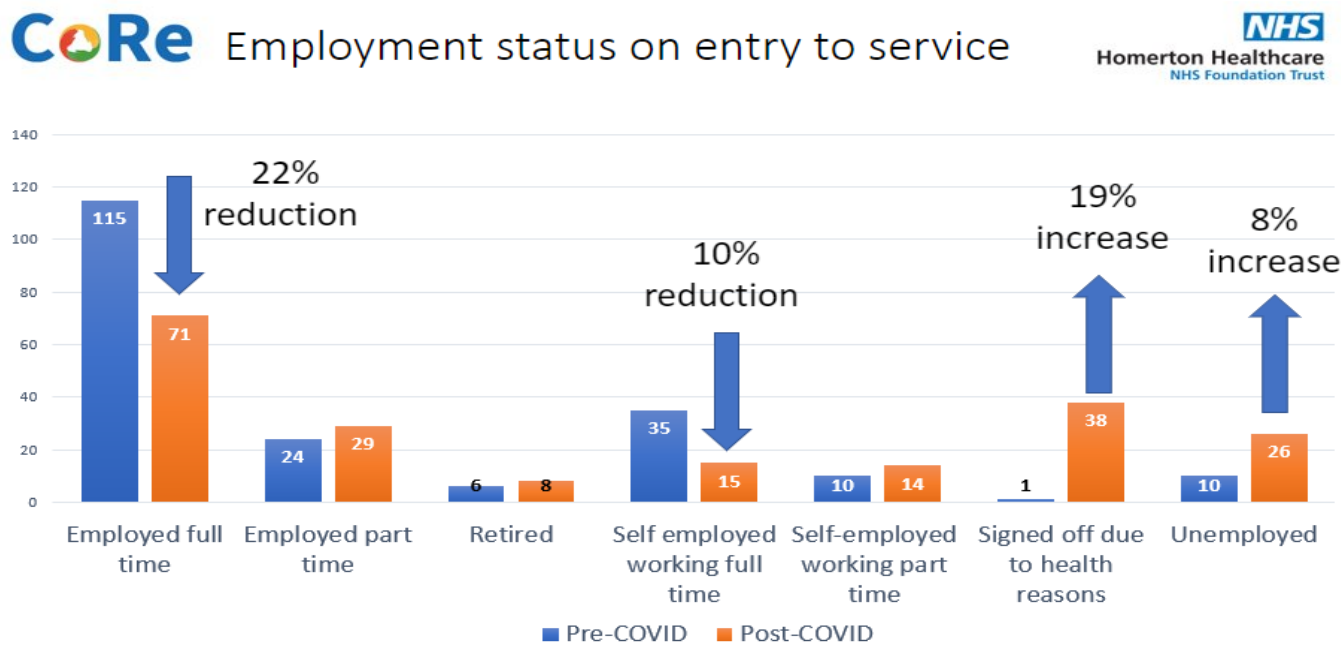
The CoRe service also provides care-coordination in navigating any employment and financial impact of Long COVID. By helping individuals understand what support is available to them and guiding them through the complex process of application forms, patients have avoided eviction, managed rent payments, bought food, paid for travel to appointments, and were provided with access to digital devices to facilitate engagement with healthcare.

Rationale

Since its establishment in January 2021, it has become apparent that the demographics of patients accessing the City & Hackney CoRe Service does not accurately reflect the population of City & Hackney, with underrepresentation from marginalised groups including Black, Asian and other ethnic minorities:



In line with NHS England Post-COVID-19 Proactive Case Finding guidance ([2022](#)), the CoRe service has been exploring community mobilisation and engagement, with the appointment of a dedicated Long COVID engagement lead.



The Long COVID engagement lead has focused efforts on listening to patient feedback, co-producing service improvements, building links with primary care services, local authority, and community partners as well as voluntary sector organisations in City & Hackney. This is done with the aim of improving access to Long COVID services for residents, particularly those from underrepresented populations, living in City & Hackney.

However, it was crucial for us to understand the scale of the impact of Long COVID in the community and the degree of unmet need amongst the local population, especially considering the data gap in this area within national Long COVID data. For this purpose, the City & Hackney Long COVID 'deep dive' survey was initiated as a collaboration between the City & Hackney CoRe service, Healthwatch City of London, and Healthwatch Hackney.

We were eager to hear from patients and residents of City & Hackney regarding their experiences of living with Long COVID. Our aim was to use our platform to amplify their voices both locally and nationally, with the intent of improving and shaping future services.

This applies not only to the direct provision of Long COVID clinical services but also to the broader services frequently required, given the severe effects of Long COVID on patients' lives.

Method

Online Survey

The online questionnaire was designed to explore issues surrounding:

- Residents' experience of Long COVID symptoms
- Residents' awareness of Long COVID services
- The impact of Long COVID in daily function
- Barriers faced by residents in seeking support

The main survey contained 31 questions and was disseminated electronically via email and social media platforms. The CoRe service and Healthwatch teams utilised our respective organisational communications teams and linked in with local authority and community partners to disseminate the survey widely through their communications networks.

We collaborated with NEL communications team to design an interactive flyer to help publicise the survey on social media, using a QR code to enable easier access to the survey.

We were mindful of digital exclusion and made every effort to minimise the impact of technological barriers by offering a telephone service for residents to call for support to complete the survey.

Furthermore, we personally attended various community events, with laptops to support residents in completing surveys in-person. We also linked up with partners to support the reach of the survey into key inclusion populations.

In total, we received 282 survey responses.

Focus Groups

The main survey also offered residents the opportunity to participate in a one-to-one interview, providing them with a platform to share a more detailed account of their experience of living with Long COVID, as well as any barriers they had faced in accessing care or support.

Initially, we received 91 responses from residents volunteering to participate in one-to-one interviews. However, due to limited capacity, we decided to offer the opportunity to share feedback in a focus group format instead.

Focus group participants were offered a £20 high street voucher, as a token of recognition for their valuable time.

To maximise accessibility for all residents within the two catchment areas, a face-to-face focus group event was held in the City of London and another in Hackney. Owing to high demand, a virtual session was also conducted via Zoom.

In total, we engaged with 22 participants via the focus groups.

Findings

Online survey

During November 2022 – January 2023, 282 people responded to our survey on Long COVID.

Overall Findings

Most survey respondents had tested positive for COVID-19 and sought medical support either from their general practitioner (GP) or by visiting the hospital.

Nearly two-thirds of the respondents (61%) had received a diagnosis of Long COVID, having experienced symptoms such as fatigue (57%), difficulty concentrating (54%), muscle ache (45%), memory problems (41%), and shortness of breath (40%).

Encouragingly, almost two-thirds of respondents (62%) indicated that they knew how to seek support, although only half of them had initially reached out to their GP. Additionally, around two-thirds of respondents (67%) were aware of the City and Hackney COVID Rehabilitation Service (CoRe).

Furthermore, over two-thirds of the participants (69%) were aware of the symptoms associated with Long COVID, while 31% admitted they had not received information about these symptoms.

People reported that the most significant impacts of Long COVID symptoms on their daily lives were difficulty with socialising (41%), inability to work (37%), needing to make adjustments at work (35%), inability to study (35%), and difficulties with caring responsibilities (29%).

60% of paid employees believed that their employer would be supportive if they disclosed their Long COVID condition, while 15% felt they would not; and a

considerable portion of respondents (28%) identified language as a potential barrier when seeking or using services.

Further barriers to seeking support mentioned included: financial challenges (35%), caring responsibilities (34%), previous negative experiences when seeking help (24%), lack of information or confidence in available services (both at 22%), and employment-related concerns (21%).

Findings by Age

We observed distinct variations in responses across different age groups. Individuals in the later working age bracket (50–59) were notably more likely to have tested positive for COVID-19. On the other hand, those in the mid-working age range (40–49) were clearly more inclined to have sought consultation with their general practitioner (GP).

The youngest respondents (aged 21–29) stood out as the group most inclined to have visited the hospital, while showing the lowest likelihood of contacting NHS 111 for medical support.

Individuals in the mid-working age range (40–49) emerged as the group with the highest likelihood of being diagnosed with Long COVID.

Surprisingly, the youngest respondents (aged 21–29) were more than twice as likely as the oldest respondents (60+) to possess knowledge about how to seek support. However, despite being diagnosed with Long COVID, the youngest respondents were significantly less likely to consult with their general practitioner (GP) compared to other age groups.

The oldest respondents (aged 60+) were notably more likely to have sought support from the Post/Long COVID clinic, as well as being the most frequent users of online services.

Respondents of mid-to-late working age (40 – 59) were most aware of Long COVID symptoms while the oldest respondents (aged 60+) were the least aware of City and Hackney COVID Rehabilitation Service (CoRe) services.

Focus Groups

1) Reported symptoms and impact on daily life

Physical symptoms

People reported a vast array of symptoms, emphasising the multifaceted nature of this condition. Some of the physical symptoms frequently mentioned included extreme fatigue, heart irregularities, a general sense of weakness, difficulty standing up due to dizziness, chronic body pain, and breathlessness.

In addition to physical symptoms, several participants reported cognitive and sensory symptoms such as brain fog, difficulty concentrating, changes in smell and touch, sleep disturbances and numbness in the hands and feet.

Some had to relearn basic tasks, such as walking, indicating a long and challenging recovery process. This wide-ranging list of symptoms underscores the complexity and severity of long Covid.

“I was feeling exhausted. Brain fog, lack of sensitivity in my feet and in hands, and just exhaustion, sheer exhaustion...”

“I was in bed at home for about six months (...) I had a lot of issues with my heart racing (...) I couldn't get out of bed, had terrible pain in my body (...) strange symptoms like skin stuff, numbness, brain fog and breathlessness. I've very slowly taught myself to walk again.”

Impact on lifestyle and mental health

People reported that their symptoms were impacting many areas of daily life, such as difficulties with employment, daily routines such as housework or moving around, and ability to socialise.

“Lost job as not fit for work. I’m not the same person I used to be.”

“I have to sit on the floor to load the washing machine and have to do the dishes in short spells as I’m too tired to stand for long periods of time.”

They also reported a lack of understanding and support in the workplace, especially as society had transitioned ‘back to normal’ following the initial COVID breakout and lockdowns.

People felt their needs for adjustments, such as remote working, had at times been ignored or denied, as the general societal attitude was that everything had returned to normal. This misconception presents a serious challenge for those experiencing Long COVID.

Many told us that they felt wary or concerned about the prospect of re-integrating into busy workplaces and social spaces, where COVID safe measures were no longer in place. We heard concerns about lack of mask wearing and ventilation, meaning some people felt more comfortable working from home.

“I feel right now that people want to ignore COVID, in business situations and in meetings, they don’t want to talk about it.”

“Everything is back to normal’ - but for quite a large proportion of people it isn’t (...) there’s a feeling in society that everything is fine and that gives you less of a reason to [speak up] and push for your symptoms.”

People reported depression, anxiety, and despair at ever recovering, concurring that friends and family had struggled to comprehend them and maintain their support as the illness persisted over time and initial support often waned as these close relationships expected a swifter recovery.

People shared experiences of feeling misunderstood and pressured by friends, family, and colleagues, leading to feelings of guilt for not being able to function as expected.

“My friends, my family, my relationships, they look at me and they think: ‘oh God, Mum, surely, you’re over this fight, over this virus by now. You can’t still be suffering from Long COVID’. They expect me to bounce back, to be the way that I used to be. And I wonder if I ever will.”

“Friends & family really expect you to be able to function and I feel guilty sometimes that I can’t.”

Several participants told us that they had been battling depression because of the impact of the illness and its symptoms on their lives, leading to feelings of hopelessness at their lowest points.

“Depression is another thing that I found has kicked in for me (...) we don’t know when it’s going to end. And if we’re ever going to feel the way we did.”

“It feels like a constant struggle, just everything is.”

2) Barriers to seeking/accessing service/support:

Lack of information from trusted sources

Due to the initial lack of information and awareness about ‘long COVID’ some, referring to themselves as ‘first-wavers’, did not know who to contact for help or whether to even seek medical attention. Consequently, they often relied on family and friends for support in the early stages of their illness.

Although there is now an increased understanding of the condition, research is still ongoing. Long COVID is still a comparatively new condition and there is still a great need for readily accessible information in keeping with new developments.

It is vital that this information is provided by trusted sources, as many people told us that in the absence of trusted information, they were likely to turn to contradictory information provided by the media.

"It wasn't immediately [that I realised I had long Covid] I didn't go too deep immediately because I really didn't have the understanding of what long COVID was about."

"I got COVID when it first started. At first it was new so it was very hard for me to know what was wrong. I was ill for close to seven months and couldn't get appropriate treatment. And eventually, it became well known to everyone and I got some kind of treatment from my GP."

This initial confusion was exacerbated by misinformation around adverse reactions to the COVID-19 vaccine. Some people with long COVID symptoms mistakenly attributed their ongoing health issues to the vaccine instead of the virus itself, which delayed them in seeking professional medical support. This underlines the importance of providing accurate evidence-based information from trusted sources.

"I thought maybe this might be the effect of the vaccine. During that period, a lot of people had said they felt fatigued after taking the vaccine. So, I just thought it was that and I persisted for a very long time [before seeking help]."

"The idea of having COVID really didn't pop up in my mind. My first thought was that 'maybe I'm reacting to the vaccine?'."

Some people independently researched their symptoms via the internet and informal channels. They used a variety of sources, including the NHS website, advice from health professionals, online forums such as Reddit, and social media platforms like Twitter.

People felt these platforms were particularly useful for gathering information on 'Long COVID', and some participants even adopted some of the self-treatment methods discussed there. However, the advice people told us they researched

was often conflicting, contradicting NHS and government advice, which inhibited their motivation to access appropriate healthcare.

"I contracted COVID-19 twice and did not access support initially but just waited it out, hoping it would go away. I looked on the NHS website which stated it might take up to 12 weeks for symptoms to improve."

"I got COVID-19 in 2020 – my mum is a GP and I spoke to her friend who was a volunteer on the COVID helpline. She informed me that no one was getting better from COVID-19."

"I turned to the internet to find support, at the time the Reddit forum was the only place that had the most information on Long COVID and people sharing their own self-treatment methods which I was drawn to."

Some expressed a sense of distrust in the UK government's approach and information on COVID-19 and Long COVID messaging and therefore a distrust in NHS advice by association. NHS online information was criticised for being 'out-of-date', which led some to seek private health care.

"I didn't bother with the NHS advice as I don't feel the UK government's ideology on COVID-19 and Long COVID is not going to lead to good public health management, and the NHS advice is aligned with the government."

"The UK government's messaging on COVID-19 and Long COVID has been dangerous – implying that people shouldn't be worrying about it and carry on with their lives."

"NHS information was out of date and irrelevant compared to the latest research found elsewhere."

"Through research I found out who in the NHS was working on Long Covid, what specialists there were, but accessed them privately."

Isolation

Some people told us they did not immediately attribute their condition to the virus. This was particularly true for those who were isolated when their symptoms developed.

Without the chance to discuss their symptoms with friends or family, they were less likely to identify their illness as 'Long COVID'. Consequently, people sometimes waited longer before seeking medical attention, due to a lack of understanding and recognition of their condition.

"I didn't go [to my GP] immediately (...) When I was first diagnosed, I was isolated for a long time."

"At the start of my journey I didn't go to the GP (...) I really didn't engage much with people during that period. So, I never really thought [it was Long COVID] (...) but eventually I went to the GP."

We heard that a lack of social support groups had had a negative impact on people's ability to seek support.

"I think of my mum in this area, there really isn't anywhere here, where I live, where she can go and connect with people and start talking about COVID. What local groups are there? If you're not in an area that's of your culture..."

Lack of understanding of the referral process

Diagnosing Long Covid is a process of elimination. When a patient reports symptoms it is important to establish, by simple blood tests, chest X-rays, ECGs etc, whether there is any other underlying cause of symptoms.

We heard a perception from patients that undergoing the tests would delay referral to the CoRe service by several months. We would not expect a referral to take longer than a month, or two at the most. However, there was a sense that patients felt discouraged by the process and there was a risk that they might disengage.

Residents told us that it was often difficult to explore the full range of symptoms experienced in a regular 6-minute GP appointment slot.

"I remember having a conversation with my GP. When [Long COVID] wasn't a thing, they thought it was chronic fatigue. And there was nothing they could do for chronic fatigue."

"I've just given up now, because when you've said something three times and you only have six minutes in a GP session, how much more do you do? All you then do is focus on one individual illness, rather than saying 'can you have a look at this whole set please?'"

"I remember one GP saying you won't get diagnosed with Long COVID until all the other things have been taken off the table. So, then my head is like 'well you're never going to get diagnosed then are you.'"

Although feedback about GP services was generally positive (see below section on GP contact), feedback about other clinical services was less so. People reported that secondary care services seemed to lack an understanding of the condition.

We were told that clinical staff specialising in other areas seemed to give advice that didn't fit with Long COVID or gave no advice at all. Often patients were left feeling there was nothing that could be done and that they should 'stop moaning' or 'try harder'.

"There's a real problem with the attitude of nearly all the [secondary care] clinicians I've come into contact with. The neurologist I saw said to me, "at least it's not dementia, and you're still relatively high functioning", despite what I would consider being a huge drop in function. 'Stop moaning', that was the tone of the conversation."

"My renal consultant was telling me I need to "try harder" He said that graded exercise needed to increase, which is the worst thing that everyone knows now [about Long COVID], it's the worst thing to do. And this was a consultant, telling me I'm not trying hard enough and I need to exercise harder."

People agreed that more training around how to understand and communicate with those living with Long COVID was important for clinical staff that don't specialise in the condition.

Patients feeling they are a burden on resources

Most people we spoke with had been living with Long COVID for a long time. They described feeling guilty for not improving despite healthcare professionals' efforts and being a burden due to their ongoing needs. Some felt "fobbed off" or forgotten.

"It's a feeling like you need too many resources because you have all the checks done and then they might come back normal because they haven't necessarily got the right tests yet to be able to pick stuff up and pinpoint it. I definitely feel a bit like a burden now."

"I do feel a bit forgotten about because aside from yourselves in these groups, I feel that we're sort of left to get on with it. You know, we walk around with this label of Long COVID but there's not much help and support out there for us."

People suggested further training for medical professionals around better communication with patients, feeling that the language used often felt disheartening and the tone dismissive. We heard that medical professionals did not always acknowledge the impact that symptoms were having on their lives and that a more empathetic approach was needed.

There was also a feeling that clinicians sometimes spoke about the prognosis in a way that left patients feeling there was no possibility their condition could ever improve.

"I was utterly dismissed, told it was the menopause and told to 'deal with it'"

"We don't want to be fobbed off! They may not be able to offer me all the support but I do have a real condition and I want to feel supported."

"I feel like somehow there needs to be training in how to work with patients in a way that recognizes [these needs] and gives us hope."

Barriers due to culture and wider society

Some patients told us of the challenges they faced when accessing Long COVID support, due to cultural, linguistic, and societal barriers. In cultures where the medical profession is highly respected, we were told that patients often struggle to assertively communicate their symptoms.

Others pointed out the reluctance among older people, especially those from immigrant and minority ethnic communities, to seek access to healthcare services, vaccinations, or discuss their health problems openly, suggesting that certain attitudes amongst this population make it harder to admit when they have health issues.

One participant, who told us she worked as a nurse in emergency services, noted that many older patients had opted not to receive the COVID vaccine. She wondered whether this refusal stemmed from a cultural disinclination to engage with health care and observed that she had sadly lost many older Afro-Caribbean patients to COVID.

"If I describe my mum, she'll say she's fine unless her arms and legs are chopped off. There's a whole thing in her generation, when she came over (...) it's a different language, you've got to be brave, bold, all these things (...) that make it harder to say "actually, I think I've got something wrong with me."

Some suggested that their communities had been more severely impacted by the pandemic, due to a higher prevalence of certain conditions like diabetes. They felt this was especially significant for people of South Asian heritage, who statistically have a higher disposition for such health conditions.

Social status was also seen as a factor that influenced the impact of the pandemic on different communities, and people expressed concern about limited access to community support.

“I’m of South Asian origin. There are probably, statistically, much higher comorbidities where COVID might have a disproportionate impact. For example, being diabetic and having other sorts of things at the same time (...) So those things add complications.”

We reminded participants that one of the aims of the consultation was to better understand why certain communities (such as those of Black, Asian and minority ethnic origin) were underrepresented in accessing Long COVID services, compared to other groups.

Some suggested that the discrepancy might perhaps be attributed to the proactive approach (or lack of) of certain GPs, rather than cultural factors. They proposed that it was not necessarily about ethnicity but more about specific GPs and the areas they served, where some were actively identifying the need for referral while others were not.

“It’s not necessarily about ethnicity, probably more about the GPs and those particular areas, who have actually said ‘you know what, you need to get this’ while the other GPs aren’t doing it?”

Barriers due to language

Language was identified as a barrier to accessing initial support through GPs. Those for whom English is a second language found it challenging at times to clearly express their symptoms.

Similarly, we know many people find it difficult to communicate in a clinical setting, including those living with autism or learning difficulties. Notably, we heard from patients that were offered longer appointment times or translation services, and that this helped overcome some of these barriers.

“Not being able to, for whatever reason, describe things in a manner that a professional can understand. Especially if people don’t have English as a first language.”

Barriers due to finance

People also emphasised the struggles they had faced in feeling marginalised due to their economic status. They expressed the sense felt by members of their communities of not being able to access treatment because they could not afford to take time off work, for fear of losing an income relied on for survival.

The cycle of poverty is such that they cannot afford to be sick as it means less food on the table and challenges in paying bills, leading to sacrifices in personal health to sustain their homes and families.

'we've got to keep going because we can't afford to take the time off work, because we need to earn the income. And if we take the time off work, we're going to be laid off.'

These fears were borne out by accounts of unsupportive employers. Some reporting the experience of forced resignations, due to being unable to keep up with the demands of work, which deeply impacted their mental health, self-image, and financial stability. Some expressed a further sense of guilt, and uncertainty about the future.

"I found that work wasn't very supportive to me at the time and said, if I'm not fit for work, then I can't work there anymore. So, I had to resign."

"I feel guilty that I can't go back to work."

3) GP contact – The Good News

When asked about their first contact in seeking medical support for Long COVID, all participants told us they had sought help from their GP, although some experienced symptoms for some time before doing so. The GPs were overwhelmingly reported to be supportive.

Some reported their GP's efforts to secure small, incremental health improvements for them, commended their GP's willingness and thoughtful

approach. Others noted the proactive attitude of their GP in securing appointments, recognising the challenge for some to do so due to their ill health.

One patient mentioned their GP setting up the last appointment of the day for them, allowing for an extended discussion of their symptoms. The GP would even arrange double appointments if the participant had missed one. Another praised their GP for being patient despite their increased irritability caused by their illness.

Overall, people's GPs were highly praised for their consideration, patience, and proactive approach to treating the condition.

"My GP keeps referring me to things to try and get some small incremental improvements for me. And he's very willing and thoughtful."

"When I was first ill my GP would make appointments to call me, he said: "I will make an appointment to make sure I see you in a week's time", so I didn't have to try and do it [when I was too unwell to organise my own appointments]."

"He would always give me the last appointment so that we would talk for an hour or longer. He was incredibly thoughtful and considerate. If I missed an appointment he phoned back and say: "I'm making another appointment with you. So, we'll have a double appointment". In terms of a GP, I could not praise him enough."

"The GPs have been very considerate. They're patient, because I found myself becoming very irritable, very unlike myself, I became very difficult to relate with."

4) Peer support

When discussing peer support with participants, we gathered valuable insights. Some expressed a preference for online sessions to minimize the risk of infection, emphasizing the importance of timing for these sessions.

Additionally, participants mentioned that incentives like local vouchers would serve as a welcome motivator to attend. In terms of content, conciseness was emphasized, especially for individuals with memory issues.

The inclusion of speakers or peers with long-term experience was seen as highly valuable by the participants.

“Having [peer support] online is better. You can get multiple bouts of COVID. I don't particularly feel comfortable in close proximity [to people].”

“With regards to peer support groups (...) give them something back (...) so you're getting something back as well as attending. Otherwise, why else are you there? (...) because everyone's time is so limited.”

“I've been in this session for seemingly not much time but my brain... I am knackered! The concentration I've had to put into listening to everybody and you guys is off the charts! (...) it's harder than just a normal peer support group.”

“...part of it has to do with how long you've had Long COVID. Quite a few people in the group that I was in are 'first wavers'. We're all sort of hitting the three-year mark (...) [we] found management tools and skills to cope with the condition as best [we] can. There may be a case for sharing that with newcomers.”

5) General Practitioner & Healthcare Professional perspective

We felt it important to obtain a primary care healthcare professional perspective, given that general practitioners currently serve as the single point of access to the Post-COVID service in City & Hackney.

We sought feedback from GP practices within all 8 neighbourhoods in City & Hackney, through a short online survey on their experience of managing Long COVID patients, referral pathway and sources of Long COVID information.

With the acknowledgment of time constraints faced by general practitioners, we disseminated a short e-survey to all GPs through the NEL practitioners'

newsletter, City & Hackney practitioners forum, and directly to practitioners' inboxes and primary care network contacts.

Referral Process

The majority of GPs told us that the referral process is time consuming, with long forms to be completed. We heard that given the current stress and work levels GPs are experiencing, the current referral process is not practical. This could result in some GPs not referring patients.

"Referral process is the most tedious process than any other. It takes me 30-45 mins for one patient. Totally unacceptable with current stresses. Leaves the GP overwhelmed with the process, instead of trying to focus on the needs of the patient."

"Referring patients is long-winded and requires a lot of information and investigation gathering. A lot of the time this is appropriate and forms part of the assessment process whilst seeing if patient fulfils long-covid criteria. For other patients who are more frail / complex, getting the information together takes too long and delays the referral."

We also heard from some GPs that the referral process can lead to patients being rejected as unsuitable for the services.

"Discouraged in general, given rejection rate when trying to refer. We are aware of the investigations required but it's an administrative burden, the odd test result sometimes doesn't get through."

"The referral process is long and arduous, seems as though it is not unusual to have referrals bounce back (has never happened to me)."

However, this is often the result of GPs failing to follow the full referral process, as the Long COVID service is unable to accept patients that may have been incorrectly referred.

This raises a concern, that we heard from residents in the focus group phase of this survey, that the referral process seems to take a very long time. This could be due to GPs not following the correct referral process, which delays the patient gaining access to the Long COVID service.

However, some practitioners felt the referral process had improved and that patients have benefited from accessing the Long COVID service.

"Referral pathways now seem quite clear information now available."

"I referred a patient with breathlessness to long covid clinic that was helpful, he saw physiotherapists and felt satisfied with the level of follow up The form is far too long however."

Resources

We wanted to gauge the efficacy and reach of clinician focused Long COVID resources currently available. Practitioners told us they sought Long COVID information from online sources, healthcare journals such as the BMJ and through personal study.

Also, 33% of GPs asked had accessed and viewed the Long COVID information videos available on the NEL Community of practice resources website and social media.

It should be noted that these videos were designed for both patient-viewing as well as healthcare professionals, indicating the need to highlight the key aim of these resources and encourage practitioners to share them more widely among patient-facing areas.

Others were either unaware of these resources or, commonly, despite being aware did not feel they had the time to watch the videos, given their workload pressures.

We also heard that the videos were "*scattered across websites*" and would be more easily accessible if held in one place.

Ongoing Support

We heard from GPs that more information about what CoRe services offer could be helpful. Feedback from the CoRe team about individual patients could also help GPs to offer them ongoing support.

“Not sure I have had much feedback from long covid team once the patients are under them?”

“Is there enough psychological support?”

“Once patients get there, they seem to be very happy with the support they receive. I do have one patient who has been severely affected by Long Covid and I have found both Joanna and Louise very helpful in thinking about her management. With regards to patients with non-Covid fatigue, fibromyalgia etc, I imagine that they would receive similar support via the CFS service?”

Practitioners felt integration with other linked specialties would be beneficial.

“It's great that this is MDT. It would be great if there was a way of also integrating, e.g. cardiology, since POTS is so common as well as respiratory and neurology, etc. Also, this was a while back so may have changed now, but think it would be useful to screen for post-exertional malaise. Thanks”

The CoRe service continue to work closely with City & Hackney primary care network colleagues and local healthcare commissioning bodies, to update and reform Long COVID resources in supporting easier access to the service.

This is being done in conjunction with feedback from general practitioner and HCP colleagues, to ensure resources are responsive to their learning needs while also feasible alongside their workload pressures.

Follow-up Patient Engagement & Co-design

Having analysed the data from the four focus groups carried out with survey participants, we took the survey findings back to patients with a view to consult and co-produce key recommendations to be incorporated within the final report. Our aim was to use this platform to amplify the patient voice and use people's experiences to help improve services for Long COVID patients in a meaningful way.

This face-to-face consultation gave us the opportunity to collaborate directly with Long COVID patients in identifying key areas requiring further support and focus. These were:

- Social, financial & housing support
- Employment support
- Resources for self-management
- Transparency in communication between different clinical specialties when treating patients with Long COVID
- Visibility & awareness of Long COVID in the community
- Language and attitude of clinicians towards patients
- Reliable sources of information and resources

(See Appendix 3 for full consultation feedback)

Conclusion

This project was undertaken to address the underrepresentation of marginalised communities accessing the City & Hackney Covid Rehabilitation (CoRe) Service, identified with the appointment of the Long COVID engagement lead.

Both the survey and the subsequent focus groups reached over 300 people across the area, listening to patient feedback, co-producing service improvements, building links with primary care services, local authority and community partners as well as voluntary sector organisations in City & Hackney. This project has helped to identify the unmet need with regards to Long COVID service provision and the associated services required to help Long COVID services across the population

A comprehensive engagement approach was implemented, involving both a survey and 4 subsequent focus groups, reaching over 300 people. This approach encouraged the receipt of patient feedback and facilitated the co-design of service improvements. Importantly, it also cultivated a deeper connection between Long COVID patients, primary care services, local authority bodies, community associates, and voluntary sector organisations in City & Hackney.

This initiative has helped to identify areas of unmet need in relation to Long COVID service provision, identifying additional services required to complement the delivery of Long COVID care across the population. These findings establish a foundation from which we can take further steps to improve service provision and, ultimately, the wellbeing of our community.

Recommendations

The recommendations aim to improve awareness, streamline care coordination, empower patients with self-management tools, and foster collaboration with relevant stakeholders. By implementing these recommendations, the CoRe Service and partner organisations can enhance their capacity to support Long COVID patients and effectively eliminate the barriers reported.

Awareness and Education:

1. Improved information from 'trusted' sources. NHS website and locally, City and Hackney public health information.
2. Clearer published information on patient pathways
3. Information campaign to GP surgeries and secondary care providers across City and Hackney with online webinars and leaflets in surgeries and hospitals.
4. Information produced in other languages.
5. Workplace education – information pack for employers, detailing workers rights and support recommendations. Provide resources to employers and unions about Long COVID and its impacts, including the need for flexibility and possible accommodations.
6. Provide up-to-date information about Long COVID and available support services on a centralised website, making it easily accessible for patients, healthcare professionals, and the general public.
7. Offer training and education programs for healthcare professionals, including GPs and specialists, to enhance their understanding of Long COVID, its diagnosis, and management and Promote transparent communication among clinicians about Long COVID patient's care. Training to include support for healthcare professionals to take a respectful and understanding approach towards CoRE patients (recognise challenges faced by those who may not appear visibly unwell but are nevertheless struggling with the condition).
8. Emphasise guidelines and protocols for healthcare professionals on diagnosing and managing Long COVID, including specific criteria for referral to the CoRe service.

9. Consider allocating a Long Covid Care Coordinator for patients as a single point of contact for patients.
10. Long Covid volunteer champion – responsible for sharing and promoting communications to communities, engaging local orgs and residents in information sharing conversations. Gathering and feeding back insights.
11. Provide guidance to Long COVID patients on how to navigate the benefits system, especially to those experiencing job loss or reduced hours due to their condition.

Enhanced Referral Process and Care Coordination:

1. Single care plan shared between care providers.
2. Streamline the referral process for Long COVID patients, ensuring that it is efficient, timely, and well-communicated to healthcare professionals.
3. Improve sharing of information between primary care providers, specialists, and other healthcare professionals involved in the care of Long COVID patients, facilitating a multidisciplinary approach to treatment and rehabilitation. This could look like a single care plan shared between care providers.
4. Consider allocating a Long Covid Care Coordinator for patients as a single point of contact for patients.

Support for Self-Management:

Co-design resources and tools for self-management of Long COVID symptoms, including guidance on lifestyle modifications, coping strategies, and techniques for managing physical and mental health challenges.

Collaboration and Partnerships:

1. Proactively target communications and information to under-represented communities. Go to where communities are rather than expecting them to come to us – share information through VCS orgs, lunch clubs, libraries, community centres, healthcare facilities, and online platforms, wellbeing groups. Recruit a volunteer to distribute comms material.
2. Outcomes appraisal – 6/12 months following report publication follow up on work by actively seeking patient feedback to measure outcomes and identify ongoing areas for improvement.

Inclusive Support Services:

1. Develop peer support programs including older individuals, men, those going through menopause, and cultural groups less likely to seek help (support groups; exercise classes; workshops on relevant topics that promote and support social inclusion and engagement).
2. Expand existing peer support groups – consider using non-clinical local settings.

Next Steps

It is hoped that the findings and recommendations of this report, on the experience of Long COVID patients in accessing rehabilitation services, will serve to influence service providers, commissioning groups and healthcare trusts to better address the discrepancies in engagement which triggered this research and increase inclusion by working on more efficient collaboration between partners to better serve the health needs of the population in City & Hackney. If implemented, these recommendations will lead to better coordinated services, providing increased access to services and support for our diverse communities.

It is our hope that the insights gained from this report, coupled with the recommendations put forth, will enable service providers, commissioning groups, and healthcare trusts to better tackle the identified discrepancies in engagement that prompted this study.

To foster increased inclusivity, it is crucial that we cultivate a more efficient, collaborative environment among all involved partners. This will not only enhance the level of service provided but also ensure it better aligns with the health needs of the population in City & Hackney.

We believe the adoption of these recommendations will contribute to a significant improvement in the coordination of services which will, in turn, pave the way for broader accessibility to services and support, thereby more effectively meeting the needs of our diverse communities.

Appendix

Online Long COVID survey of 231 City & Hackney residents – Summary of findings:

During November 2022 – January 2023, 231 people completed our survey on Long COVID. This section summarises key findings – see [here](#) for findings in full.

Overall Findings

- A broad majority of respondents (84%) have tested positive for COVID-19.
- When seeking medical support for COVID-19 infection, the GP (48%) and hospital (40%) are the most common services used.
- Just under two thirds of respondents (61%) have been diagnosed with Long COVID.
- Symptoms most mentioned are fatigue (57%), difficulty concentrating (54%), muscle ache (45%), memory problems (41%) and shortness of breath (40%).
- Just under two thirds of respondents (62%) know how to seek support.
- When seeking support following diagnosis of Long COVID, the GP, at 54% is clearly the most commonly used service.
- Over two thirds of respondents (69%) are aware of the symptoms of Long COVID.
- The greatest impacts on daily life are difficulty with socialising (41%), inability to work (37%) or having to make working adjustments (35%), inability to study (35%) and difficulty with caring responsibilities (29%).
- Around two thirds of respondents (67%) are aware of the City and Hackney COVID Rehabilitation Service (CoRe).
- 60% of paid employees feel their employer would be supportive, while 15% feel they would not be.
- A sizeable minority (28%) feel that language may present a barrier, when seeking or using services.
- Disincentives, or barriers to seeking support include money issues (35%), caring responsibilities (34%), previously poor experiences when seeking help (24%), a lack of information or confidence in services (both at 22%) and employment issues (21%).

Findings by Age

- Respondents of later working age (50 – 59) are significantly most likely to have tested positive for COVID-19.
- Those of mid-working age (40 – 49) are clearly most likely to have consulted with their GP. The youngest respondents (aged 21 – 29) are by some margin, most likely to have visited the hospital, and also least likely to have contacted NHS 111.
- Those of mid-working age (40 – 49) are most likely to have been diagnosed with Long COVID.
- The youngest respondents (aged 21 – 29) are over twice as likely, to know how to seek support, compared with the oldest (60+)
- Following a diagnosis for Long COVID, the youngest respondents (aged 21 – 29) are by far, least likely to consult with their GP. The oldest respondents (aged 60+) are by some margin, most likely to have received support from the Post/Long COVID clinic, and also most likely to have used online services.
- Respondents of mid-to-late working age (40 – 59) are most aware of Long COVID symptoms.
- The oldest respondents (aged 60+) are by some margin, least aware of City and Hackney COVID Rehabilitation Service (CoRe) services.
- The youngest respondents (aged 21 – 29) are noticeably most likely to consider language as a potential barrier