

The Experience of Post-Covid-19

A report by Healthwatch Redbridge, Havering and Barking & Dagenham, in collaboration with the NELFT Long Covid Clinic at King George Hospital, and NEL CCG



local healthwatch
working together



research and engagement

“It’s been devastating - I’m a completely different person, and have physically aged significantly.

Waiting a year for any support was too long.”

Local Resident

‘This has been infuriating. I have had no idea what to do.’

Local Resident

“I cannot walk fast, I become breathless. I am always exhausted ”

Local Resident

Contents

1. Introduction	5
2. Background	5
3. Methodology	6
4. Impact of Interim Findings	6
5. Limitations	7
6. Executive Summary	7
7. Analysis of Feedback	8
8. In-depth interviews	17
9. GP perspectives	18
10. Health Inequalities and Post-Covid 19 Syndrome	20
11. Conclusion and Recommendations	21
12. References	24

Demographics

Appendix 1: 25

This page is intentionally blank.

1. Introduction - a new and evolving syndrome

Long COVID is a new and evolving syndrome 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. A recent report by the Institute of Fiscal Studies (2022) estimate the aggregate impact of the current prevalence and severity of Post-Covid-19 syndrome is equivalent to 110,000 workers being off sick (IFS, July 2022).

Evidence from other Healthwatch reports (Healthwatch Barnet, 2022) and the Royal College of Nursing (RCN, 2022) indicate that treatment varies across the country, with long waits for specialist provision and disagreement about referral structures common.

2. Background - definitions, and our mandate for the work

The National Institute for Health and Care Excellence recommendation (NICE, 2021) is that ‘Ongoing symptomatic COVID- 19’ be used to describe symptoms that 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.

Long COVID presents itself through a wide range of clustered symptoms. The most recent data from the Office for National Statistics show that an estimated 2 million people self-reported experiencing Long COVID symptoms as of June 2022.

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 (NHS England, 2021). 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.

What we wanted to achieve

We wanted to hear and present the perspectives of local service users at key stages along the NICE clinical pathway for post-Covid-19 syndrome (*guideline NG188 11.11.21*). In summary, the prevailing context suggests a need for patient insight because:

- The reported symptoms vary widely
- As a new clinical area there remain uncertainties in treatment pathways*
- Recent clinical guidelines indicate holistic assessment and shared decision-making
- Routes of access to support are not well evaluated
- There are potential demographic factors affecting uptake of support and equality of access

We wanted to support the recent call of Healthwatch England to gather data on patient experience. We wanted to mirror the clinical pathway in our research, from seeking GP support, or not, being referred to the Long Covid clinic at King George Hospital and subsequent experience.

We wanted to clearly articulate and present Redbridge, Barking and Dagenham and Havering community patient voice to shape and develop services in this new clinical area. We were able to work in collaboration with our neighboring Healthwatch colleagues to design and disseminate the survey, particularly with regard to reaching our homeless community. For example, one Healthwatch volunteer was able to take her laptop and sit with members of the homeless community in order to complete the surveys online, given the digital exclusion facing many service users.

3. Methodology and Collaboration with NHS partners

We had three main strands of data collection:

- Tri-Borough survey with 169 responses; with free text comments for additional qualitative analysis, promoted by the North East London Clinical Commissioning Group (NEL CCG) Comms team; North East London Foundation Trust Long Covid service comms team; NELFT patient experience and expert patients comms team; Barking, Havering and Redbridge University Hospitals NHS Trust Long Covid Clinic; and our local Healthwatch comms teams.
- 10 In-depth interviews with local service users who identify as experiencing Long Covid, accessed through the survey and by referral from the Clinic and other local contacts.
- 4 Interviews with local GP's and a further focus group with their service leaders, in conjunction with Dr Adam Ainley [still to come] Clinical Lead of the BHRUT Long Covid service

The survey was designed in collaboration with the NELFT Long Covid service and BHRUT Clinic, with a focus on inequalities and deprivation. Survey design meetings took place online to facilitate this process between all the project partners identified above, and the 3 local Healthwatch. Many different perspectives were discussed, including the possibility of including part of the respondents' postcodes in order to assess markers of deprivation; and a request for an extensive demographics section to also deepen our understanding of the impact of health inequalities in this area. There was a tension between keeping the survey short, knowing that service users with Post-Covid-19 syndrome can often experience fatigue, and the opportunity to gather critical data. Solutions were found by using partial postcodes, and sharing the Healthwatch England new publication advising on the collection of demographic data. The survey has a wide reach as a result, and the broad use of the data have proved beneficial to increasing knowledge and insight into local service user experience and also the direct shaping of the service.

4. Impact of interim findings - service change

Interim findings were presented when the survey had been open for one month to:

- Dr Ainley and the Long Covid Clinic
- NELFT Long Covid service
- BHR Integrated Care Partnership Complex Care and Whole Systems Pathways Operational working group transformation Board meeting

At these meetings, the complexities of access to support and specialist provision highlighted in the findings below were identified. Many free text comments identified that service users were being told by GPs that they had to wait for one year with symptoms before referral. A potential confusion was identified between a 12-week referral window and a 12-month structure. These findings helped inform topics to be covered and reinforced the need for pre-existing education sessions delivered by the local long covid service, and the broader NEL ICB long Covid taskforce. Additionally alongside updated national guidance, the findings provided feedback to a review and re-design of the GP referral form which aimed to provide uniformity in the pathways across NEL ICB. We were also asked to develop a quality-of-life impact scale from the data for the syndrome. This was then used to request access to further funding for Long Covid in the year to come.

Over the course of the 8 week survey there was also an increase in diagnosis of Post-Covid-19 syndrome from 32% to 44% and a corresponding increase in visibility of the highly-rated Long Covid clinic by 6%. Whilst the reasons for this are likely to be multifactorial, it was an encouraging finding. Ikenna Obianwa, Planned Care Programme Manager for North East London Clinical Commissioning Group, introduces this impact:

‘The partnership between Healthwatch and NELCCG has been helpful in generating understanding of local patient experience of Post-Covid-19 syndrome (Long COVID), with a high quality of life impact and complexities of access to our specialist provision. It has been good to see the high value given by patients to the Long COVID Clinic here at King George Hospital in the survey and interviews. We are working to increase the referrals to this clinic as a system in the light of the findings and are pleased to see recent data suggesting this is now taking place.’

4th July 2022

5. Executive Summary of Findings

During March-June 2022 169 people from North East London completed our survey on Post-Covid Syndrome. 10 service users gave in-depth interviews and 4 GPs gave interviews. **It is important to state that only 29% of the respondents to the Survey were referred for support for long COVID, and only 16% of these had accessed the long COVID service. Questions did not specifically reference the long COVID service and were answered by all survey respondents.**

The findings therefore, include a 71% majority of patients who experienced help only from primary care or other services. Access difficulties need to be interpreted accordingly.

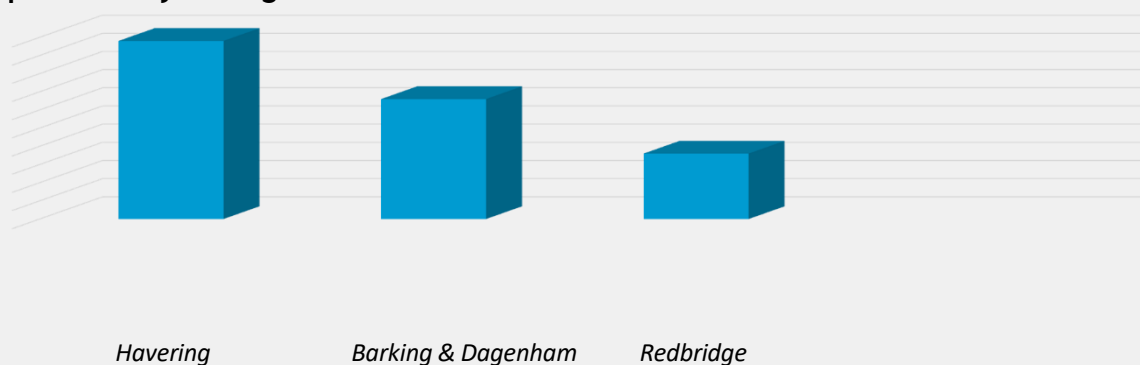
Summary of key findings - see section 6 for the analysis in full.

Key Findings

General

- A clear majority of respondents (86%) have tested positive for Covid-19, while under half (45%) have been diagnosed with Long Covid.
- On impact on daily living, most (93%) feel that their enjoyment of life has been impacted, with three quarters (76%) finding it more difficult to undertake hobbies.
- Half of all respondents (50%) say their ability to work has been affected.

Respondents by Borough:



Services

- Respondents are almost twice as likely to seek self-help, than consult with their GP.
- Just under a third of respondents (30%) have been referred for support for Long Covid.
- Just over half of respondents feel that hospital and community based services (**not including the Long COVID service itself**) have not been helpful (54%), while a similar number (54%) say that primary care services have not helped.
- Almost a fifth (18%) have self-referred, or found support elsewhere.
- A third of respondents (35%) have heard of the Long Covid Clinic.
- Just under three quarters (70%) say their physical support needs are unmet, while 71% indicate that their mental health needs have not been met. This is in the context of a majority of service users (71%) who had not been seen by or have not accessed specific support.

Health inequalities

Although we had a relatively small number of survey respondents who were from Bangladeshi, Pakistani, Black African, and Caribbean backgrounds (8%), it is worth noting that in every area of life, respondents from these communities identified a greater effect on their day to day lives. Particularly of note is in the areas of self-care and caring for others. 33% of service users from BAME backgrounds felt that Long Covid had affected their ability to care for others, whereas 19% of service users from White backgrounds identified this impact. 60% of service users from BAME backgrounds felt their ability to work had been affected; whereas 44% of service users from White backgrounds identified this issue.

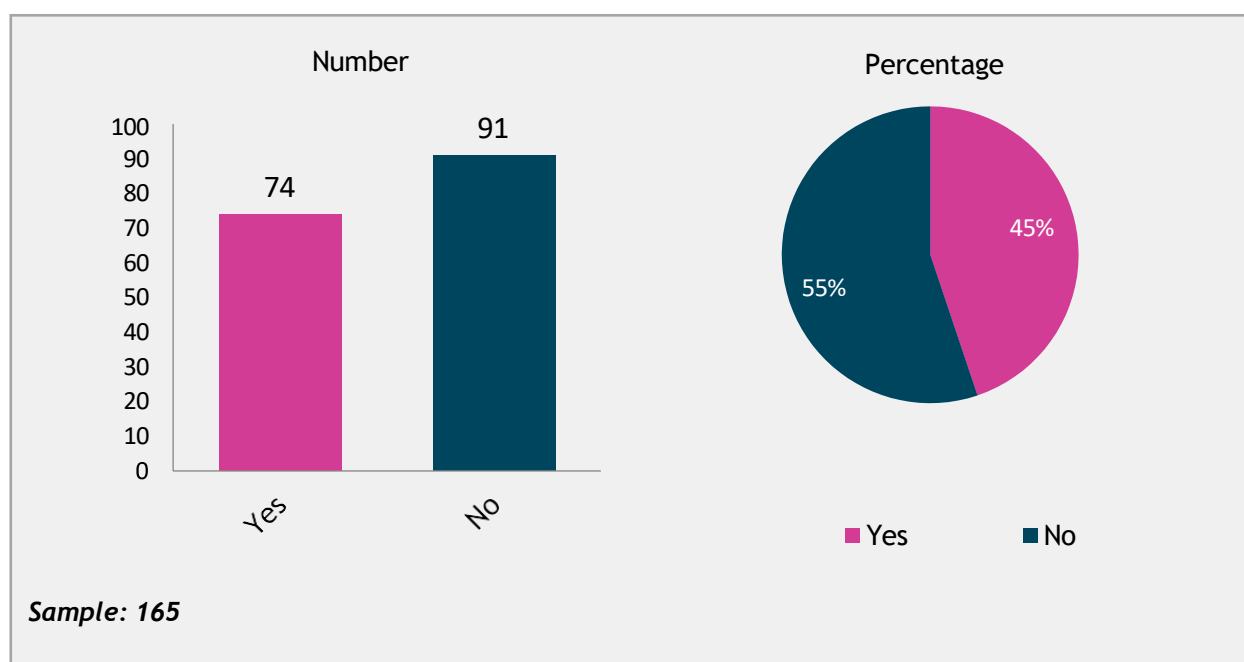
What are people saying - themes in the free text comments

- As the condition is relatively new, many doubt the effectiveness of interventions and some, citing ‘overstretched services’ are fearful of being a burden on the NHS.
- Levels of information on what support is available are said to be lacking.
- While some people feel their GP would be sympathetic, others fear that symptoms may be dismissed. The ability to obtain appointments is a key issue.
- Participants identified long waits to be referred for support, with many commenting this took one year. Service users also felt that children, or those without a diagnosis, are not eligible. These are findings from comments left in the Survey and not NHSE guidance. There is a pan-London service for children and a diagnosis is not required before referral. These clarifications will be sent to all the survey respondents who left an email address for contact.
- We hear that waiting lists for general support have been ‘too long’, and services offered have been generic, with ‘one-to-one’ options lacking.
- It is also suggested that some packages suggested by GPs, such as a six week mobility class are insufficient, and therefore ineffective.
- Those with caring responsibilities have found it difficult to support themselves and also their loved ones.

6. Analysis of survey feedback

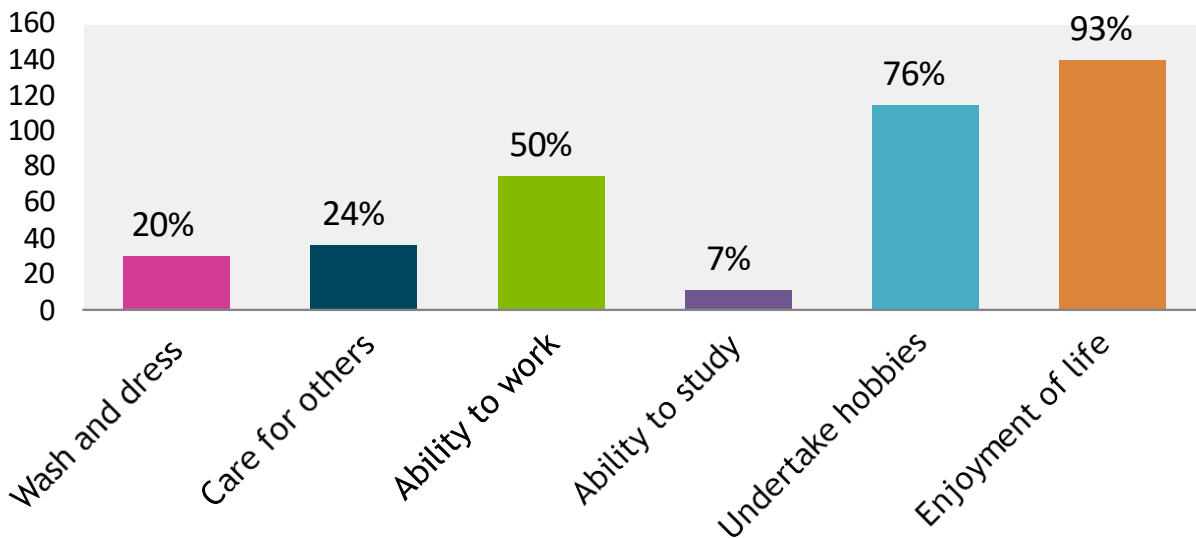
During March - June 2022, 169 people from North East London completed our survey on Post-Covid Syndrome. 86% of people had been diagnosed with Covid-19. The key survey questions are illustrated below. Please note that not all respondents answered each question, as a small number skipped different questions. The percentages given are therefore devised from the number of respondents:

6.1 Have you been diagnosed with Post-Covid-19 syndrome (Long Covid)?



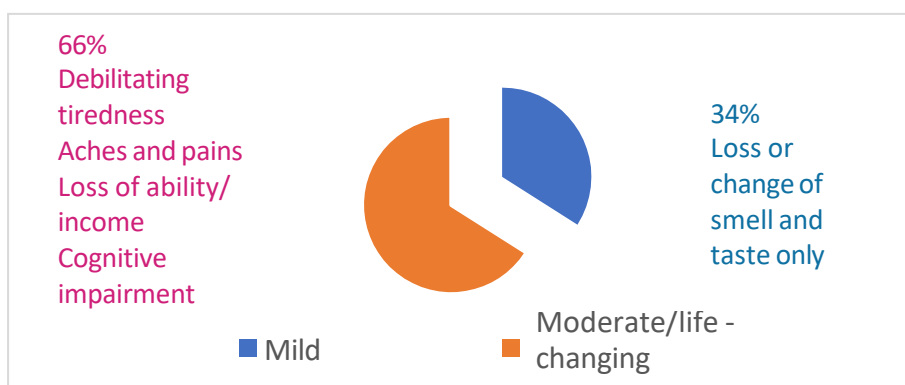
6.2 Has Post Covid syndrome (Long Covid) affected your day to day living in any of these areas?

Sample size 151
Number (Percentage)



When looking at effects on daily living, a majority (93%) feel that their quality of life has been impacted, with three quarters (76%) finding it more difficult to undertake hobbies. Half of all respondents (50%) say their ability to work has also been affected.

6.2.1 Quality of life scale, derived from qualitative free text comments



We looked at each comment about impact in the free text responses, using a qualitative scale of single issue symptoms as mild/moderate and multiple impact symptoms as life changing. We can see more of the high impact of Post-Covid-19, with 66% of all respondents identifying a combination of symptoms - constant headaches, aching limbs,

brain fog, fatigue/extreme tiredness, low mood. Respondents identified this combination as significantly affecting their entire lives:

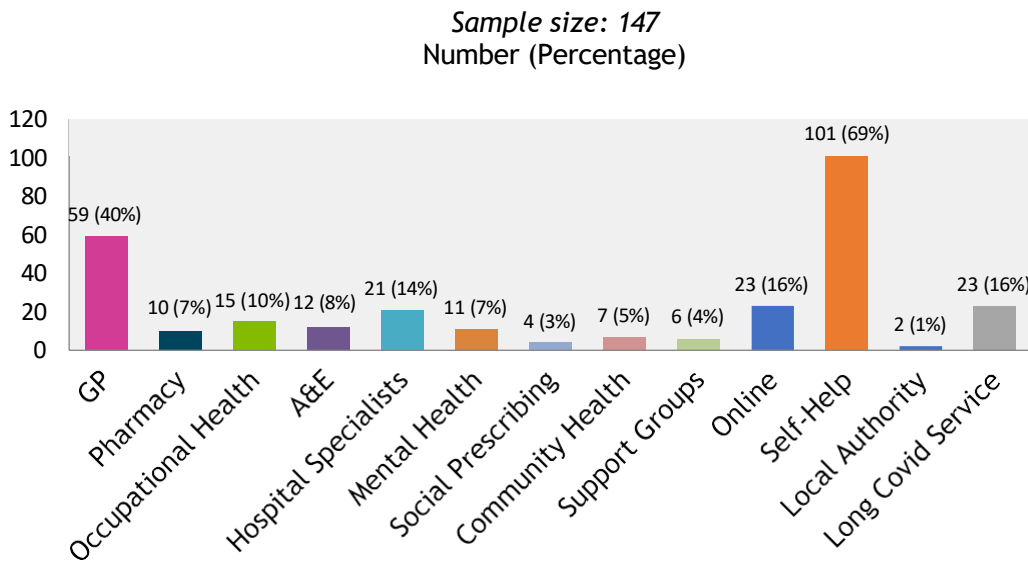
'15 months on, I still have no smell and my taste only comes occasionally. I am an asthmatic and am extremely tired every day and suffer with headaches and breathlessness.'

'I have symptoms of tiredness, breathless, cannot do hobbies ie gardening and walking without getting out of breath and need to rest, life style has changed'

'I have constant joint, bone and muscle pain. I am seriously fatigued, I have periods of brain fog, my mental health is not good I have needed to rely on the emergency departments as I am unable to get a GP in person appointment'

These findings are also linked to the high levels of anxiety found in the in-depth interviews.

6.3 Where have you found support for Post Covid Syndrome (Long Covid)?



Respondents are almost twice as likely to seek self-help, than consult with their GP.

As the condition is relatively new, many doubt the effectiveness of referrals or interventions and some, citing ‘overstretched services’ are fearful of being a burden on the NHS. Participants felt that they encountered a lack of information about the support available.

An increasing number of respondents (16%) have accessed a designated service for Long Covid. The survey began with this figure at 10%.

Examples of comments from participants (who have not accessed the Long COVID service)

“No one seems to know how to help and I understand that it is because we are all still learning about Long Covid symptoms.”

“My wife and I were told the medical community are still learning about the effects so nothing they could do.”

“Like most people I know - we just carried on without any seeking any NHS help.”

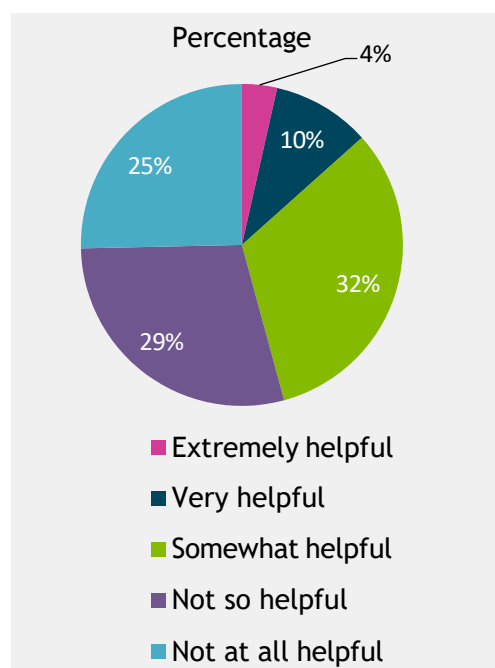
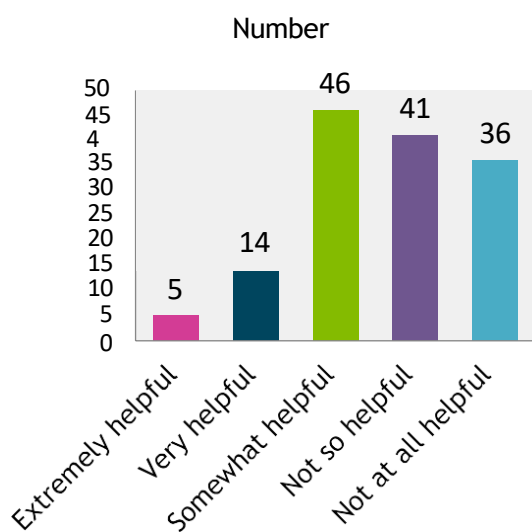
“No additional help outside of family was asked for. With all the NHS departments being pushed to their limits my family stepped in to help.”

“No one really offered support at all and just told you will eventually recover...”

“I did not know where to find help.”

6.4 How helpful did you find the experience of using primary care, if applicable?

Sample size 142



Just over half of respondents (54%) feel that primary care services have not been helpful, with 46% of service users feeling they had been a helpful support.

Accessibility is a key issue, with congested telephone lines and long waits for appointments commonly reported.

While some people feel their GP would be sympathetic, others fear that symptoms may be dismissed. Support is commented to be lacking in cases, with patients told to 'get on with it'.

Examples of comments about experiences of primary care based support

"I haven't sought post Covid support as it is almost impossible to get through to my doctor's surgery. With the help of my family, I am getting by."

"Waiting weeks for a telephone appointment to speak with my GP."

"My doctors have been very helpful, they've sent me for chest X-rays, scans blood tests etc and have listened to me when I've tried to explain how I feel without making me feel like I was imagining things."

"My doctor and staff at the surgery have been marvelous without their help I don't think I would have got through this."

"I haven't looked for help at the doctors in case I'm not believed."

"My GP has been good. But I have generally been told to get on with it." "I have continuously tried to talk to my doctor but they won't even answer the phones."

"Tried contacting the GP, a waste of time, cannot sit on the phone at 8am to get an appointment, tried 111 and just as bad. No hub appointments available."

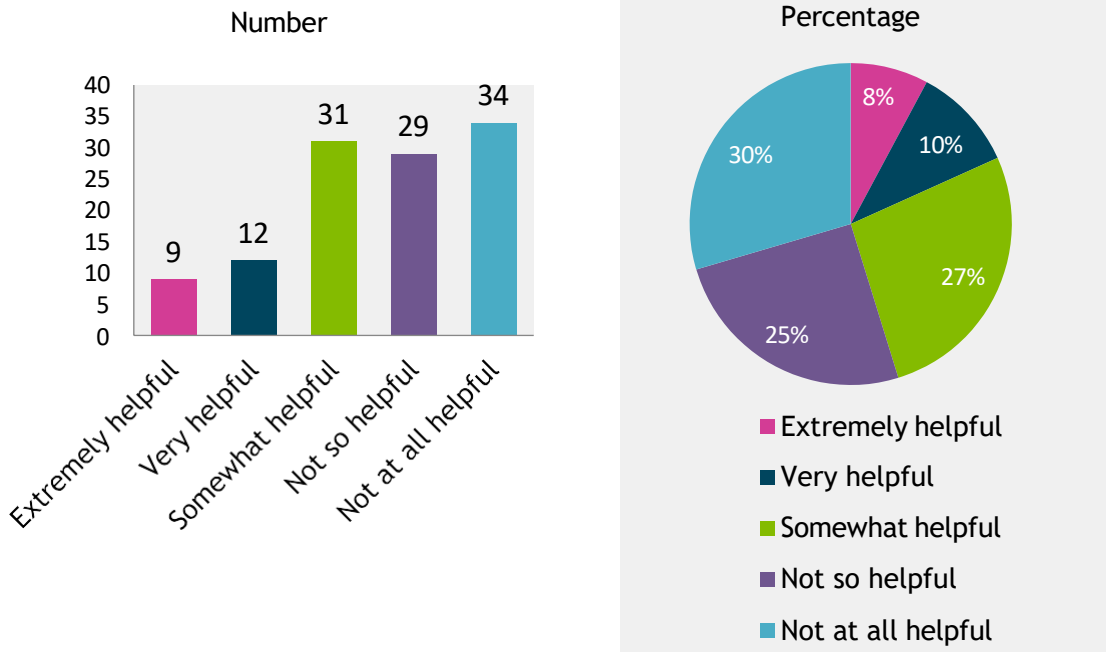
"I was unable to see my GP for a long while - could not get an appointment, which delayed me being able to talk to someone about how Covid is impacting my health and get help."

"I feel as though all of the doctors that I spoke to weren't really interested in what I was telling them about how unwell I was or how I was feeling, there was little to no help given, in the end I stopped calling them."

"I've mentioned to the GP about a lack of energy, fatigue, loss of taste and smell and headaches and he didn't act."

6.5 How helpful did you find the experience of using hospital or community care, if applicable? This was answered by all survey respondents. Only 16% had been able to access the Long Covid Service. These findings are more likely to reflect other services.

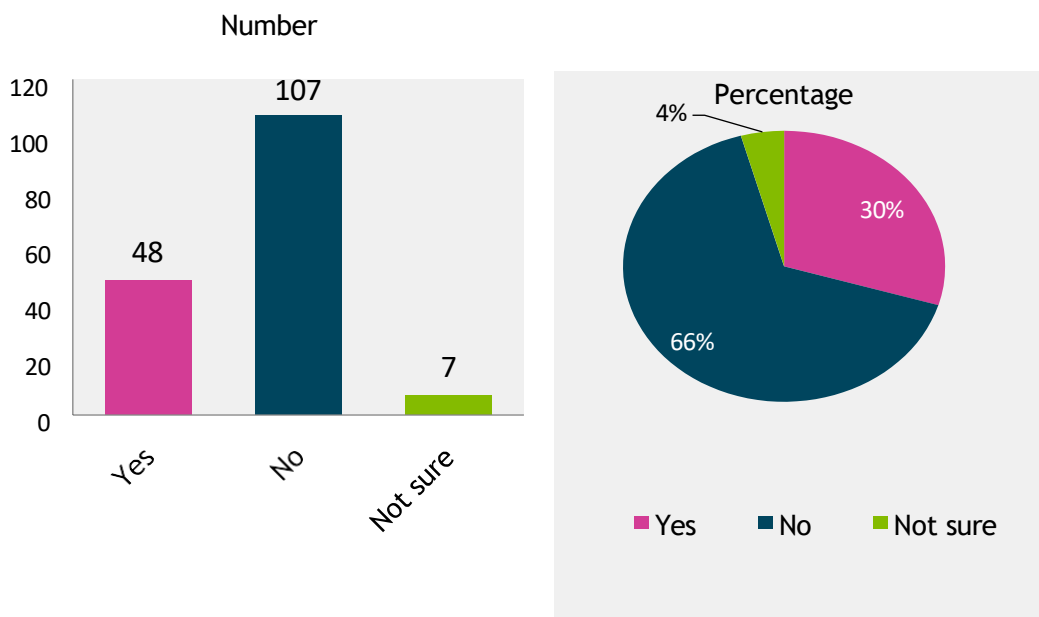
Sample size 115



A majority of respondents (55%) feel that hospital or community based services have not been helpful. It is important to state that only 29% of the respondents to the Survey were referred for support for long COVID, and 16% to the long COVID service. The findings therefore include a 71% majority of patients who experienced help only from primary care or other services.

6.6 Have you been referred to support for Post-Covid-19 Syndrome (Long Covid)? This includes any follow-up or referral to the long COVID service.

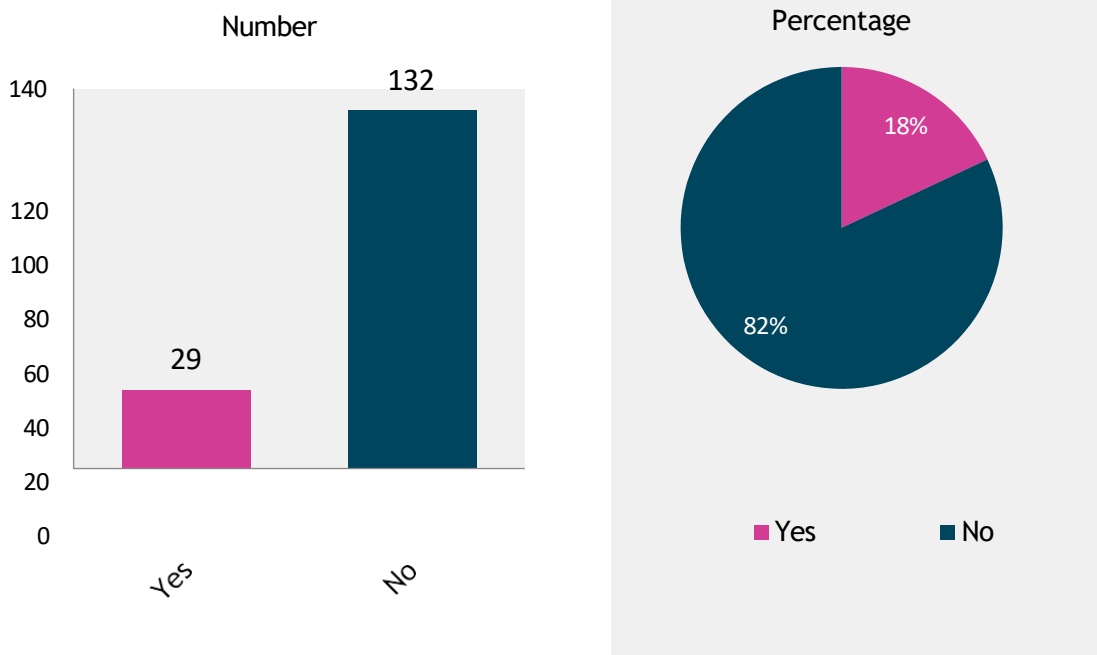
Sample size 162



Just under a third of respondents (29%) have been referred to receive support.

6.7 Have you self-referred or found support elsewhere?

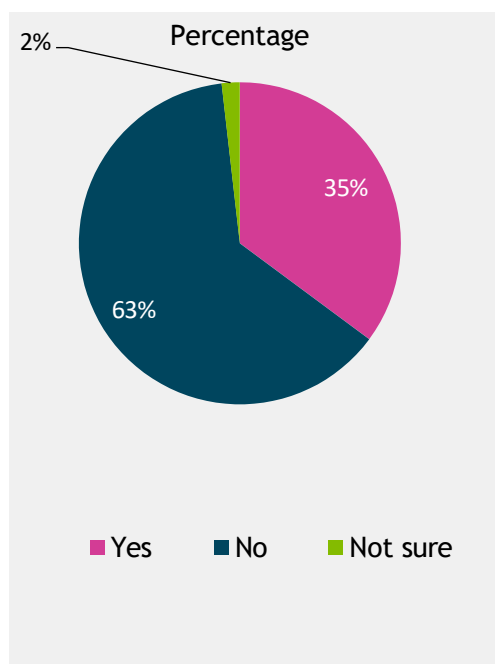
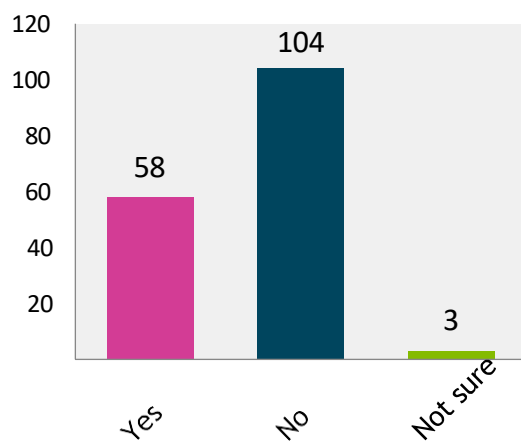
Sample size 161



Around a fifth (18%) have self-referred, or found support elsewhere, with online resources, physiotherapy and community mental health services among the options mentioned. Some people have utilised their private medical insurance.

6.8 Have you heard of the Post-Covid-19 (Long Covid) Clinic provided by NELFT?

Number (sample size 165)



Highly rated specialist provision with long access

A third of respondents (35%) have heard of the Long Covid Clinic, operated by NELFT (North East London NHS Foundation Trust) and BHRUT (Barking Havering and Redbridge University Trust). Many service users identify a long gap between first seeing their GP and being referred to the Clinic. Treatment and sessions are highly valued, along with a phone app which offers some support while on the waiting list.

In some cases, people have had to be proactive in chasing referrals. There was a perception amongst service users that children, and those without official diagnosis are not eligible. In fact, there is a pan-London paediatric service and diagnosis is not necessary for referral. All survey participants will be informed of these provisions. General awareness levels of the service were inconsistent and lacking in detail and accuracy in places.

Examples of Comments from respondents who have been under the care of the Long COVID service

“Took a year to get seen by someone from the Long Covid Clinic and still to this day haven't been seen by a doctor. That said, the phone app has provided me with support.”

*“Waited a long time for the Long Covid Clinic but was glad to have attended the sessions.”
“Being referred to the Long Covid Clinic helped a lot.”*

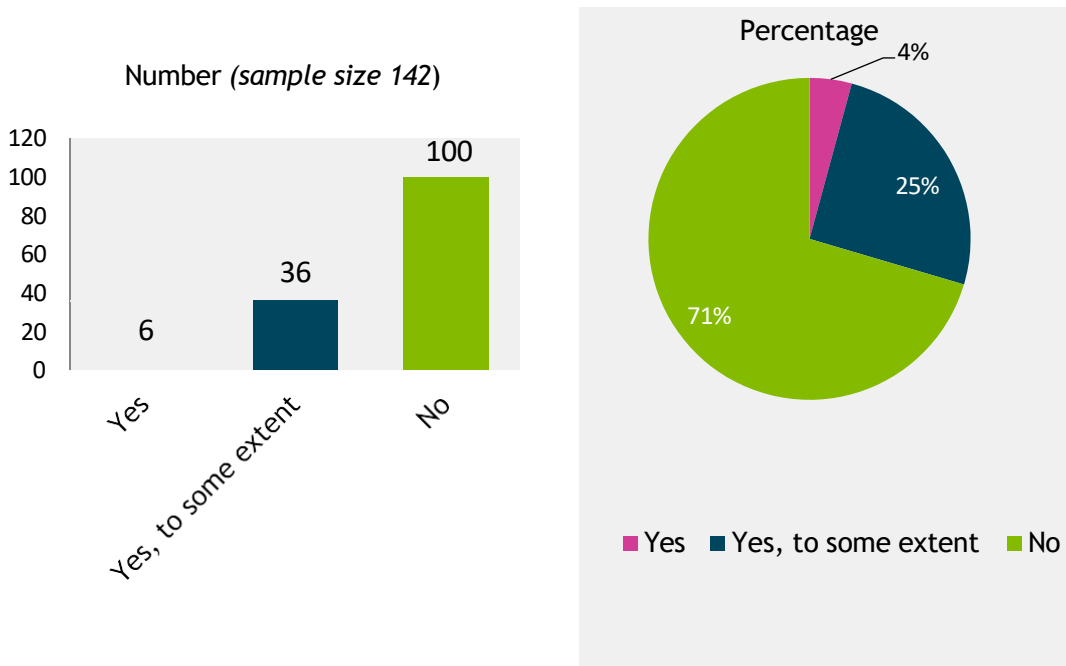
“No support for the first year, until I got on the Long Covid Clinic, which I had to chase because no one was interested in helping.”

“Took a year to get into the Long Covid system.”

“Referred to the Long Covid Clinic in December, appointment given for March then cancelled and offered for April.”

“All professionals from the Long Covid team have been very supportive and informative.”

6.9 In the support that you have received for Post Covid Syndrome, have your physical support needs been met? This question was answered by all respondents, not solely those treated by the long COVID service. It could therefore reflect self-help, primary or secondary care.



Almost three quarters of respondents (71%) say their physical support needs are unmet.

We hear that waiting lists have been ‘too long’, and support offered has been generic, with ‘one-to-one’ options lacking. It is also suggested that packages suggested by the GP, such as a six week mobility class are insufficient, and therefore ineffective.

Those with caring responsibilities have found it difficult to support themselves and also their loved ones.

Examples of Comments from all survey respondents

"I don't think I've had the help I've needed. The wait has also been too long."

"Most online sessions are about fatigue and breathing issues which I completely understand. But personally this does not meet my need."

"No one-to-one."

"I was discharged even though still not walking properly."

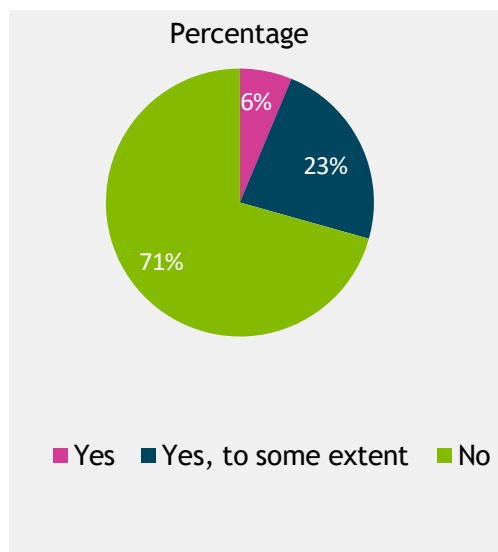
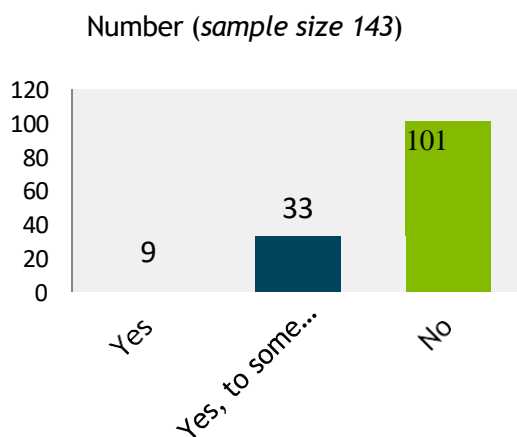
"It's been difficult as well seeking support as I am supporting my Mum who is under palliative care for cancer that has now reached her heart. I don't have enough time for me."

"I have experienced a range of symptoms and medical staff at the hospital and my GP simply say it's Long Covid and there is no solution."

"No real support provided. Told to use inhalers and Google breathing exercises." ?

"At times it was difficult to access the support required but now I have it's much better."

6.10 In the support that you have received for Post Covid Syndrome, have your mental health support needs been met? This question was answered by all respondents, not solely those treated by the long COVID service. It could therefore reflect self-help, primary or secondary care.



A similar number (71%) felt that their mental health needs have not been met.

Almost a third did feel their mental health needs have been met. Long waiting lists for mental health support are reported.

Examples of comments

“Dealing with the mental effects has been most difficult. I’ve struggled to find support in this respect - there are long waiting lists.”

6.11 In-depth interview analysis

None of the service users interviewed had accessed the Long Covid clinic.

10 interviews were conducted by telephone, 7 from the survey itself and 3 by word of mouth. The themes matched the free text data in the survey:

- *Self-doubt and loss of confidence*
‘I’m not sure if this is worthy of medical attention; I’m just living with it, but it means I can’t care for my children properly, or do the things I used to do.’
- *Uncertainty as to the nature and designated symptoms of Post-Covid-19 syndrome: ‘I’m just going round in circles. My relationship with my partner, my work and my sleep have all been affected. I can’t get anyone to help me deal with my symptoms, and getting answers seems impossible. There is something that affects me seriously, yet I can’t find a name for what I have or a solution.’*
- *Confusion and frustration in access*
- *Distress and severe disease impact*
‘Really hard to explain how this had impacted my life. Not having the use of my voice which I lost with covid has been a real change. GP said he knows nothing about covid and didn’t know where to send me: I had to use the private sector to get answers at a cost. I feel like if you don’t help yourself you are just left, my fatigue is the most debilitating, I am setting in a decompression chamber with oxygen trying to help myself, costing a fortune. I am that desperate, I would see a vet at this stage if I thought it would help. You need to look in to this treatment. I have never felt so desperate and out of control as I do now. A year and half later: it’s nothing short of a nightmare which I am in.’

A strong theme in each interview was that service users were unsure of their own views of the syndrome, and of their health. They were often seeking reassurance and mentioned that the research call had been the first time they had been able to speak about their symptoms. This led to questions being posed to the researcher rather than questions answered. It was difficult to signpost people to services as they articulated the many barriers they had encountered already.

Recommendations made in the interviews:

- *To be recognized and acknowledged*
- *Information for peace of mind*
- *Time limits for when to seek advice regarding loss of function*

It is interesting to note that the Long Covid clinic provides reassurance and support in exactly these areas. None of the service users interviewed had been able to access the Long Covid clinic.

6.12 GP perspective

It was extremely difficult to find GP's who were able to share their experiences. However, the Long Covid service and Clinic put out requests to their GP intranet portals to facilitate this process. To date, we have been offered a meeting with Londonwide Local Medical Committees to meet GPs in the area. This is still to take place. 4 GPs were interviewed with the following themes:

- *Feeling overwhelmed*
- *Dealing with intense patient anger*
- *Subject to constant changes in referral structures for Post-Covid-19*
- *Frequently updated National Guidance*
- *Perceptions of inappropriate requests for referral*
- *Feeling under intense scrutiny*

It was salutary to hear, although in a very small sample, that on occasions GPs were going home in tears, needing the support of colleagues and considering leaving the profession. Signposting was again difficult as GPs identified that they are often operating in isolated situations without time to access support for themselves.

7. Health Inequalities

There is clear evidence that COVID-19 does not affect all population groups equally. There has been a disproportionate effect on people from Bangladeshi, Pakistani, Black African and Caribbean backgrounds.

We analysed the responses provided by people from those communities and compared them to the responses given by people from White communities.

Although we had a relatively small number of survey respondents who were from Bangladeshi, Pakistani, Black African, and Caribbean backgrounds (8%), it is worth noting that in every area of life, respondents from these communities identified a greater effect on their day to day lives. Particularly of note is in the areas of self-care and caring for others:

Has Post Covid syndrome (Long Covid) affected your day to day living in any of these areas? Please tick any that apply.	Total	BAME	White
Ability to wash and dress	(20%)	(27%)	(16%)
Ability to care for others	(24%)	(33%)	(19%)
Ability to work	(50%)	(60%)	(44%)
Ability to go to a place of education	(7%)	(7%)	(6%)
Ability to carry on previous activities, such as sport or hobbies	(76%)	(67%)	(69%)
Enjoyment of life	(93%)	(80%)	(85%)

8. Conclusions and Recommendations

Many people in Redbridge, Barking & Dagenham and Havering with Post-Covid-19 syndrome feel isolated, anxious and distressed. Having a new condition that is not widely understood is an important feature of this. Together with fears of getting ill again, not being believed, lengthy waits for support and unclear pathways to access information, service users reported often feeling invisible. **It is important to state that only 29% of the respondents to the Survey were referred for support for long COVID, and 16% had accessed the long COVID service. Questions did not specifically reference the long COVID service and were answered by all respondents. The findings therefore include a 71% majority of patients who experienced help only from primary care or other services. The poor outcomes identified in terms of physical and mental health unmet need are therefore likely to be related to difficulties in access. This finding is in common with other broader Healthwatch research and is reflected in our recommendations.**

The Long COVID service is well evaluated by service users. The multi-disciplinary nature of the team is particularly appreciated, as the symptoms seem to be managed best by a multi-faceted holistic approach. However, there are acute access difficulties in being referred to the Clinic. These include conflicting information being given to service users within primary care; fear of being disbelieved and in fact having symptoms dismissed during primary care consultations; and a long wait from being seen by the GP to referral. These difficulties are compounded by a high quality of life impact taking away enjoyment of life and reducing capacity to work by 50% in our survey respondents. There was a high level of distress in the in-depth interviews, affecting relationships in every sphere of life.

Interim findings of this report were shared with clinical colleagues both in primary care and in the Long Covid service and clinic. The findings helped to inform ongoing review of the service provision across the pathway and the referral processes. The findings also highlighted a greater need to continue educating clinical staff within primary and secondary care and re-enforced the need for the ongoing education program that had already been established by the Long COVID taskforce and Local BHR clinic. An increase in the Post-Covid diagnosis rate was noted in

the penultimate weeks of the survey, and also an increase in visibility of the Long Covid clinic itself. Whilst not able to directly correlate, the changes made did seem to impact the experience of service users.

Dr Adam Ainley, Consultant Respiratory Physician and Clinical Lead for the BHRUT Long Covid clinic, commented:

'The partnership between Healthwatch and members of the BHRUT/NELFT Long Covid service has been useful in exploring patient experience and in particular, access to support. We have been able to respond to challenges evident from the data obtained by undertaking steps to increase awareness of our specialist clinic at King George and working with stakeholders to simplify the referral process. It has been good to see an increased visibility of the clinic during the data collection window and increase in the number of patients getting support. I look forward to similar research across North East London as the project is rolled out.'

RECOMMENDATION 1: *Continue to simplify primary care referral structures and improved education of staff within primary care about the condition itself and available resources.*

As seen in our findings, GPs are central to determining the service user's quality of care for Post-Covid-19 syndrome. Their ability to help their patients access support is vital; With improved education, awareness of the condition, of the services accessible and how to refer to them and resources available for support, patients may receive a more reliable, holistic and comprehensive experience at point of initial contact. We recommend GPs continue to receive support in their role and that the concerning distress and burnout referenced in the interviews is urgently addressed.

RECOMMENDATION 2: *Peer-led support groups with clinician oversight*

Recommended by Healthwatch Kingston, following their large study into patient experience of Long Covid, we have also observed a clear demand for peer support to address isolation and access to more widespread accurate knowledge about Post-Covid-19. Diabetes UK have created support groups in this way, for example, which are a valued resource to patients. Support groups in local libraries and community venues would provide a much-needed form of shared understanding and reliable information. Clinician support could be given to group leaders along with relevant publications and evidence.

RECOMMENDATION 3: *Increase promotion of the Long Covid service in social media communications*

To support primary care, information about the nature of Long Covid and the length of referral windows could be widely disseminated in self-care forums. This would address the variable quality of information available in the forums and strengthen the awareness of Post-Covid-syndrome.

RECOMMENDATION 4: *Further research across North East London to replicate the project*

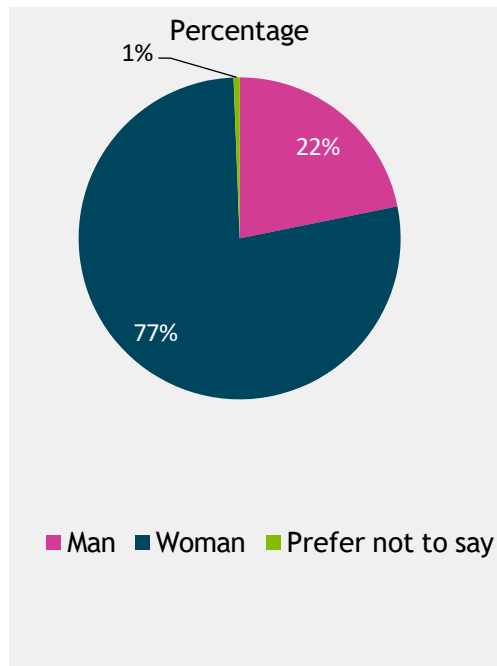
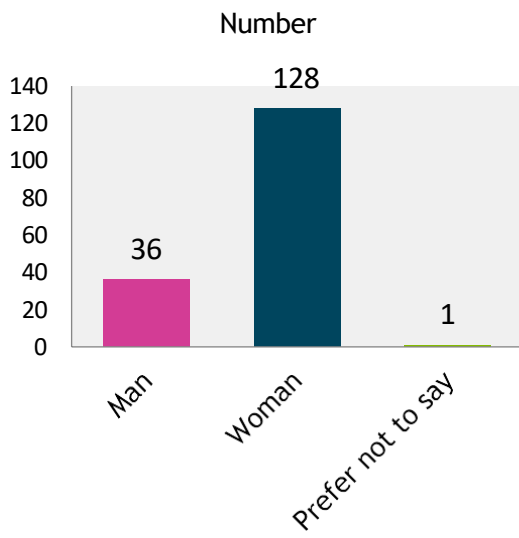
Given the access difficulties described in our findings, we feel that further research is required across North East London to ascertain the prevalence of these barriers in other areas. Research is underway in City and Hackney and also Newham as a result of sharing these findings at the NHS NEL Covid Pathways Operations meeting.

REFERENCES

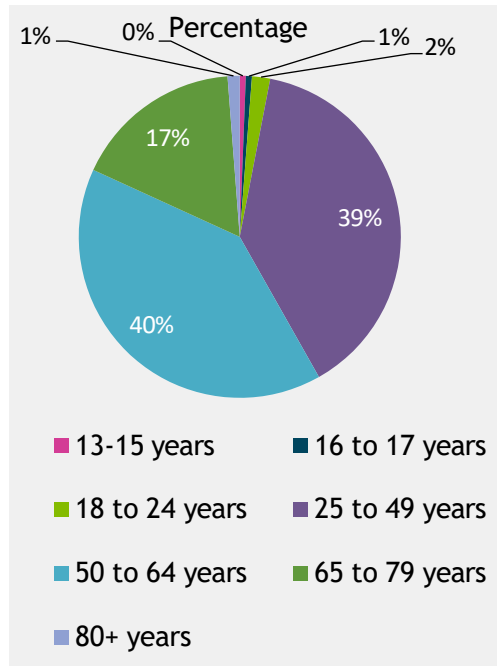
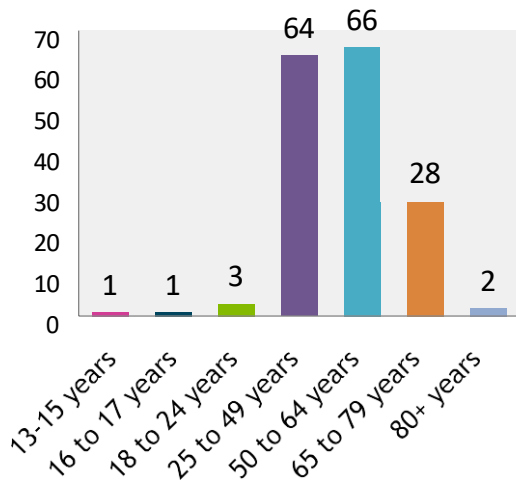
- Healthwatch Barnet (2022). *People's experience of Long Covid in North Central London*. London: Healthwatch National Reports Library.
- Healthwatch England (2022, May). <https://www.healthwatch.co.uk/report/2022-05-30/what-people-told-us-about-long-covid>. Retrieved from healthwatch.co.uk:
<https://www.healthwatch.co.uk/report/2022-05-30/what-people-told-us-about-long-covid>
- Healthwatch Kingston (2022) *Living with Long Covid* Healthwatch National Reports Library.
- Institute of Fiscal Studies. (2022). *Long Covid and the labour market*. Economic and Social Research Council.
- National Institute for Health and Care Excellence. (2022, January). *Key learning points: updated NICE guidance on managing long COVID*. Retrieved from
<https://www.guidelinesinpractice.co.uk/infection/>:
<https://www.guidelinesinpractice.co.uk/infection/key-learning-points-updated-nice-guidance-on-managing-long-covid/456680.article>
- NHS England. (2021, June). *Long Covid NHS Plan 2021-2022*. Retrieved from www.england.nhs.uk:
<https://www.england.nhs.uk/coronavirus/documents/long-covid-the-nhs-plan-for-2021-22/#treatment>
- Office For National Statistics. (2022, July). *Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: 7 July 2022*. Retrieved from
<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/7july2022>
- Royal College of Nursing. (2022). *Long COVID: postcode lottery of care will exacerbate health inequalities*. London: Royal College of Nursing.

APPENDIX 1 DEMOGRAPHIC DATA

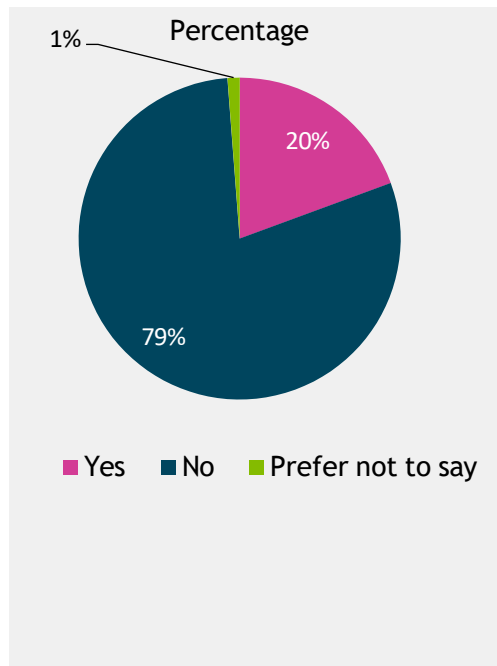
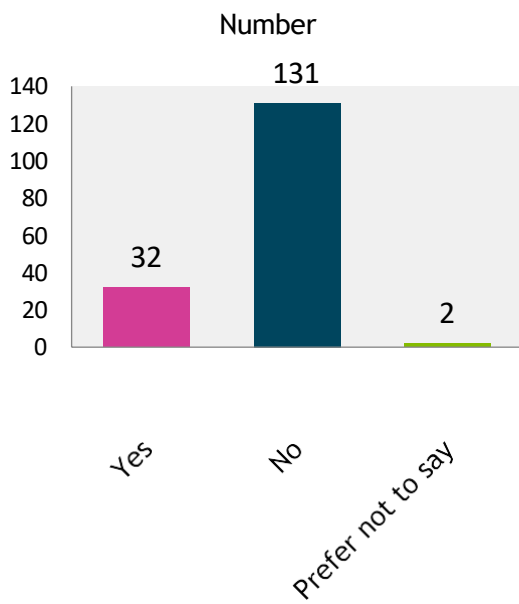
1. Gender



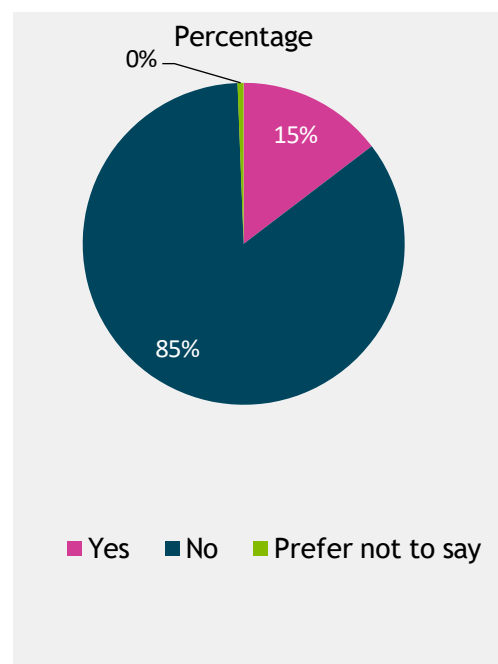
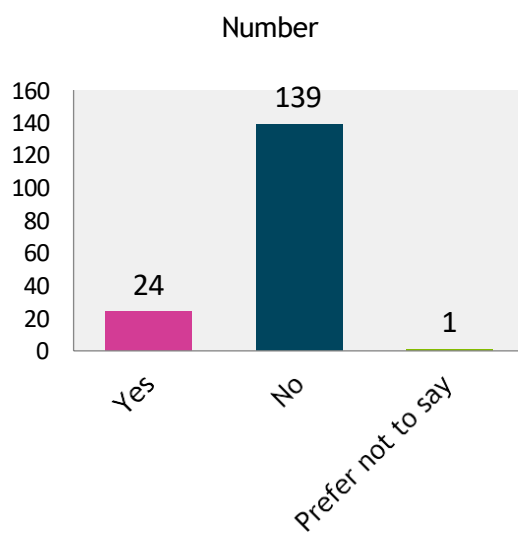
2. Age



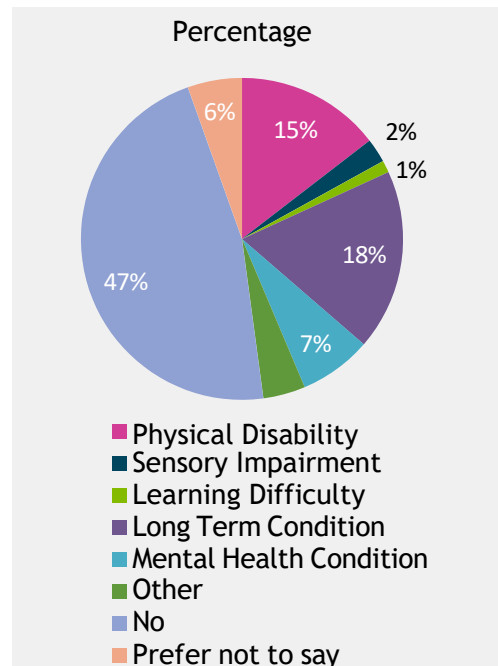
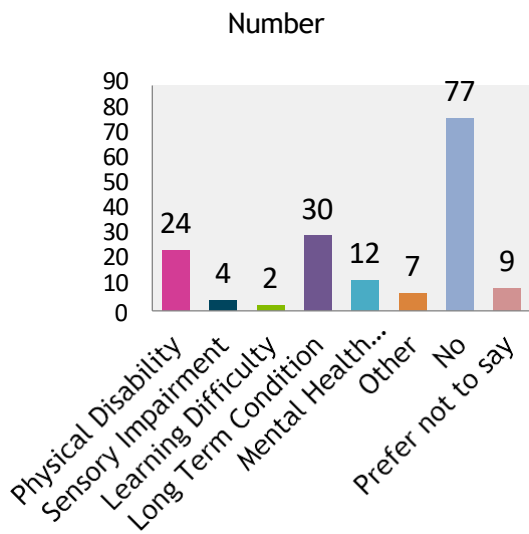
2. Are you a carer?



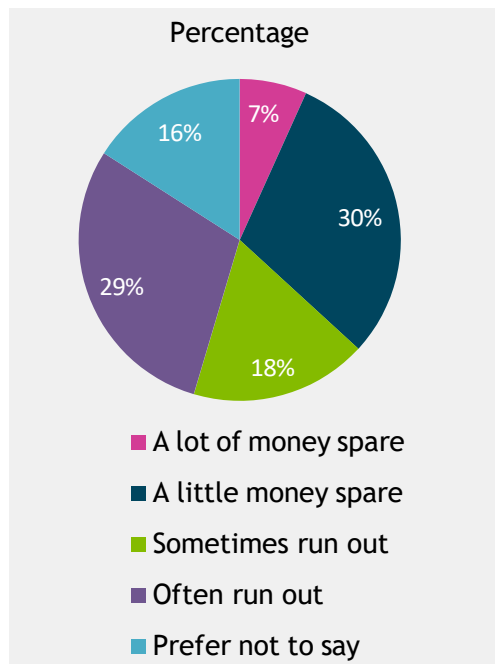
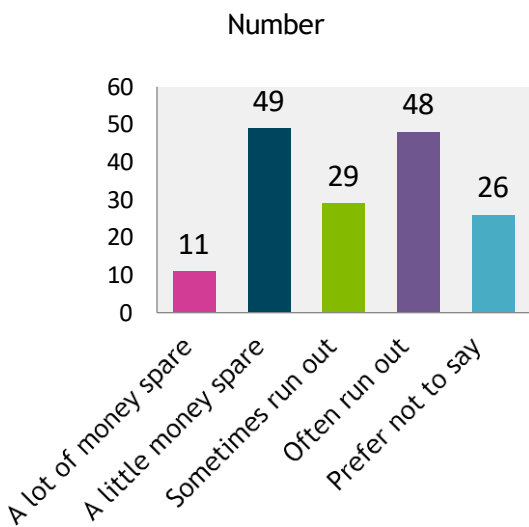
3. Are you a healthcare worker?



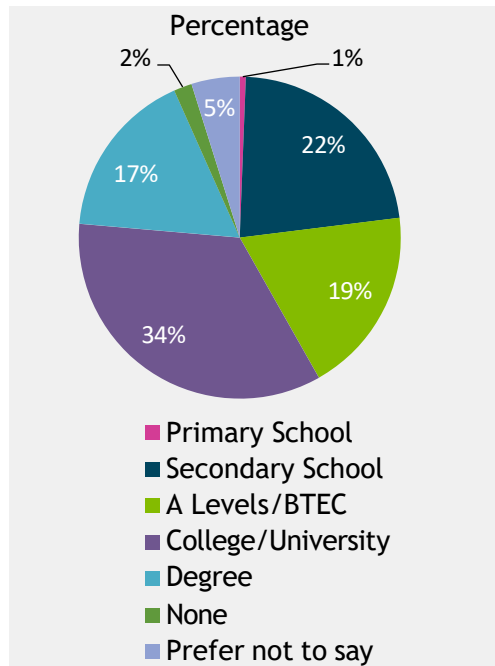
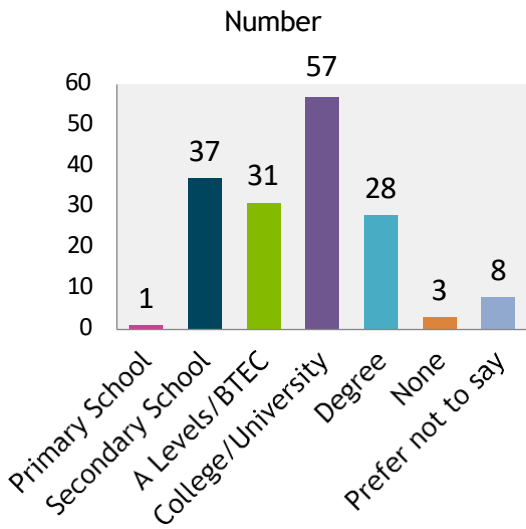
4. Do you have a disability or long term condition?



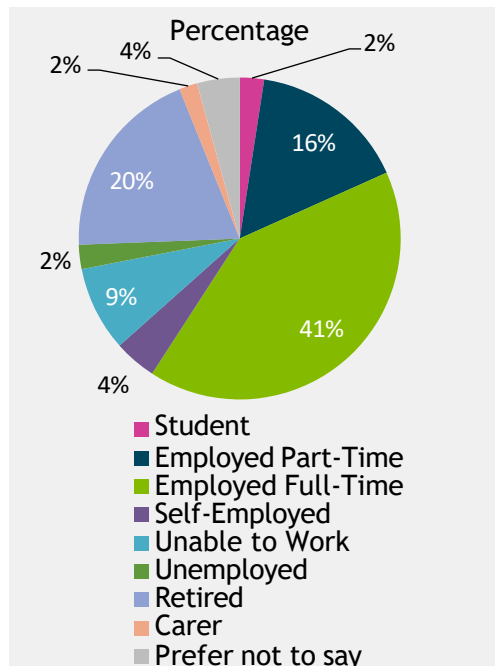
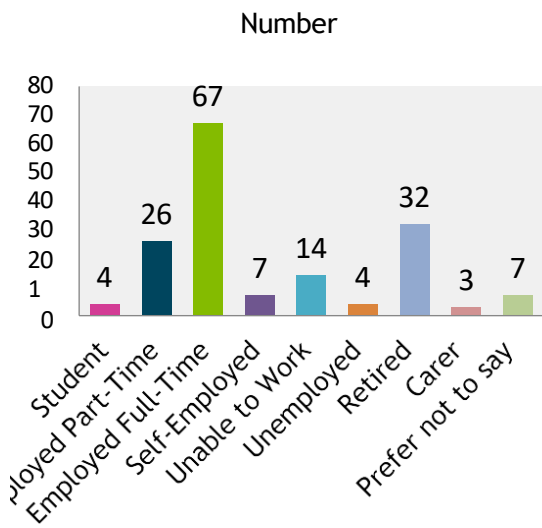
5. What is your money situation?



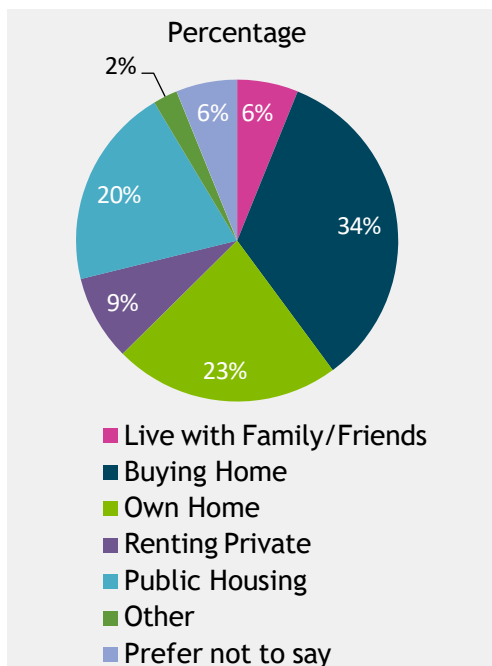
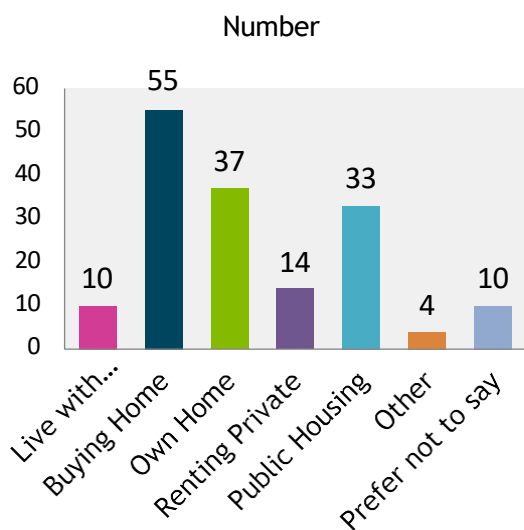
6. What is the highest level of education you have completed?



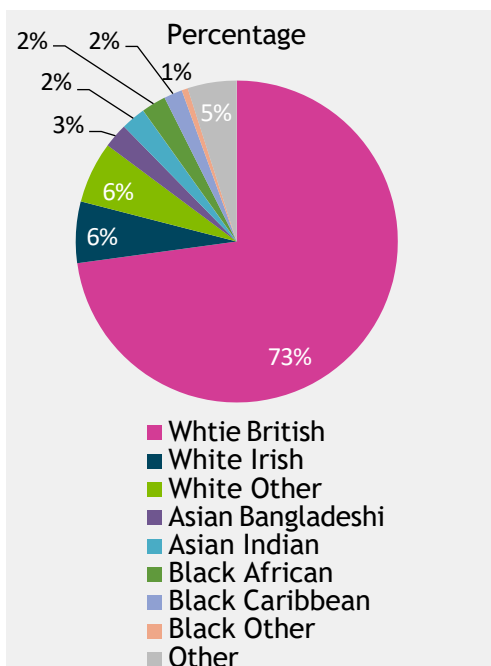
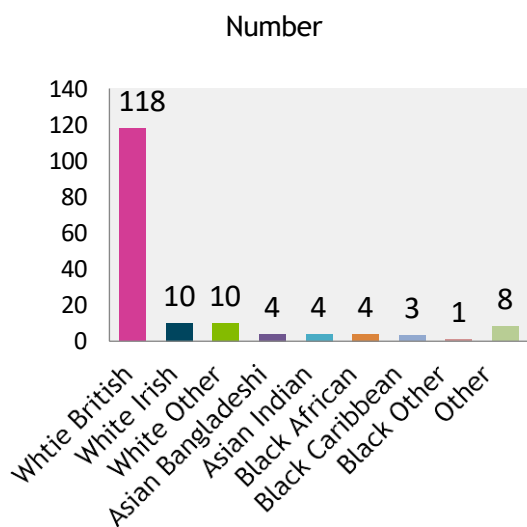
7. What is your employment status?



8. What type of housing do you live in/what is your housing tenure?



9. What is your ethnicity?



Glossary

NELFT	North East London NHS Foundation Trust
BHRUT	Barking, Havering and Redbridge Hospitals University Trust
NICE	National Institute for Health and Care Excellence
ICB	Integrated Care Board
CCG	Clinical Commissioning Group
NHSE	National Health Service England

Distribution and comment

This report is available to the general public, and is shared with our statutory and community partners. Accessible formats are available.

If you have any comments on this report or wish to share your views and experiences, please contact us.

Healthwatch Redbridge
103 Cranbrook Road, Ilford IG1 4PU
02085531281
www.healthwatchredbridge.co.uk