

healthwatch

Barnet Camden Enfield Haringey Islington

People's Experience of Long COVID in North Central London

April 2022

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Background

Long COVID is a new and evolving condition that can greatly impact the health and quality of life of many people. The precise causes of Long COVID are not yet known and the recovery time varies for each patient. More research is required to develop a standardised treatment pathway from diagnosis to treatment and management of the condition.

There is currently no agreed clinical definition, however the National Institute for Health and Care Excellence recommendation is that 'Ongoing symptomatic COVID-19' be used when symptoms continue after 4 weeks of contracting COVID-19 and are not explained by an alternative diagnosis; and 'Post-COVID-19 syndrome' is used when symptoms continue beyond 12 weeks or newer symptoms develop. Both are commonly called Long COVID by laypeople.

Long COVID presents itself through a wide range of clustered symptoms. A study conducted by University College London¹ identified Long COVID patients self-reported over 200 symptoms across 10 organ systems². The most recent data from the Office for National Statistics show that an estimated 1.5 million people self-reported experiencing Long COVID symptoms as of 31st January 2022³.

To tackle the debilitating impact of the condition, the Long COVID NHS Plan for 2021/22 outlined an investment of £100 million to support patients. There are now approximately 90 Post-COVID Specialist Clinics across England that support patients where previous medical care did not aid their recovery. These specialist clinics provide physical, cognitive and psychological treatment. The plan

also outlines the establishment of paediatric hubs to support children and young people suffering from Long COVID.

University College London Hospitals (UCLH) provides the Post-COVID Specialist Clinic service for residents across North Central London (NCL). The chart below shows the Long COVID patient pathway.

¹ www.nice.org.uk/guidance/ng188/resources/COVID19-rapid-guideline-managing-the-longterm-effects-of-COVID19-pdf-51035515742

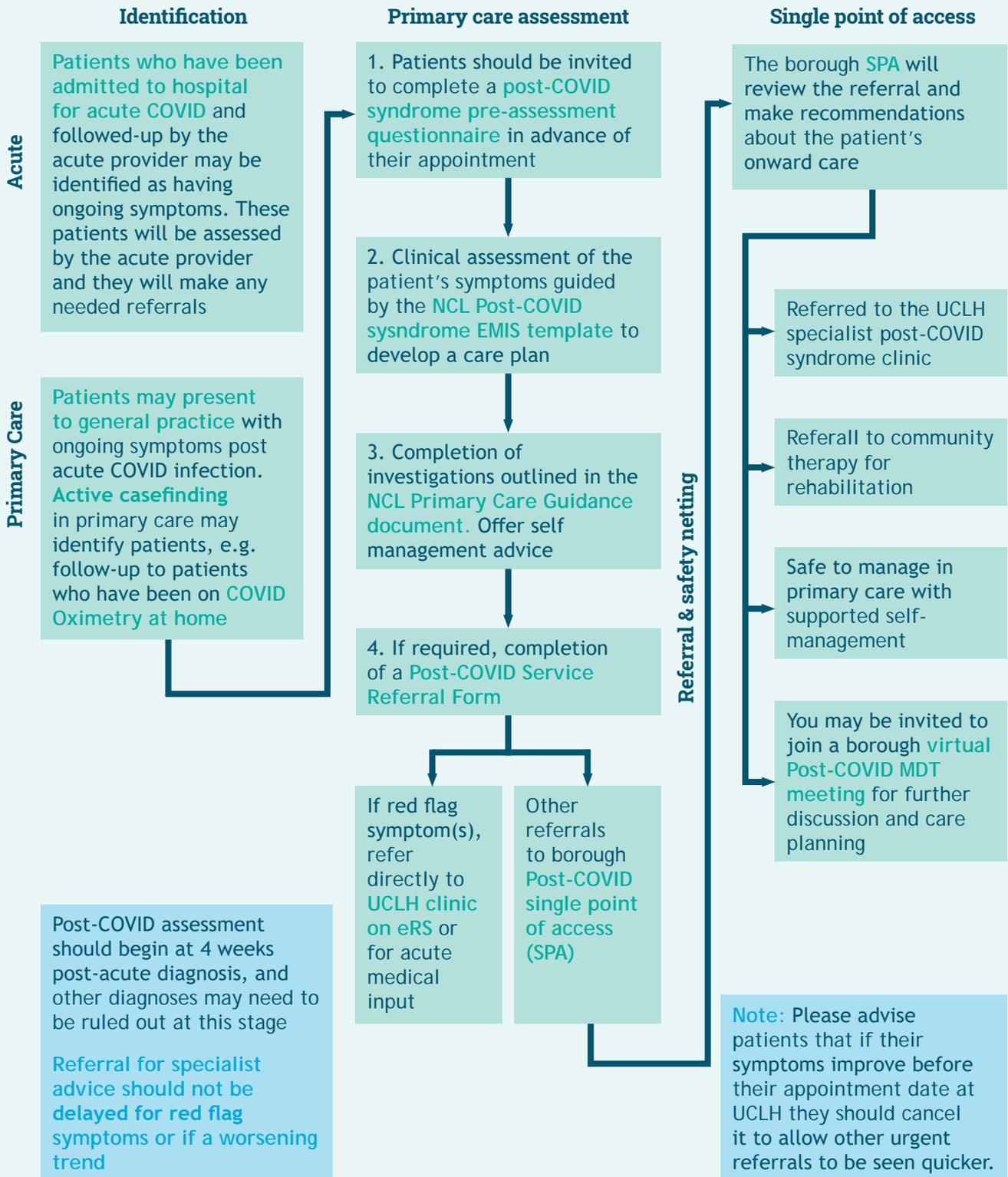
² www.ucl.ac.uk/news/2021/jul/identification-over-200-long-COVID-symptoms-prompts-call-uk-screening-programme

³ www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/3march2022



North Central London Integrated Post-COVID Syndrome Service

NCL Patient Pathway



What we did

The five Healthwatch organisations across NCL (Healthwatch Barnet, Healthwatch Camden, Healthwatch Enfield, Healthwatch Haringey, and Healthwatch Islington) agreed in the summer of 2021 to work in partnership together on a joint NCL Long COVID project.

The core aims of this project were:

- To capture local people's experiences of Long COVID in order to identify any gaps in current provisions.
- To support the better development of services and systems to help local people to manage their symptoms.

To gather insight on local NCL residents' experiences of living with Long COVID, we jointly agreed on a hybrid methodology: an anonymous online survey, 1-2-1 interviews and community focus groups.

Survey respondents had the option to participate in a follow-up 1-2-1 interview to enable us to gather detailed in-depth qualitative data.

We also shared our draft survey with the North Central London Clinical Commissioning Group, who developed the local patient pathway, and we implemented their feedback in our online survey.

Each Healthwatch worked with local voluntary sector organisations to broaden their reach and gather robust responses, and we entered every person who took part into a prize draw to win one of five £50 gift vouchers to increase engagement.



We also engaged and shared our survey with local press and statutory healthcare services that support people with Long COVID.

We aimed to gather experiences of people across the whole treatment pathway, from those seeking support in primary care from their GP, those receiving support in the community, those who required support from a specialist Long COVID clinic, and those who had never reached out for help and were managing symptoms on their own.

The survey covered the impact of Long COVID on patients' lives, their physical and mental health, access to NHS treatment, experience with healthcare professionals and suggestions for improvement. Subsequent 1-2-1 interviews and focus groups loosely followed a similar structure of questions. In total, we gathered 300 local peoples' experiences of Long COVID across NCL. The data from this report was collected from September 2021 to February 2022.

Local Healthwatch	Survey Reponse	1-2-1 Interviews	Focus Groups	Community Event/Others
Healthwatch Barnet	63	18	2	1
Healthwatch Camden	79	5	0	3
Healthwatch Enfield	53	0	0	0
Healthwatch Haringey	21	4	0	0
Healthwatch Islington	38	14	1	0



Respondent profiles

For our online survey, we provided an option for the respondent to contribute additional information if they wished to share their details or they could skip this section. We gathered demographic data from approximately 190 of 254 respondents.

A full breakdown of the demographic data can be found in the appendix 2.

- 87% of people surveyed answered on their own behalf, 2% on behalf of a child under 18, 2% for an adult they are caring for and 7% for others, which includes local organisation partners, staff members and family.
- More than half (51%) of the people surveyed were aged 45 to 64.
- 79% of the people surveyed were female, 20% were male and 1% were non-binary.
- 43% of people surveyed were from ethnic minorities.
- 24% of people surveyed said English was not their first language.
- More than half (54%) of people surveyed have a long-term condition.
- One-quarter (25%) of people surveyed considered themselves to have a disability.



Summary of findings

Impact on Health

Physical Health
Mental Health
& Wellbeing

Impact on Life

Employment & Job Security
Home Life

Experiences with the Health Care System

Accessing the Long COVID Pathway
Healthcare Support & Referrals
Useful Interventions
Diagnosis
GP Knowledge

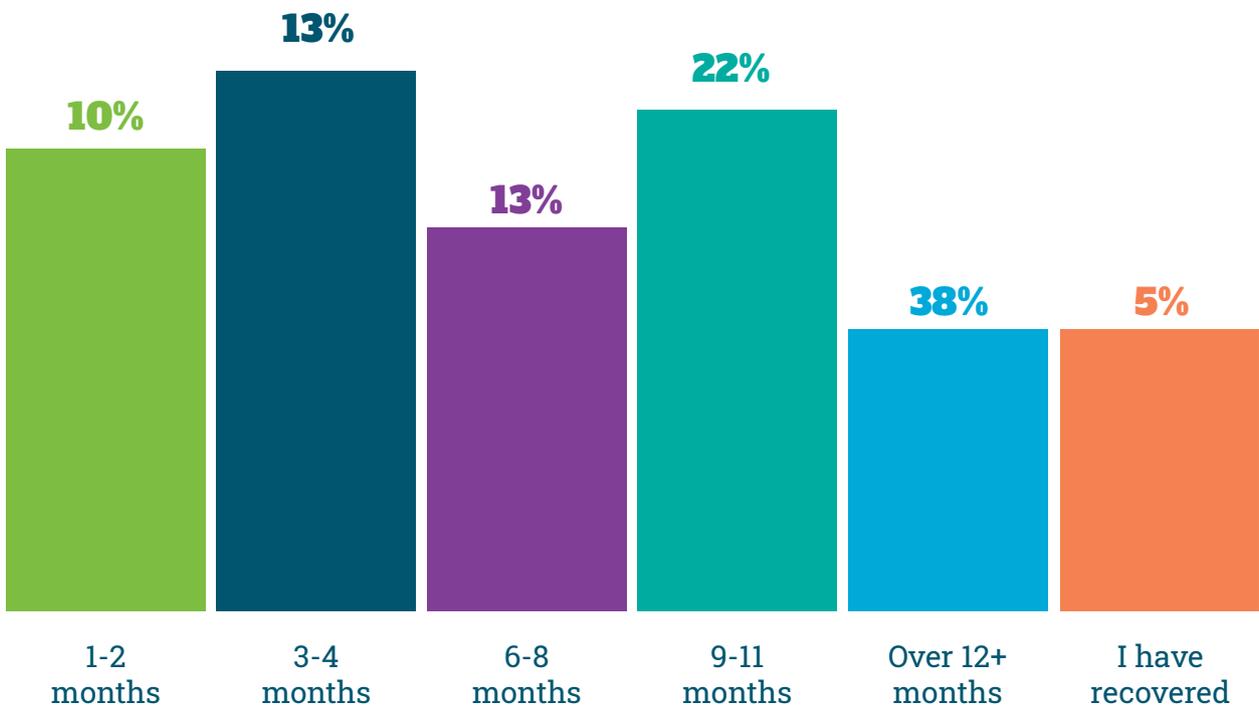
Moving Forward

Improve GP's Knowledge
Recognise Patients' Symptoms and their Impact
Improve Awareness of the Support Already Available
Improve Access to Primary Care
Improve Access to Specialist Care Where Needed
Enable Continuity of Care
Share Self-Management Techniques Early
Peer Support Groups



What we found

Almost three quarters (73%) of respondents reported that they had been living with Long COVID for 6 months or more, with various symptoms affecting their physical and mental health. People who have been long-term Long COVID sufferers describe different phases of the illness, where symptoms might change, be less frequent or more severe and where symptoms may not present during the transition from acute COVID to Long COVID.



Physical Health

Patients described an array of physical symptoms, most of which are in line with the current understanding of Long COVID symptomatology, such as fatigue, tiredness, muscle and joint aches, coughing, 'brain fog', shortness of breath, general pain, pins and needles, dizziness, gastric distress, sleeping difficulties, tinnitus and rashes.

Recurring earache, mucus at the back of throat, tiredness, headaches, sore throat, wheezing/shortness of breath.

Islington Resident

Fatigue, poor concentration, insomnia, impaired taste and smell, abnormal toes.

Camden Resident

Severe pins and needles in my arm which was so painful that I went to A&E as I couldn't walk without extreme pain. This lasted nearly 6 months. Additionally fatigue and sleep problems for 6 months.

Barnet Resident

Breathlessness and other respiratory difficulties, severe fatigue, muscle pain, fever, severe loss of taste/smell, severe problems with memory and concentration, severe anxiety, chest tightness/heart palpitations, headache, mild insomnia, moderate memory loss, Low mood anxious/fear. Fever, tightness in the chest, headache, and breathlessness - has improved. Fatigue. Tiredness, little appetite, anxiety, brain fog has continued.

Barnet Resident

I am tired all the time. I am breathless, have palpitations chest pains, pain in muscle and bones. I suffer from brain fog and forget all the time. Mentally and physically I am tired I am stuck in this nightmare can't make plans and don't know when it will end.

Haringey Resident

The symptoms make me tired and brain fog, random spasms aches and pains stiff joints. Palpitations. Insomnia. Migraine. Chest and thought tightness/ feels like blocked.

Reoccurring coughs with mucus.

Camden Resident

I am constantly tired and need to sleep more, my joints hurt, I still have a persistent dry cough which wakes me so my sleep at night is disturbed every night. It's difficult to explain but my bones hurt I have headaches and earaches which is making me feel useless like I can't do anything anymore as every time I start to do anything I cannot finish it because I get too tired and I have to stop and sit down. **Enfield Resident**

I have been unable to smell at all for months and my taste has been affected by a bad aftertaste on everything I eat.

Islington Resident

Body aches, have to make a real effort to do things. Headaches. Difficulties concentrating. Loss of taste. General lethargy.

Enfield Resident

I felt exhausted. Had no energy and couldn't walk very far. I had digestive problems such as severe stomach acid. I felt nauseous after eating. My chest hurt. I couldn't smell anything.

Barnet Resident

I wake up EVERYDAY with a splitting migraine. Although I did get migraines, they were perhaps once a quarter or so. I also get random bouts of nausea. The feeling is strong and very sudden. So I have to lock myself in a toilet and just heave. I get fatigued for no reason. It's not like being just tired- it's the inability to get up and take care of yourself. I often have to lie down or drink something sugary.

Barnet Resident

I cannot smell and taste which affects my enjoyment. I now have developed Parosmia and so things that should smell nice, perfume, shampoo, and certain foods make me feel ill and are so overpowering. They do not smell as they should.

Enfield Resident

At the age of 35, I'm not able to live a normal life. I'm in so much pain and I'm so exhausted that all I can do is force myself to work from home and stay in bed. All the joy is gone, there is only pain, exhaustion and anticipation of more pain. I used to be an active smart person now due to the brain fog I feel like an idiot most of the time.

Haringey Resident

Mental Health & Wellbeing

A secondary impact of developing Long COVID is the effect it can have on a person's mental health. Respondents often reported struggling, particularly compared with who they were before to who they are now. Effects on patients' wellbeing include: lower self-esteem and confidence, reduction in engagement with their family, friends and other social activities, increased anxiety and low mood, as well as depression.

This has had a knock-on effect on my mental health. Not being able to work, take care of my household or family is very frustrating and relying on others is demeaning.

Barnet Resident

My mental health has been bad as a result. I've been depressed and anxious, started self-harming a bit, have given up on trying to look after my physical health at times. I feel like my physical and mental health has been really low. And that there is very little support. I am lucky to have some friends even if they are not close by. One tried to phone the local mental health crisis team for me.

Enfield Resident

Confidence and self-esteem are low. GP didn't believe me.

Barnet Resident

I have never been diagnosed with depression or anxiety, I have always been really positive and energetic. This whole year however I have viewed things really differently I have looked at things really negatively and have had really intrusive bad thoughts, obsessive thoughts. I have been really down (this is not due to lockdown as I have continued to work through the pandemic as frontline staff for a homeless charity) so I have kept active but I have become a shell of a person.

Camden Resident

All of these physical health symptoms have impacted my mental health. I get really down from not being able to do as much as I'd like with my son, or have to be really picky on what plans I make with friends. I get really anxious and stressed about how much I am behind in work and other aspects of life, which then impacts my relationships with friends and family. Long COVID has crept into every aspect of my life in silent, insidious ways - it's debilitating & demoralising.

Camden Resident

All these of course have had an impact also for my mental health made me feel depressed. Because Long COVID is a relapsing illness, it is extremely hard to mentally cope with a relapse in the symptoms after a better period (when I have thought that finally I am almost back to normal and then the daily pains and exhaustion are back again).

Barnet Resident

It's a yo-yo: anxiety is there all the time but I never know what else I'm going to feel eg anger/irritation/depression/ gnawing anxiety/irritation/apathy/ bouts of crying etc.

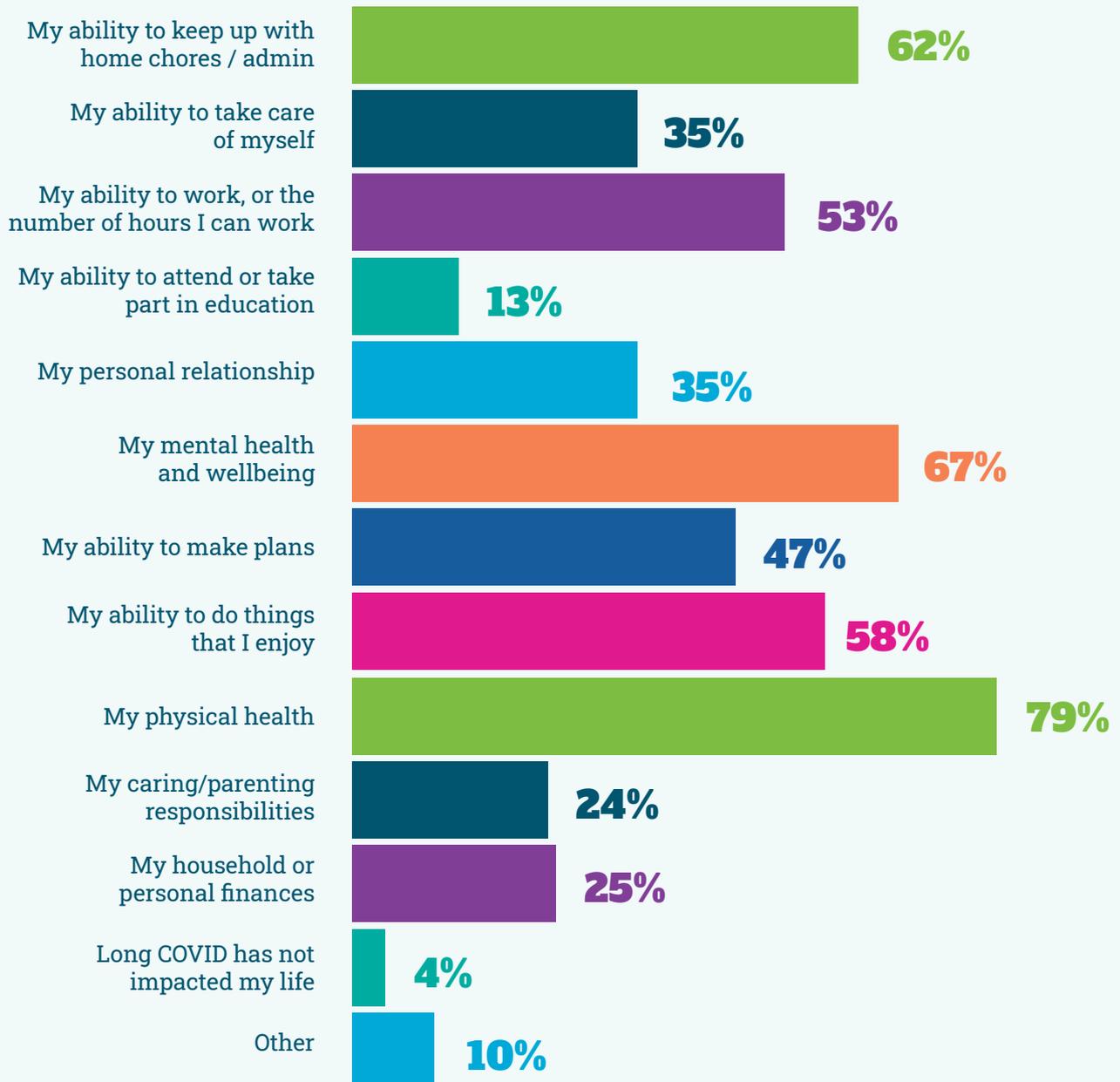
Haringey Resident

My mental well-being is pretty bleak because of the gaslighting and lack of support I received. I can manage mentally with the ups and downs of Long COVID but being denied adequate support is hard to bear. I feel useless and hopeless.

Camden Resident

Impact on Life

Long COVID has negatively impacted patients' lives, from their employment status, job security, finances, relationships with the family and friends, to their home life completely debilitating some patients' lives.



Employment & Job Security

The various symptoms patients experienced caused challenges in their ability to work, leading to some respondents having to reduce their working hours, voluntarily stop working or be made redundant. Consequently, this had an adverse impact on some respondents' household finances.

Those in active employment have felt pressured to return to work due to the lack of understanding of the challenges Long COVID can present. Many also worried about the number of days which they have taken off work, which for some could result in disciplinary action.

Furthermore, respondents whose job relied on skills that Long COVID particularly impacts, such as memory, cognitive skills, or strong physical strength, found it more difficult to go back to work or maintain their employment. Examples included acting, DIY/handyman, medical professionals and interpreters. Those who were on a zero-hour contract were impacted the most as they only get paid for the days they have worked and do not receive the wider benefits associated with a permanent role.

“ Yes, I lost my job after 25 years.
Islington Resident ”

“ I was unable to work for 40 days.
Camden Resident ”

“ Too many sick days and fear of being replaced.
Barnet Resident ”

“ I have had to drop down my hours at my job due to COVID.
Camden Resident ”

“ It has put me on universal credit. I am self-employed and having Long COVID meant that I accrued a work debt that I am still trying to pay off. I was unable to claim for a self-employment grant or anything similar because I didn't fit the narrow criteria.
Haringey Resident ”

“ Long COVID has badly affected the organisation I used to work for and I, along with many others, accepted voluntary severance.
Haringey Resident ”

“ I was a sign language interpreter so I’m not able to process two languages at once at the moment and because I suffer from chronic fatigue, I just don’t have the energy to be processing.
Barnet Resident ”

“ I work as a nurse but I’m on a zero-hour contract so I only get paid for the days I work and I can’t always manage much.
Islington Resident ”

Notwithstanding, not all respondents experienced negative concerns about their employment and job security. Some were retired, on furlough or in receipt of welfare benefits. A few found their employer to be understanding and made accommodations to enable them to work flexibly.

“ It hasn’t impacted my job as such, because my job is quite flexible. Some days my productivity is very low because my energy and mood are low, but I can make it up out of hours or not do lower priority tasks.
In another job, I might well have had to stop working or reduce my hours.
Enfield Resident ”

“ I’m new in my post, I’ve only been in my job for like a couple of months. And I didn’t tell them immediately. But obviously, I had to tell them that, I didn’t have to, but I decided to because they are so nice. And they’ve been really supportive and understanding.
Barnet Resident ”

“ I’m very lucky as I work 2-night shifts a week and I can spread them out if I have a bad spell.
Islington Resident ”

“ Work has been very understanding as I have been able to work from home.
Haringey Resident ”

Home Life

Participants described struggling with a range of activities in their home life. These included personal care, leisure activities, maintaining a healthy lifestyle including regular exercise, life planning, relationships, caring responsibilities and education.

“ I've had to move home, I was in rented accommodation. I couldn't afford to stay there, I also couldn't look after myself and remain independent. So around the house, I rely on other people to help me like they do the shopping, cooking cleaning. I have help washing as well, sometimes on bad days. So it's been a huge life change from being very independent to relying on people around me for support. ”
Barnet Resident

“ Not being able to work, take care of my household or family is very frustrating and relying on others is demeaning. ”
Barnet Resident

“ I now have limited mobility I use a stick or a wheelchair to get around for longer distances. I've had to move home. This is a huge life change to rely on family members so in turn has affected my mental well-being. ”
Barnet Resident

“ I can't exercise as my heart rate goes up and I get chest pain and then so exhausted after a short amount of slow walking. I'm gradually building this up but over 5 months I can still only walk for 30-40 minutes. I'm gaining weight. I am so down a lot of the time, feel guilty for not working and sad about missing so many of my usual social activities. My relationship is suffering as I'm so down and not at all fun. ”
Haringey Resident

“ Can't do the things I used to be able to do - even though I was young, fit and healthy before catching COVID. ”
Enfield Resident

“ I've been exhausted for 11 months and it has been a struggle to do daily life maintenance tasks such as cleaning, changing the duvet covers, hoovering. My normally very active social and cultural life has been reduced enormously and I have become somebody who watches TV most nights having not watched TV for 30 years! ”
Camden Resident

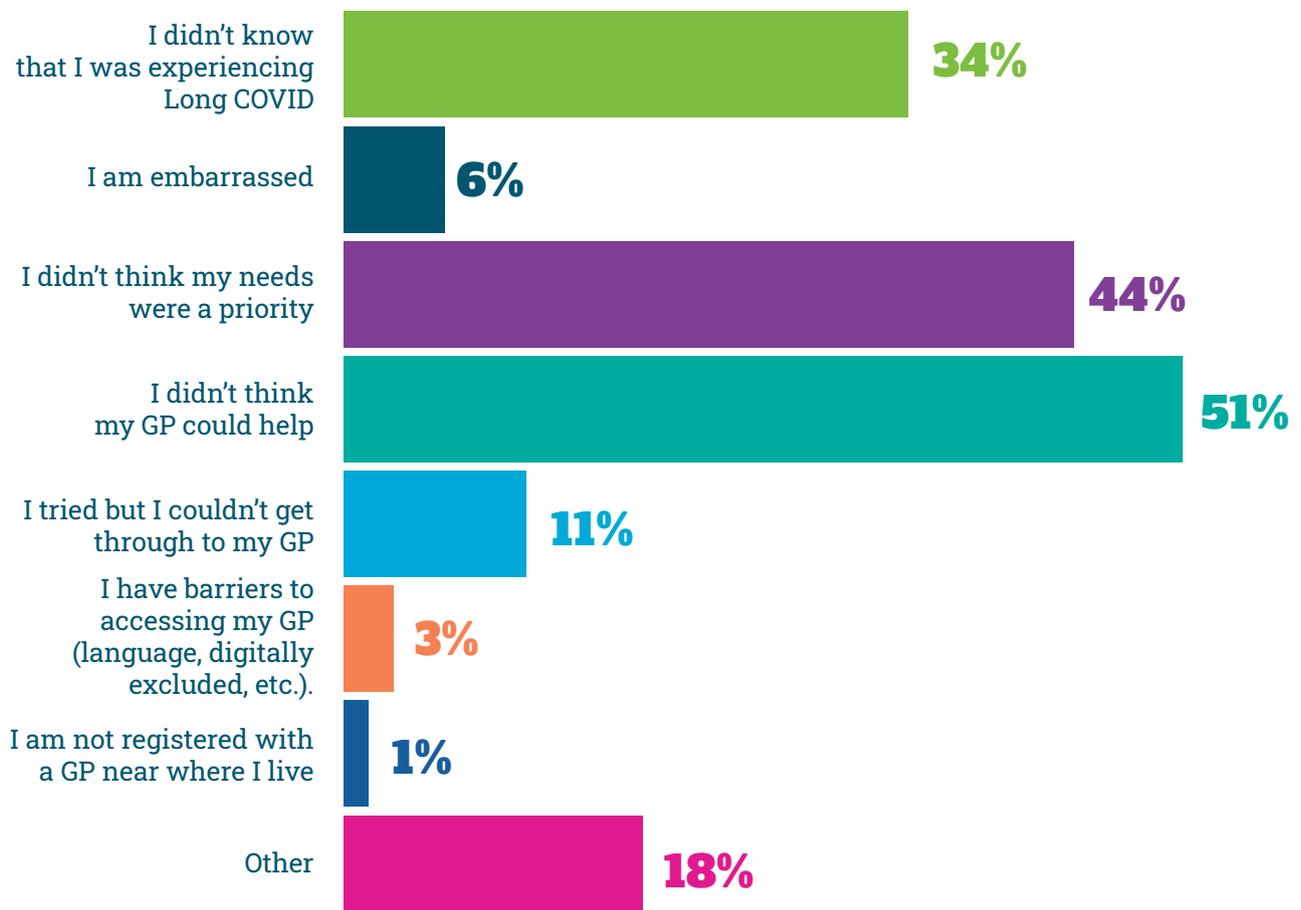
Experiences with the Healthcare System

Respondents described their experience of accessing and using the healthcare system, with challenges in receiving a diagnosis and referral and a lack of knowledge of Long COVID among GPs, causing low satisfaction rates amongst patients. Respondents also discussed interventions that had helped their condition and any self-management techniques they had used.

Accessing the Long COVID Pathway

67% of respondents went to see their GP or other health care professional about their Long COVID symptoms.

33% of respondents did not see their GP or other health care professional about their Long COVID Symptoms. A breakdown for the reasons why these people did not contact their GP is below, with 51% of respondents reported that they did not think their GP could help them followed closely by respondents reported they did not think their needs were a priority, which was common amongst most of the nation during the initial lockdowns when people otherwise would have sought medical help.



Diagnosis

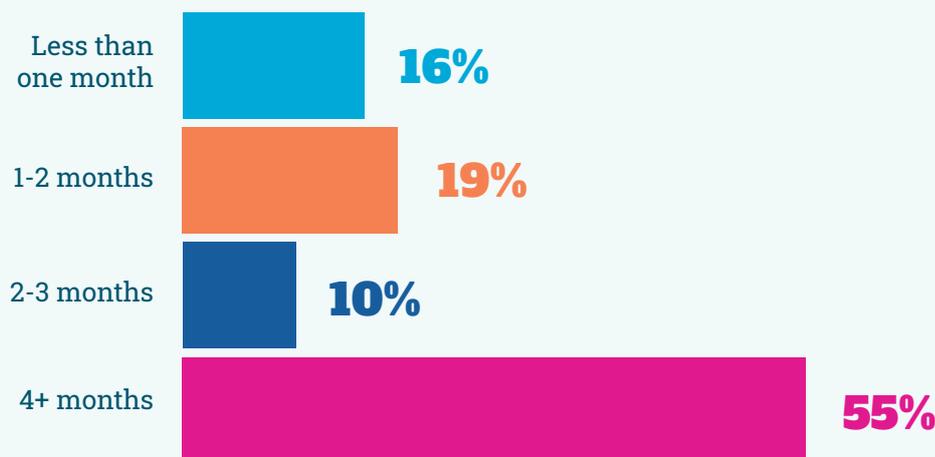
Of those who went to their GP or other health care professionals, 61% of respondents were formally diagnosed with Long COVID.

Some of our one-to-one interviews showed that those who got COVID early in the pandemic, ‘first-wavers’, had difficulty getting COVID-19 tested. For some, this has caused an extra barrier to diagnosis and help, which left them feeling forgotten.



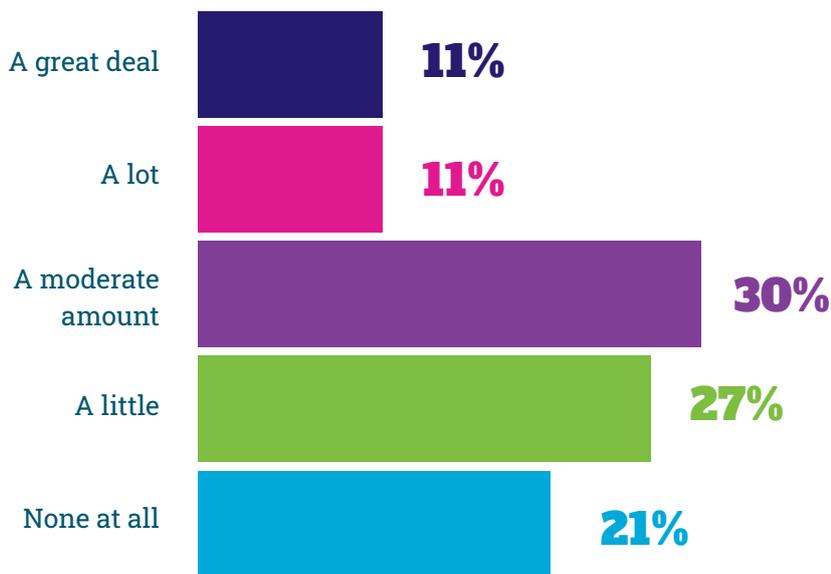
More than half (55%) of the respondents who have gone to their GP and been diagnosed with Long COVID reported it took 4 months or more to receive the diagnosis.

The lack of a timely diagnosis has contributed greatly to many peoples’ negative experiences. Better processes and systems need to be put in place to enable diagnosis of Long COVID for patients.

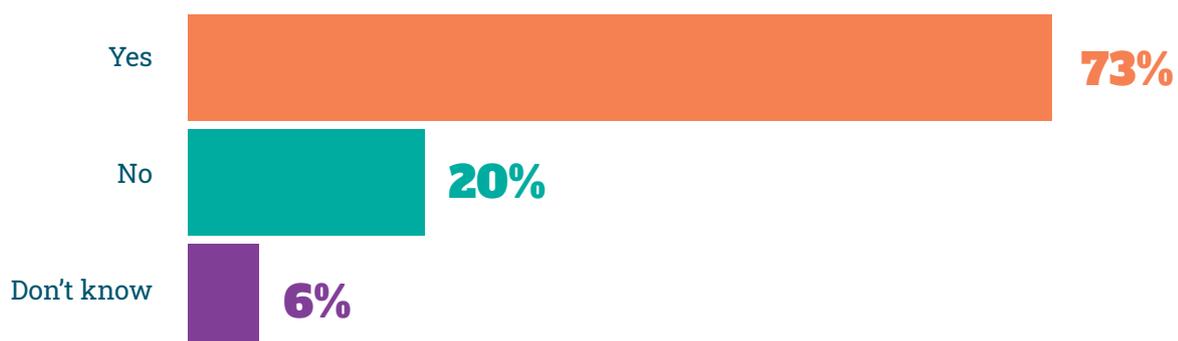


GP Knowledge

A common theme that was repeated by respondents was the feeling that GPs lacked the knowledge to help patients with Long COVID. 27% of respondents said they think GPs had 'a little' knowledge about the symptoms and effects of Long COVID, and 21% of respondents said they think GPs had 'none at all' about the symptoms and effects of Long COVID.



Consequently, almost three quarters (73%) of respondents reported they had to conduct their own research into Long COVID. There were multiple reasons why people felt the need to conduct their own research which include experiencing symptoms unaccounted for; not having been given sufficient information about their condition from their GP; taking ownership of one's own health needs, looking for treatment options; an awareness of the novelty of the condition and therefore cognisance that medical professionals may not have all the answers; looking for other people with similar experiences for support and sharing of treatment and self-management ideas.



- “ Initially, there was limited support from the GP practice. I ‘saw’ three different doctors until one understood what I was experiencing.
Camden Resident ”
- “ Complete lack of advice and support on how to manage my symptoms. I’ve been told to rest, to drink lots of water and eat well. This is advice you’d give anyone and isn’t at all helpful. I haven’t got a clue what to do - should I try to exercise more? How to manage breathing problems? Is chest pain a concern?
Camden Resident ”
- “ I feel very unsupported and alone and need to manage the 20 plus symptoms endured in some way during the past 20 months.
Camden Resident ”
- “ As no local support groups offered and I felt just left to my own after hospitalisation.
Islington Resident ”
- “ My GP is unaware of Long COVID and where to refer me to, and they have yet to tell me my symptoms are actually Long COVID. So I have been researching online to find out more information and see if there are other people like me. I also wanted to find out what I could do to help myself. GPs really lack knowledge here and need training by the NHS.
Barnet Resident ”
- “ I work in a medical setting so this has been easier for me. I have been struck by the lack of knowledge re Long COVID and the lack of compassion shown by some GPs. They have been dismissive, lacking in any management plan and keen to psychologise my symptoms. I’ve had to push for the referrals. I worry about those patients who are not able to advocate for themselves.
Haringey Resident ”

- “ I had several visits to the GP but did not improve or receive any diagnosis. The GP advised there was nothing they could identify and I had to contact them again if symptoms persisted. It was only after approx 6-9 months that a rheumatology referral was made following repeated visits to the GP. During this time I had to research chronic fatigue & Long COVID myself for further information.
Barnet Resident ”
- “ I wanted an NHS self-help type of leaflet you get for medical problems but my GP said she didn't have one so I started to look online for advice.
Barnet Resident ”
- “ When I spoke with my GP she didn't have much to offer me. So I went online and found support groups like the Long COVID support network where I've learned so much.
Barnet Resident ”
- “ Not much help from NHS until 10 months in.
Islington Resident ”



Healthcare Support & Referrals

Respondents described difficulties in accessing healthcare support and referrals:

- Half (51%) of the respondents had difficulties in getting appropriate healthcare support for Long COVID such as referral to the specialist Post COVID Clinic, Community Teams, diagnostic testing within primary care, or being informed of general self-guided support.
- Respondents not being made aware of the available support.
- Reluctance to recognise and poor understanding of Long COVID by GPs.
- Significant delays in referral acceptance from primary care to secondary care.
- Poor communication between the Long COVID Clinic, GP services and other secondary care providers that left patients without adequate support resulting in the patients needing to chase up for results and follow-up appointments.
- Pre-existing challenges with patients trying to book appointments with their GPs.
- Lack of treatment options once patients are at the Long COVID Clinic because unlike other conditions managed in secondary care by Consultants who have access to treatment not available at primary care, the Long COVID Clinic Consultants have limited options and resources to treat Long COVID.

“ I didn't get referred to that long COVID unit until I think maybe March 2021. I spent a whole year until I got any kind of real support. That November 2020 when they discussed Long COVID, I got referred to respiratory but I've never ever been seen by respiratory because my referral, in the end, got cancelled. It kept getting moved due to the lockdowns and I just got a letter saying that has been cancelled. I didn't bother to chase it because I was under Long COVID unit and I just was a bit tired of chasing everything myself. Barnet Resident ”

“ I had to speak to 3 GPs at my practice before I was referred to the Long COVID clinic (roughly 5-6 months after suspected onset). Since being referred to the Long COVID clinic I have had to self-initiate follow up during a serious relapse and self-initiate treatment options which I had been refused by my GP. I am also still yet to hear from the community team that I had supposedly been referred to in March 2021 by the clinic. Camden Resident ”

I had to wait 3 months to be referred by my GP to Long COVID clinic and then another 2 months before a call/appointment. After the excitement of being finally seen by the 'experts' and a few tests being organised (and a lot of signposting for me to do), there was nothing for months. No feedback on test results, I did message and got another phone appt. 10 months in and feel completely despondent with the clinic in so many ways.

I need someone to help me with the physicality of Long COVID not just the emotional aspects of Long COVID.
Haringey Resident.

I contacted Queen Square over a year ago - 'Brain Fog' focus as long COVID clinic opens at London hospital' an article by Ross Lydall Health Editor but was told I did not qualify for enrolment.

Camden Resident

I had a fairly quick referral to the Long COVID clinic at UCLH, but when the results did not show any issues, I was left to find ways to manage the recurring symptoms myself.

Islington Resident

My first two referrals were turned down by the hospital but my GP never did anything to address this. So after 7 months of waiting for someone from the Long COVID clinic to contact me, I found out by myself that the referrals had never been accepted. My GP left me without any care. They did however prescribe medication for depression after asking 10 questions about my mood over the phone while I was suffering from terrible pain and high fever. I was recently referred to the clinic by a new GP, however, I don't actually believe anything will happen. I also got referred to have blood test done however that was cancelled too, due to a shortage of the testing tubes.

Haringey Resident.

The whole Long COVID clinic experience has been almost non-existent and has had a terrible effect on my mental health.

Barnet Resident

“ I have seen my husband struggle for over a year to get his referral to the Post COVID clinic. I didn't even want to attempt to tell them about me because of all the extra barriers. I haven't got the energy to fight to be seen.
Islington Resident ”

“ Such a nightmare getting a referral to cardiology for my heart problems. Numerous phone appointments were made and then after waiting at home all day for a call, I never received one. Then I got a call at 8 am unexpectedly so wasn't prepared with what I wanted to say and didn't mention all my symptoms
- I'm more confused and foggy in the morning.
Feels so unfair not to have a warning. Waiting for months still for an appointment at Long COVID clinic, still no news on that - I first saw my GP in July.
Haringey Resident. ”



Useful Interventions

44% of respondents said the most helpful intervention to support their Long COVID recovery was self-management techniques, and 61% of respondents found out about the self-management techniques themselves. People were desperate for answers, for coping strategies, and to understand how long this condition might last. Many patients, desperate for relief, paid large sums out of pocket for additional services such as acupuncture, supplements, massage and more. This further exacerbates health inequalities as not all people can afford such additional treatment.



I was desperate to make progress...
Didn't want to just sit around being helpless.

Camden Resident

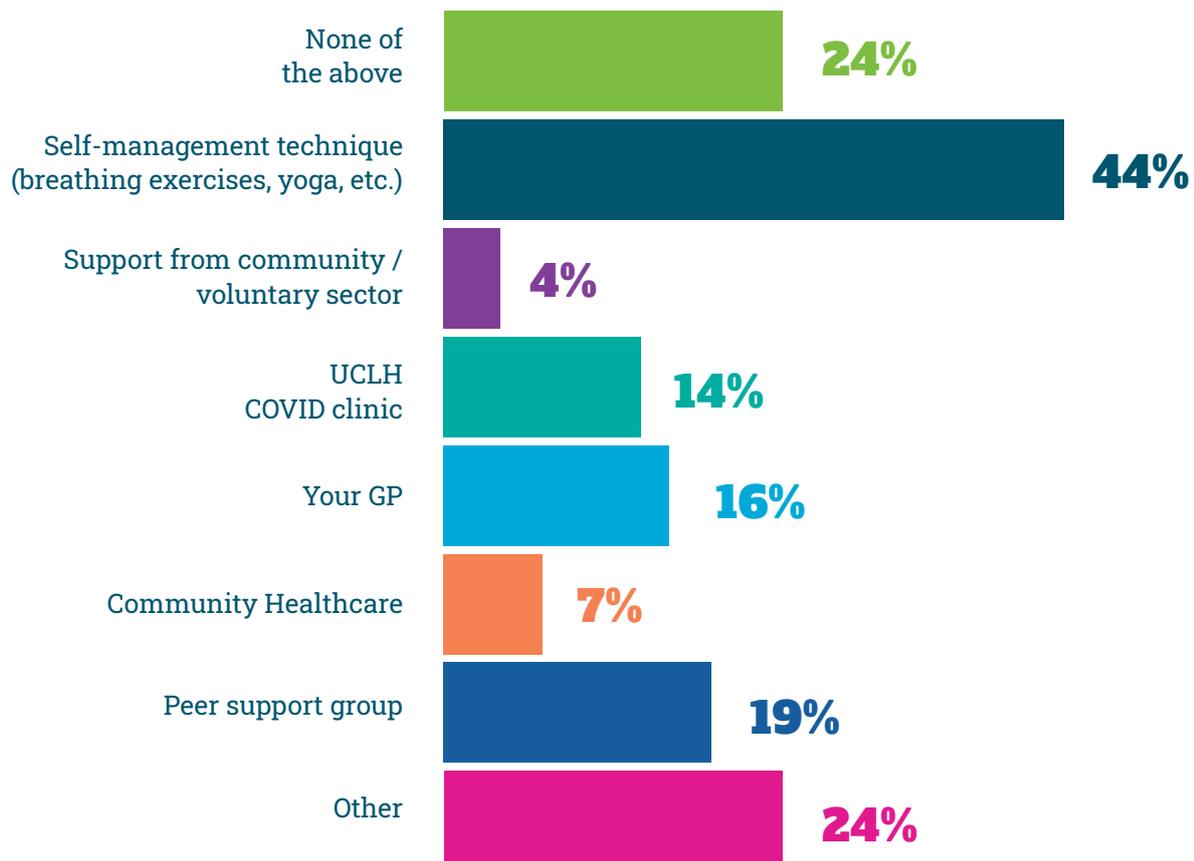


There are long gaps between having COVID, seeing GP, referral bloods & x-ray, being seen etc so I carried out my own research to try and plug the gap. It helped me get a rough idea of what type of things I could / should do at home to help manage the condition.

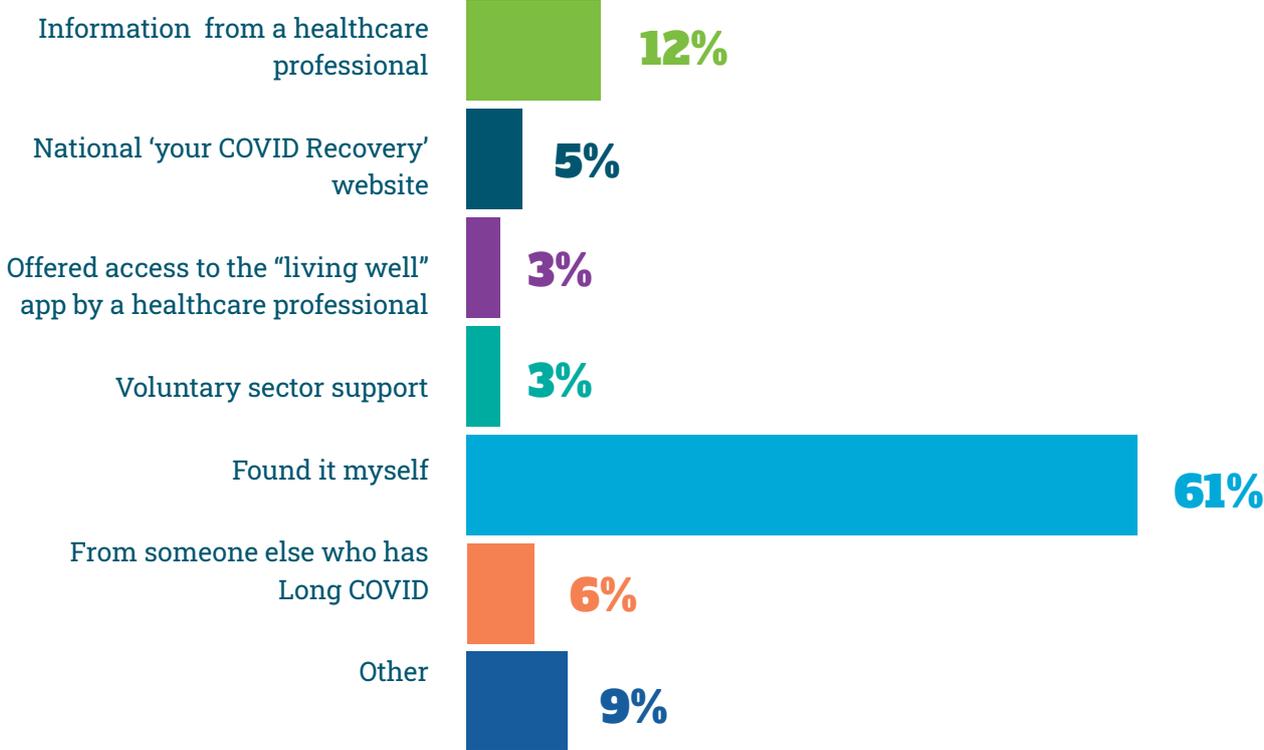
Camden Resident



What interventions have helped the most with your Long COVID recovery?



How did you access and learn about self management techniques?

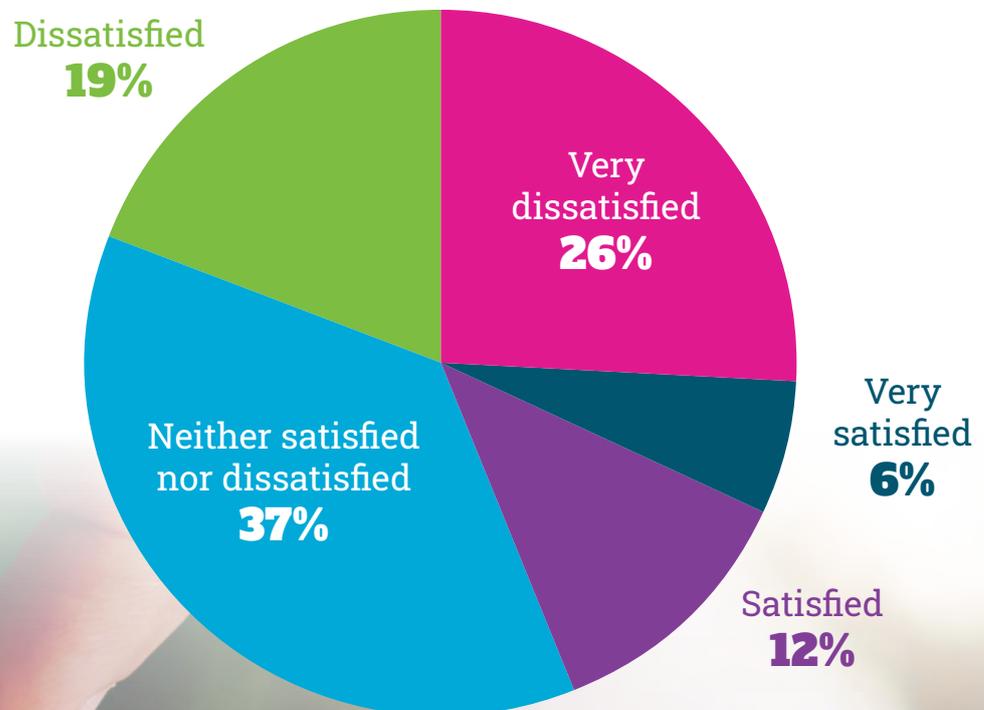


Moving Forward

Overall Sentiment

Of respondents:

- 18% were satisfied or very satisfied with the local Long COVID support.
- 37% were neither satisfied nor dissatisfied with the local Long COVID support.
- 45% were dissatisfied or very dissatisfied with the local Long COVID support.



Respondents were given the opportunity to provide suggestions that could improve their experience and recovery. The most common themes were:

- Primary care clinicians to be more knowledgeable about the symptoms so they can identify them better in patients.
- Recognise patients' symptoms and their impact immediately as patients were often not believed or the condition was considered psychosomatic, which only extended patients' suffering in isolation.
- Improve awareness of the support that is available so people can begin their recovery journey early.
- Recognise that existing support is only as useful as the strength of the communications, e.g. some patients only discovered what is available by attending a Healthwatch event.
- Improve access to primary care and its service model as already reported by all NCL Healthwatch
- Improve access to specialist care as many reported slow referrals and long waiting times.
- Ensure continuity of care with regular follow up appointments to assess progression but also to reduce the isolation felt by many, and especially those with support groups.
- Share self-management techniques early, such as support groups, yoga, breathing exercises, digital apps, living a healthy lifestyle etc, resources that do not need to be confined only to secondary care.



Improve GP's Knowledge

“ GPs need to be more aware of the impact and know where to signpost.
Camden Resident ”

“ A better understanding for GPs.
Barnet Resident ”

“ GPs to have more information on symptoms, recovery and make suggestions.
Enfield Resident ”

“ GP to pay more attention to patients and when something is asked it is because they want to feel safe and if they do research is because they need to understand the symptoms and by asking other people, friend specialists or by eliminating every issue of them thinking.
Barnet Resident ”

“ Please make sure GP practices are informed of the latest research.
Camden Resident ”

“ It would be great if GPs were a bit more knowledgeable about Long COVID so that they could advise on how patients can support themselves whilst waiting for further help.
Barnet Resident ”

“ For GPs to be fully aware of Long COVID symptoms and not just brush them off, this type of behaviour makes me feel even more worthless.
Enfield Resident ”

Recognise Patients' Symptoms and their Impact

“ Long COVID is very real I can assure you. Treatment needs to come or further testing for people like me who don't fit the traditional box. I'm not wasting GPs time on purpose. Barnet Resident ”

“ We should be made aware that we are not alone and we are not pretending the symptoms. More media coverage from the government. Enfield Resident ”

“ Take an interest in people with mild symptoms because fatigue ruins your life... Even though you cannot see it or prove it! Camden Resident ”

“ I know that it's a new illness and it's so difficult to know what to do, but I am so frustrated and upset, it feels hopeless as I've not been offered anything that's helped me so far. One doctor told me it's all psychological and it's down to the patient to figure out what to do for themselves. Haringey Resident ”

“ Ultimately if my GP as my first point of contact had shown support and interest I wouldn't have felt so alone but there is also a lot of harm being done to those with Long COVID in the community by the perpetuated belief that unless you die from COVID you have nothing to complain about. The fact that you are conducting this survey gives me hope, so thank you! Camden Resident ”

“ Contact from my local healthcare providers informing myself and others that the condition is real and that help is available. Enfield Resident ”

“ Doctors to recognize that Long COVID exists, and for GPs to pay attention to the patients' complaints, and acknowledge it and recognize the feelings of the patient with empathy. Not dismiss it as imaginary. Camden Resident ”

Improve Awareness of the Support Already Available

- “ It was clear from your webinar that a lot of work IS going on, but not so clear as to how to access it, I'm sure that there is some help 'out there', it's a question of how to access it.
Camden Resident ”
- “ Would have been good to know help is available.
Enfield Resident ”
- “ Healthwatch could provide a summary of what support opportunities are currently on offer to Camden residents. There seemed to be lots of people/agencies doing something that could help me but there was no time to make a note of their contact details during the event.
Camden Resident ”
- “ Some support for people in my situation would be good. I feel very alone with it.
Enfield Resident ”
- “ Access to the Living Well with COVID app ASAP - from the initial consultation with GP instead of after months and months of waiting. It's a great app and it would have been great to have that virtual support while waiting for appointments to come through. ENO Breathe is fantastic - really pleased I was referred to that.
Camden Resident ”
- “ Be more clear that help is available and from where.
Islington Resident ”
- “ Have teams that offer breathing work and information on pacing etc early on. I could have possibly improved months earlier if this information was public. I believe it is now.
Camden Resident ”

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Camden Resident ”

Improve Access to Primary Care

“ Being able to get a GP appointment would be helpful.
Enfield Resident ”

“ Doctors should see patients face to face instead of telephone consultations. Not months down the line when the situation got worse. Referrals should have been made to the relevant specialist.
Camden Resident ”

“ It would be better to be seen in person and not online. It would also double up as a day out that would force me to get ready and fight the fatigue. Also, much quicker and regular access to specialists.
Barnet Resident ”

“ I don't know what would help. Having a GP that you can see face to face would help to start with. I had a host of other medical problems during the pandemic like a broken foot that was misdiagnosed and couldn't see anyone about that until many weeks after where it was getting worse.
Islington Resident ”

“ Make it easier to access primary healthcare resources, not necessarily a GP. The fatigue management that helped me was written by an OT.
Haringey Resident ”

“ Getting help from my GP early. The government not changing the rules all the time. Local support groups. A special NHS service for sufferers.
Barnet Resident ”

Improve Access to Specialist Care When Needed

- “ The GP service was extremely slow to make a referral for clinical support and appeared to just hope my symptoms would improve on their own without medical intervention. When this didn't happen it left me feeling very isolated without support. It should not require repeated visits to the GP to prompt further action.
Barnet Resident ”
- “ Immediate referral and regular access and checks from a specialist clinic that looks at all the symptoms being experienced together. Online or telephone at least. Advice and tests for really debilitating and scary unusual symptoms. Physical overall check-in at the specialist clinic.
Camden Resident ”
- “ Access to specialist support for advice and reassurance. Recognition at an earlier stage and placed on my records at an earlier stage so I could have had access to research projects.
Barnet Resident ”
- “ Easier to be referred to the Long COVID team.
Enfield Resident ”
- “ Better information to GPs on how to refer. 'Being the only child at the surgery with Long COVID and not knowing what to' is not a valid reason to do nothing.
Barnet Resident ”
- “ I have had no support or guidance just advised to take paracetamol.
Camden Resident ”

Continuity of Care

- “ Since everyone is so different, and everyone suffers from different ailments as well as the well-known Long COVID symptoms, a regular phone call, email, or even questionnaire would be so supportive to those suffering. It would help map symptoms and also help health providers know who is still suffering and who still needs referrals and who would just benefit from a friendly call to let a patient know they are still being cared for and looked after.
Barnet Resident ”
- “ There needs to be regular examinations of how we're doing - just to check that our cognitive skills are still intact. I haven't had any support with coping with brain fog, anxiety, tearfulness and worry etc.
Enfield Resident ”
- “ A point of contact that 24 hours after release from hospital contacts you and assesses the situation, you have weekly contact and a separate unit to deal with Long COVID patients and this is not going away and needs urgent attention.
Islington Resident ”
- “ I would welcome some follow up after the initial diagnosis.
Barnet Resident ”
- “ Try and keep in touch with people suffering. It feels very lonely trying to deal with it on your own.
Enfield Resident ”

Sharing Self-Management Techniques Early

- “ Staying safe and eating healthily and taking some vitamins. Camden Resident ”
- “ Helping people with breathing exercises. Camden Resident ”
- “ NHS to get Long COVID persons more ideas to help them. Lists of breathing apps/videos. Mediation/ mindfulness app/ video. Give Long COVID app earlier in their journey. Islington Resident ”

Peer Support Groups

- “ I think having some sort of support group would be just fantastic. Because you really just want to be able to speak to someone who's going through the same thing as you and can, you know, you can just talk to them. I think will be immensely helpful. Barnet Resident ”
- “ Long COVID groups so you can share stories with other people as many people around you don't believe in your symptoms. You don't feel alone is good for mental health. Haringey Resident ”
- “ Additional resources need to be put into support groups and services, as it appears very little is available even after a GP referral. Barnet Resident ”

Conclusions

We recognise that NHS services across North Central London, as well as nationally, have been exceptionally busy during the COVID-19 pandemic. This has placed NHS staff under a considerable amount of pressure and has been compounded by the additional challenge of Long COVID, requiring NHS staff to learn about this new condition quickly under incredibly difficult circumstances. The Long COVID patient pathway developed by the NCL CCG, whilst dealing with these unprecedented challenges, has aided the recovery of many patients experiencing this debilitating illness.

From the data we have gathered, there are many lessons to be learnt from the experiences of Long COVID patients, who have had to become experts by experience, in helping them on the road to recovery. Like with any new condition or service, there is great room for improvement in aiding patients to access the treatment they require which we outline in our recommendations in this report. We believe our report accurately reflects the challenges faced by Long COVID patients in North Central London and we hope they can be mitigated by implementing our recommendations.



Recommendations

NHS

Primary Care

- Improve access to GP services and face-to-face appointments, for which there are already existing reports and insight from all five NCL Healthwatch.
- Increase training and support for primary care clinicians so they can be better informed on Long COVID and its symptoms. This will also help identify patients with potential Long COVID.
- Build awareness of local support and treatment already available for patients through multi-platform communications campaign.

NCL CCG

- Ensure there is more consistency in people's experiences accessing the Long COVID pathway taking into account patients' physical, mental and social needs.
- Ensure at the point a patient is referred for Long COVID support the Long COVID Pathway is explained and communicated to them in an accessible method.
- Ensure all patients on the Long COVID pathway are clear about how they will be followed up after their first appointment, including planned and patient-initiated options.
- Patients who are diagnosed with Long COVID or referred for further support should be given immediate access to applicable self-care and self-management resources regardless of the 12-week NICE guidance.
- Invest in the development of local peer support groups for Long COVID.

Long COVID Clinic & Community Teams

- Ensure all patients on the Long COVID pathway understand how to contact the clinical team responsible for their care accurately through telephone and email.

Councils

- Local Education Authorities should work proactively with teachers through education and training to support families whose children are absent from school due to Long COVID.
- Local Public Health teams should continue to monitor data and conduct an ongoing needs analysis of Long COVID in communities to inform how NCL CCG can make the Long COVID services more equitable and address inequalities.
- Local Public Health teams should publish their data on Long COVID to make it more visible.

Employers

- Human resource departments of employers in North Central London statutory services, such as NHS Trusts, Councils and the NCL CCG, working with the NCL's Long COVID Vocational Rehab Service, should recognise and adequately accommodate employees diagnosed with Long COVID through flexible working policies.

North Central London Clinical Commissioning Group Response

We would like to thank our Healthwatch colleagues for their work to produce such a comprehensive picture of the experience of people living with Long Covid in NCL. Hearing feedback from our communities and their personal stories is vitally important to help us reflect on the care we offer. This report and its recommendations will help us to better understand what our residents need from us, and how we can improve access to services, experience of care, and clinical outcomes for everyone.

There is still much we don't understand about Long Covid, and we know that for people affected, this uncertainty can be hard to deal with. We also recognise that for many, getting access to support, a diagnosis and clinical care, at a time when clinicians are still learning about this new condition themselves, has been difficult. For health and care staff, the uncertainties of Long Covid, how many people it affects, and how to best care for them, has also been challenging. Many staff themselves have also been personally affected by Long Covid.

We are proud of the work that our colleagues across NCL have done to set up holistic Long Covid services in such a short space of time, and of the commitment to patient care shown by staff working in these new services. However, as this report reminds us, we have more work to do to make sure we provide the best possible care for all NCL residents. The feedback and the recommendations in this report will be an important tool to help us do this.

NCL's Long Covid clinical and operational leads are committed to working in partnership with Healthwatch and other health and care organisations across NCL to implement the recommendations in this report. As our knowledge of the clinical aspects of Long Covid continues to develop, the services we offer will also need to change to accommodate this. We are also committed to continue listening to patient and resident voices to make sure that we are also continuously improving services to best meet their needs.

Dr Katie Coleman, Clinical Lead for Primary Care Network Development

Sarah Mansuralli, Executive Director of Strategic Commissioning

On behalf of NCL CCG.

Appendix 1

Full Demographic Data

Age Group	Number	Percent
18 - 24	4	2%
25 - 34	19	10%
35 - 44	37	19%
45 - 54	48	25%

Age Group	Number	Percent
55 - 64	49	25%
65 - 74	25	13%
75+	8	4%

Gender Identity	Number	Percent
Male	38	20%
Female	151	79%
Non-binary	1	1%

Gender Different from Birth	Number	Percent
No	180	93%
Yes	12	6%

Ethnicity	Number	Percent
Arab	1	1%
Asian / Asian British: Bangladeshi	17	9%
Asian / Asian British: Indian	7	4%
Asian / Asian British: Pakistani	2	1%
Asian / Asian British:		
Any other Asian / Asian British background	3	2%
Black / Black British: African	9	5%
Black / Black British: Caribbean	8	4%
Black / Black British:		
Any other Black / Black British background	1	1%
Mixed / Multiple ethnic groups: Black African and White	1	1%
Mixed / Multiple ethnic groups: Black	1	1%
Mixed / Multiple ethnic groups: Any other Mixed / Multiple ethnic background	2	1%
White: British / English / Northern Irish / Scottish / Welsh	79	41%
White: Irish	2	1%
White: Any other White background	31	16%
Polish	2	1%
Romanian	1	1%
Turkish	3	2%
Another ethnic background	2	1%

Sexual Orientation	Number	Percent
Asexual	2	1%
Bisexual	3	2%
Gay	5	3%
Heterosexual / Straight	153	82%
Lesbian	2	1%
Pansexual	1	1%
Others	4	2%
Prefer not to say	16	9%

Disability	Number	Percent
Yes	47	25%
No	131	69%
Prefer not to say	12	6%

Religion	Number	Percent
Buddhist	2	1%
Christian	46	24%
Hindu	2	1%
Jewish	14	7%
Muslim	32	17%
No religion	66	35%
Other	12	6%
Prefer not to say	14	7%

English as First Language	Number	Percent
Yes	142	75%
No	46	24%
Prefer not to say	2	1%

Carer Status	Number	Percent
Yes	37	19%
No	148	78%
Prefer not to say	5	3%

Long Term Health Condition(s)	Number	Percent
Yes	101	54%
No	74	40%
Prefer not to say	11	6%

COVID Vaccination Status	Number	Percent
Yes - 1 dose	24	10%
Yes -2 dose	185	80%
No	23	10%

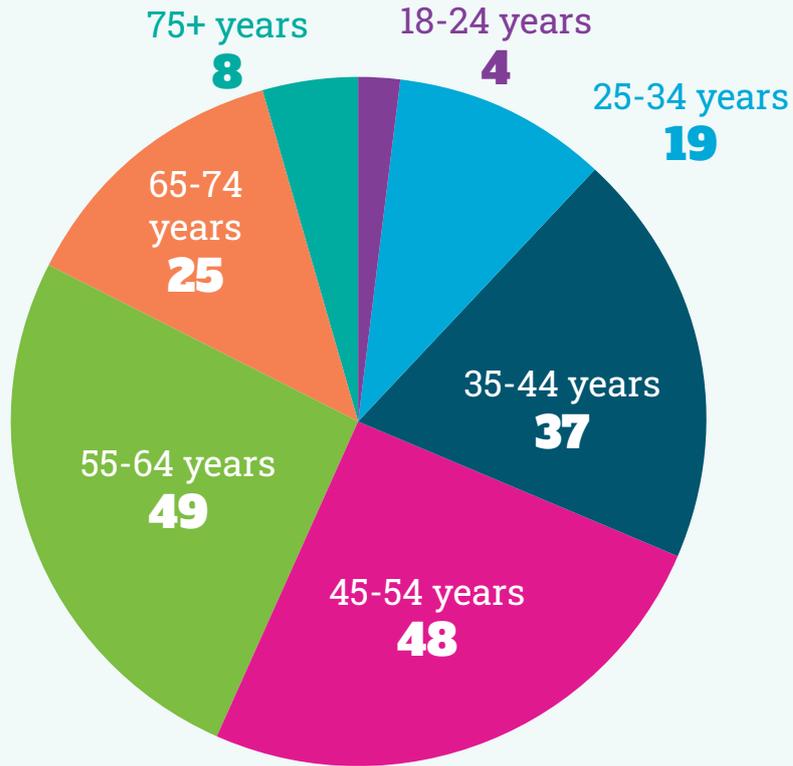
Highest Level of Qualification	Number	Percent
GCSE	21	11%
A Level	19	10%
Bachelor's degree	52	28%
Master's degree	44	24%
PhD or higher	10	5%
I'd prefer not to say	14	8%
Other	14	8%
None of the above	11	6%

Annual Household Income	Number	Percent
Under £15,000	39	21%
Between £15,000 and £29,999	23	12%
Between £30,000 and £49,999	23	12%
Between £50,000 and £74,999	21	11%
Between £75,000 and £99,999	12	6%
Between £100,000 and £150,000	7	4%
Over £150,000	2	1%
I'd prefer not to say	58	31%

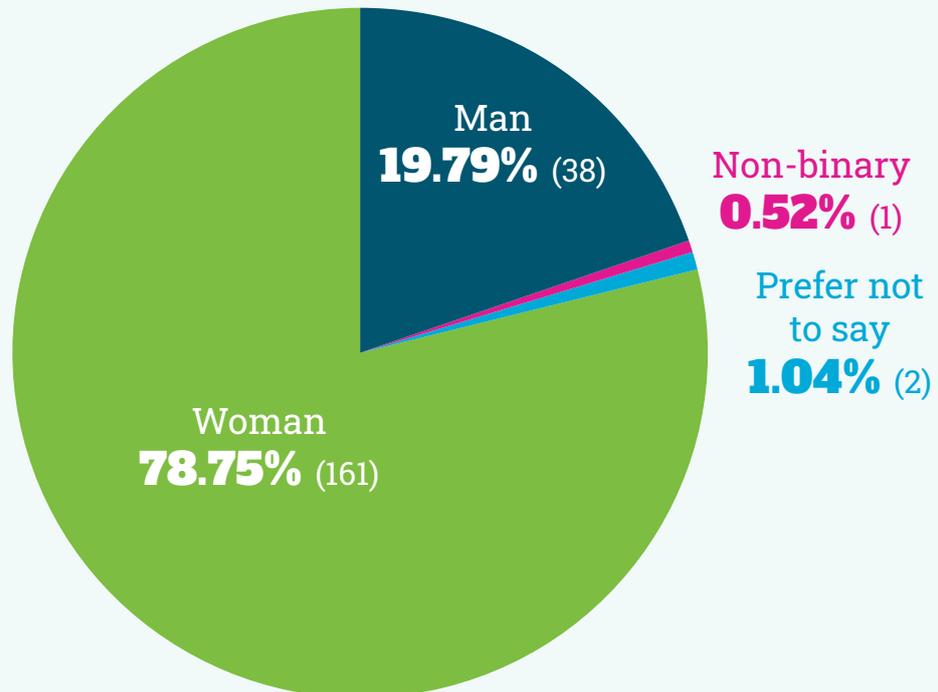
Appendix 2

Respondent profile

Age



Gender



Ethnicity

Arab	1	Mixed / Multiple ethnic groups: Black Caribbean and White	1
Asian / Asian British: Bangladeshi	17	Mixed / Multiple ethnic groups: Any other Mixed / Multiple ethnic background	2
Asian / Asian British: Indian	7	White: British / English / Northern Irish / Scottish / Welsh	79
Asian / Asian British: Pakistani	2	White: Irish	2
Asian / Asian British: Any other Asian / Asian British background	3	White: Any other White background	31
Black / Black British: African	9	Polish	2
Black / Black British: Caribbean	8	Romanian	1
Black / Black British: Any other Black / Black British background	1	Turkish	3
Mixed / Multiple ethnic groups: Black African and White	1	Another ethnic background	2



Word Cloud of Commonly Used Phases for Long Term Health Conditions

heart disease long term health
problem diabetes
hypertension **high blood pressure**
long covid damage
asthma arthritis
hypothyroidism



Healthwatch Barnet

 Barnet & Southgate College
7 Bristol Avenue, Colindale
London NW9 4BR

 020 3475 1308

 healthwatchbarnet.co.uk

Healthwatch Camden

 85-87 Bayham Street
Camden
London NW1 0AG

 020 7383 2402

 healthwatchcamden.co.uk

Healthwatch Enfield

 Community House
311 Fore Street, Edmonton,
London N9 0PZ

 020 8373 6283

 healthwatchenfield.co.uk

Healthwatch Haringey

 Tottenham Town Hall
Town Hall Approach Road
London N15 4RX

 020 8888 0579

 healthwatchharingey.org.uk

Healthwatch Islington

 6-9 Manor Gardens
Islington
London N7 6LA

 07538 764436

 healthwatchislington.co.uk

healthwatch

Barnet Camden Enfield Haringey Islington