

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



“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

“There’s absolutely no support, it’s like people with Long Covid are invisible.”

Local Resident

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Demographics

Appendix 1

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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.

There is evidence from other Healthwatch reports (Healthwatch Barnet, 2022) and the Royal College of Nursing (June 2022) (RCN, 2022) 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

There is no currently agreed clinical definition. However the National Institute for Health and Care Excellence recommendation (NICE, 2021) 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.

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. 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.

3. Methodology and Collaboration with NHS partners

We had three main strands of data collection:

- Tri-Borough survey with free text comments for additional qualitative analysis, promoted by the NEL CCG Comms team; NELFT Long Covid service comms team; NELFT patient experience and expert patients comms team; BHRUT 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, 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. Although this took slightly longer, the wide reach of the survey 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. Changes were made in the light of interim findings.

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 ICP 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. This led to primary care training webinars being designed and delivered by the Long Covid service. Additionally, the referral form from NHSE was simplified to make the referral structure easier for GPs. At the same time we were asked to develop a quality of life impact scale from the data for the syndrome. This was then used in requesting 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%. 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.

This is a summary of key findings - see section 6 for the analysis in full.

Key Findings

General

- A clear majority of respondents (87%) have tested positive for Covid-19, while under half (44%) have been diagnosed with Long Covid.
- On impact on daily living, most (**93%**) **feel that life has become less enjoyable**, with two thirds (76%) finding it more difficult to undertake hobbies.
- **Half of all respondents (50%) say their ability to work has been affected.**

Services

- Respondents are almost twice as likely to seek self-help, than consult with their GP.
- Just under a third of respondents (30%) have accessed a designated service for Long Covid.
- A majority feel that hospital and community based services have not been helpful (54%), while a similar number (54%) say that primary care services have not helped.
- Around a quarter of respondents (27%) have been referred to receive support.
- 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.

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.

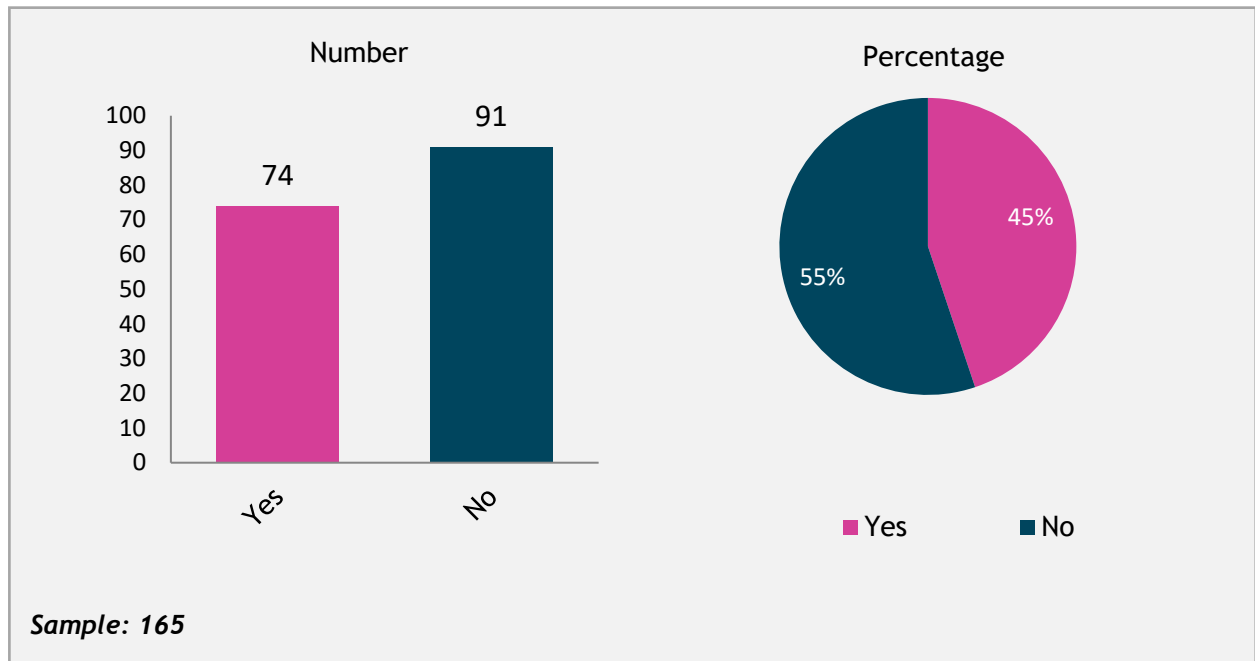
What are people saying?

- 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.
- Waiting lists for the Long Covid Clinic are reportedly around a year. It is commented that children, or those without a diagnosis, are not eligible.
- 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 packages, 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.

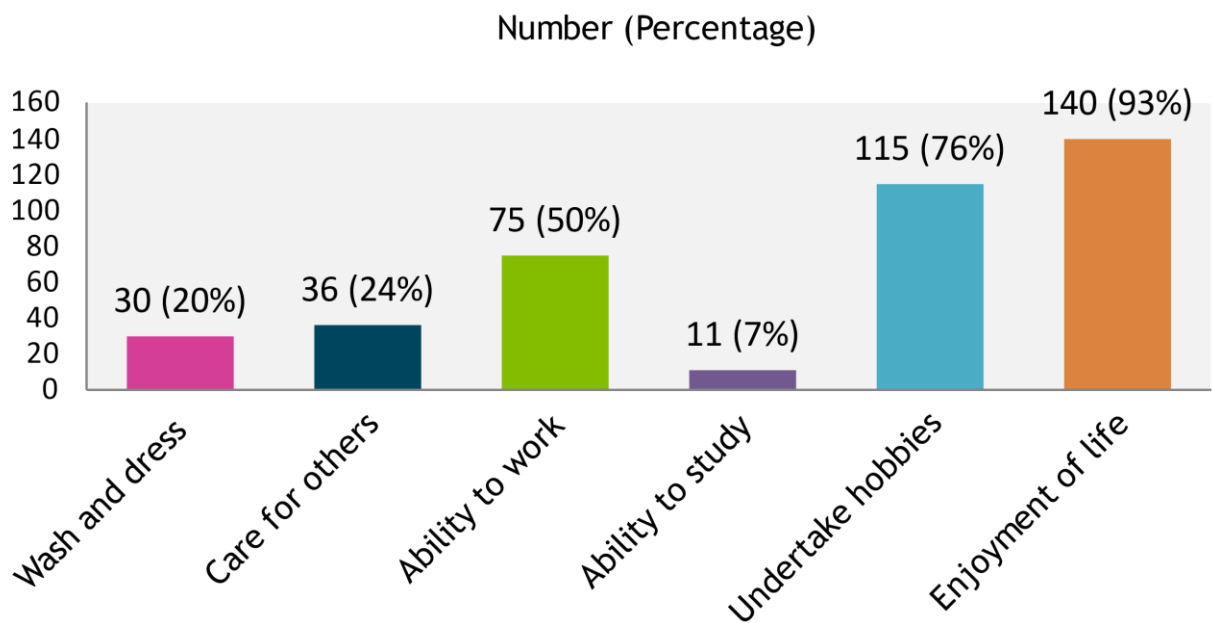
6. Analysis of survey feedback

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:

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

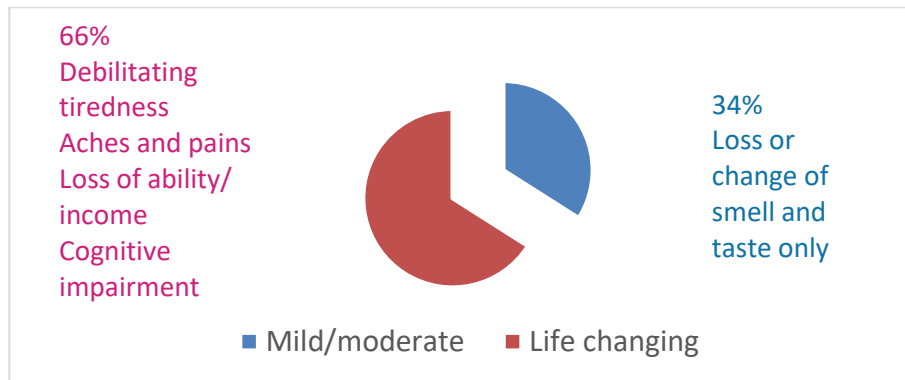


6.2 Has Post Covid syndrome (Long Covid) affected your day to day living in any of these areas?



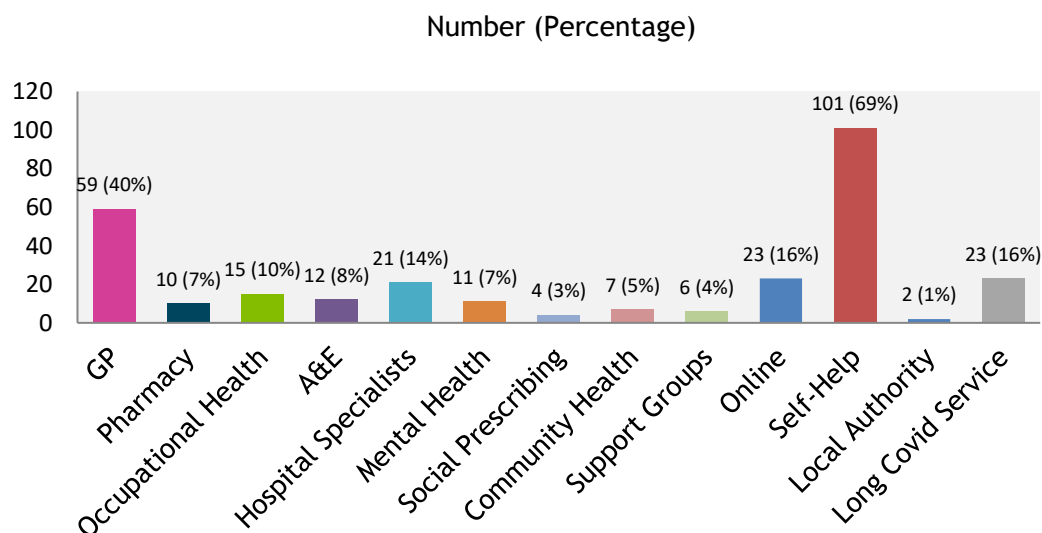
When looking at effects on daily living, a majority (93%) feel that life has become less enjoyable, with three quarters (76%) finding it more difficult to undertake hobbies. Half of all respondents (50%) say their ability to work has also been affected.

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 life-changing symptoms. This 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. Levels of information, on what support is available are said to be lacking.

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

Selected Comments

"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."

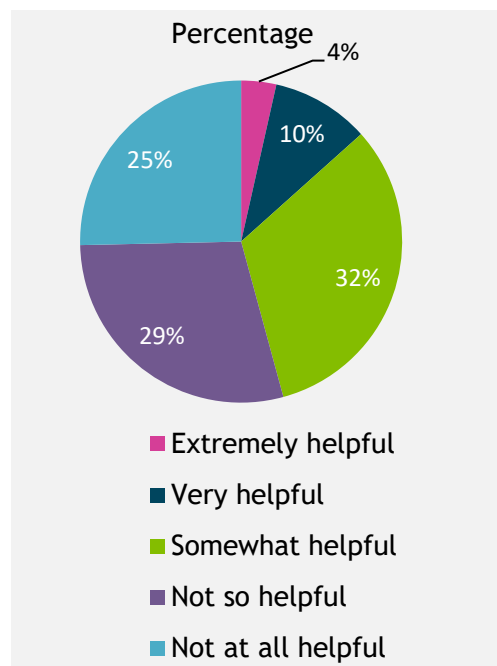
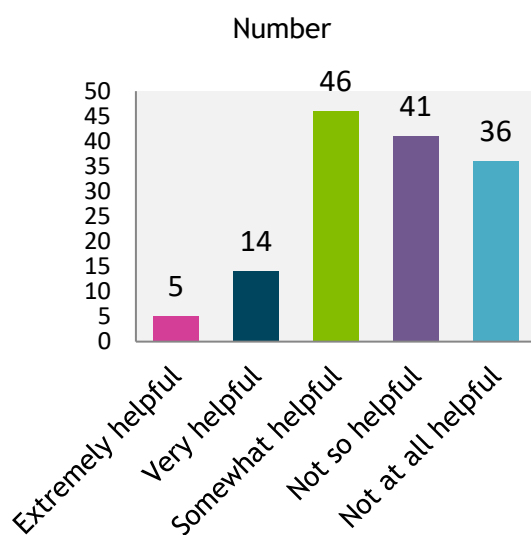
"Like most people I know - we just carried on without any seeking any NHS help."

"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?



Just over half of respondents (54%) feel that primary care services have not been helpful.

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'.

Selected Comments

"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."

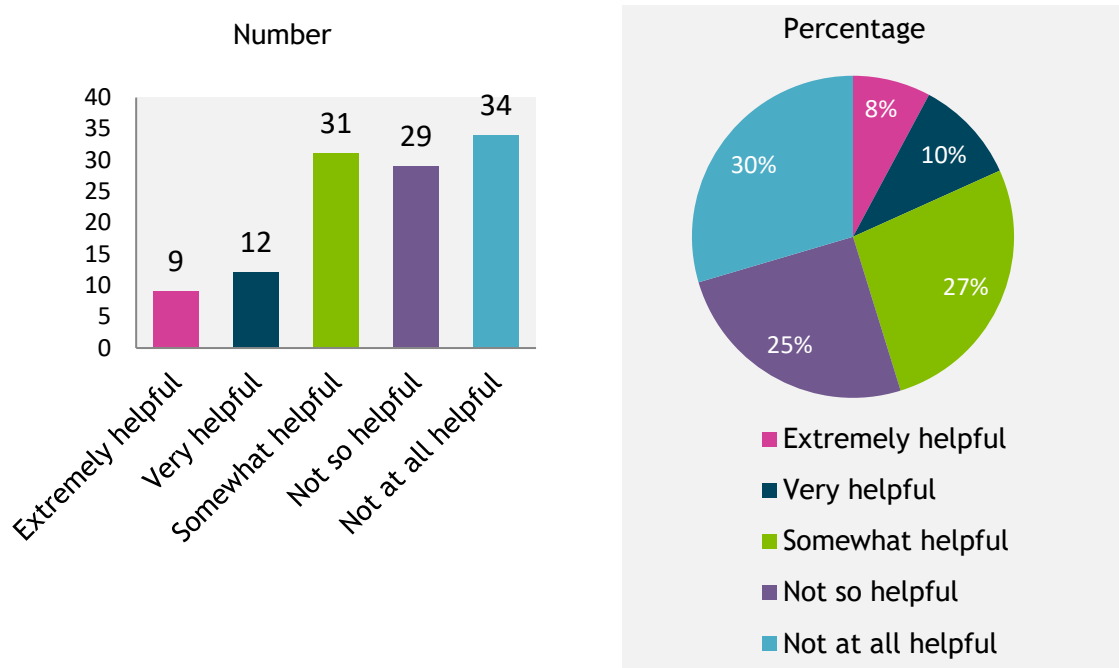
"Tried contacting the GP, a waste of time, cannot sit on the phone at 8am to get an appointment, tried 111 and just as bad. No hub appointments available."

"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."

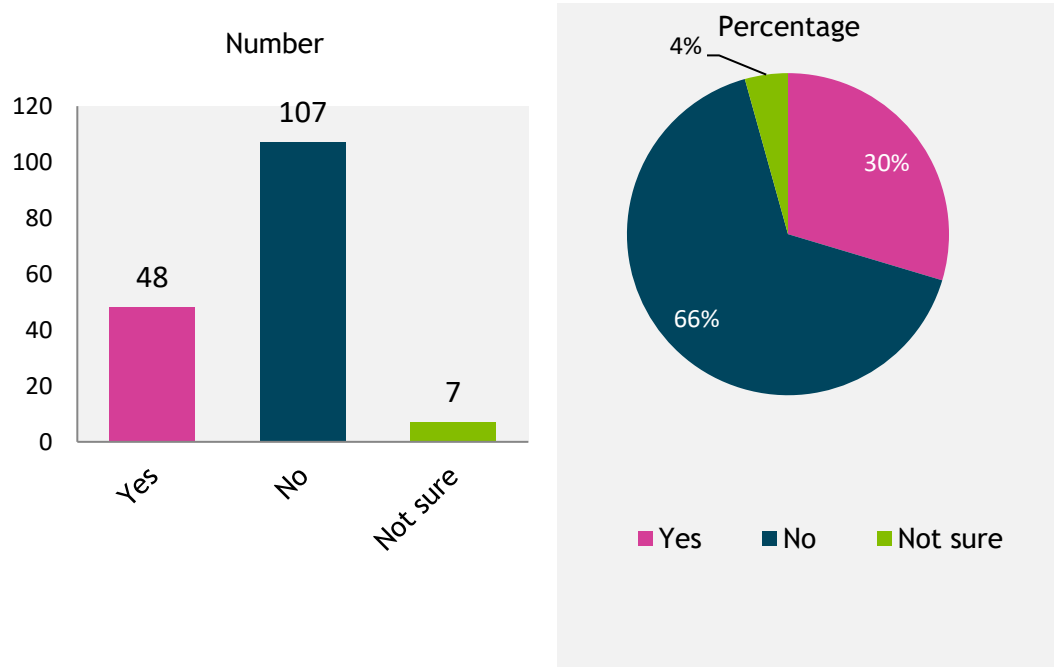
"I've mentioned to the GP about a lack of energy, fatigue, loss of taste and smell and headaches and he didn't act."

6.5 How helpful did you find the experience of using hospital or community care, if applicable?



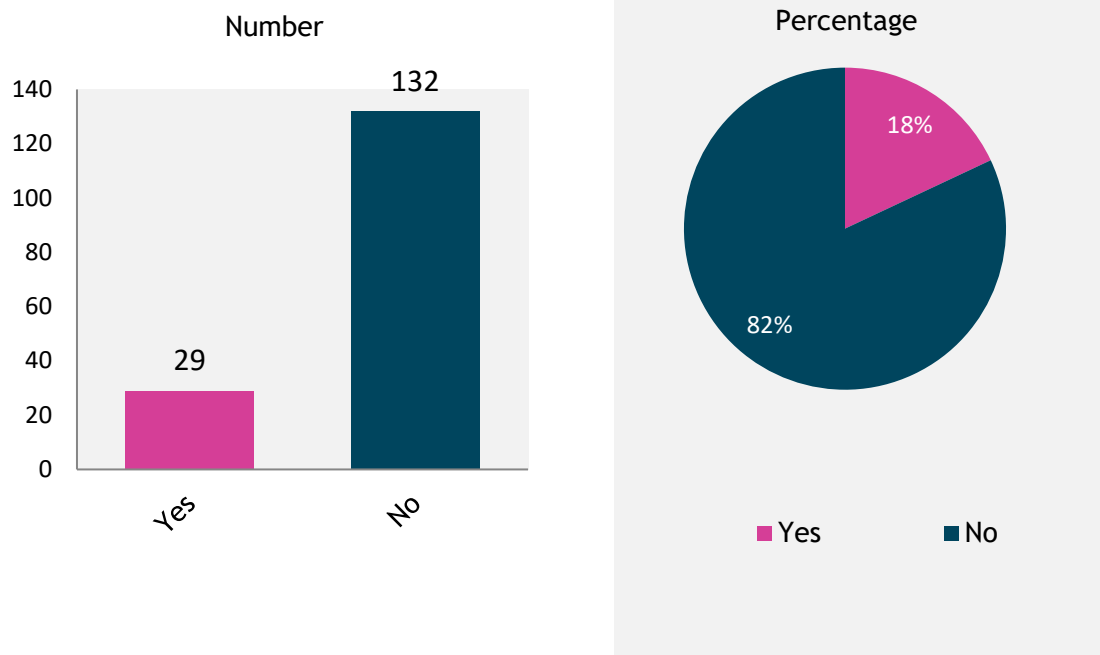
A majority of respondents (55%) feel that hospital or community based services have not been helpful.

6.6 Have you been referred to support for Post-Covid-19 Syndrome (Long Covid)?



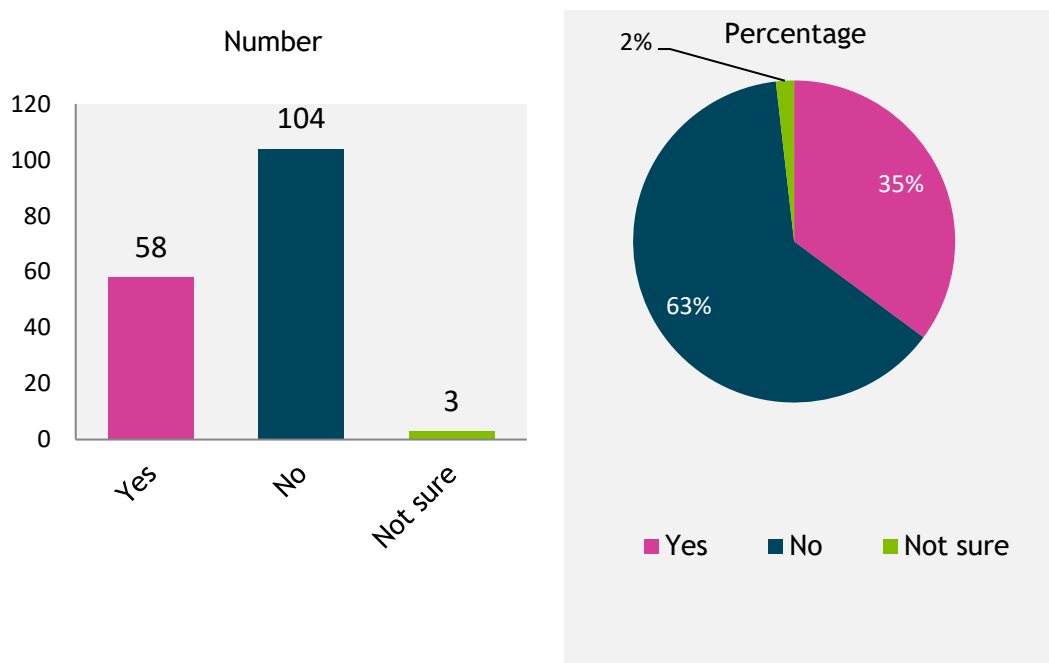
Just under a third of respondents (30%) have been referred to receive support.

6.7 Have you self-referred or found support elsewhere?



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?



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).

Those with experience of the service report waiting lists of around a year. 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, we also hear that children, and those without official diagnosis are not eligible. Awareness levels of the service are lacking in cases.

Selected Comments

"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."

"My experience has been terrible in seeking help and support. My parents have had to pay for private consultations as I was turned away from the Long Covid Clinic due to being under 18."

"I feel that those of us who contracted Covid-19 so early on that we were not able to be tested for it, have not had the support we could have had, as we have not been able to prove that we had the infection."

"I did not know that there was a Long Covid Clinic so have not been referred to it, and would like to be assessed by clinic."

"Still haven't had an appointment over a year later."

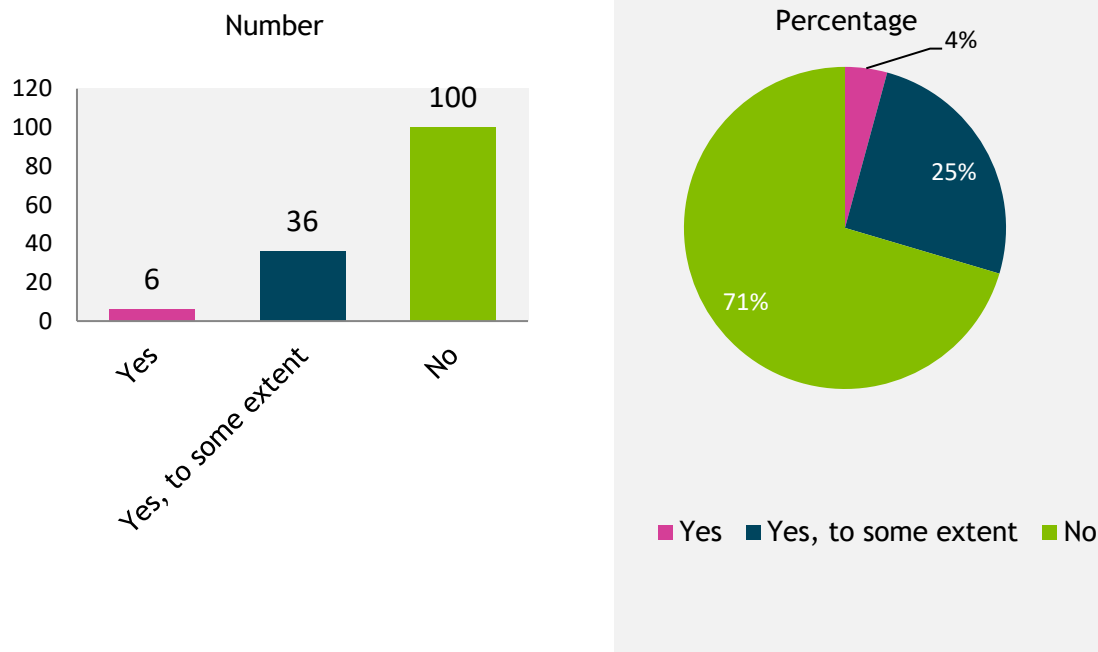
"Took a year to get into the Long Covid system."

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

"My son isn't able to get access."

"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?



Approximately 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, 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.

Selected Comments

“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.”

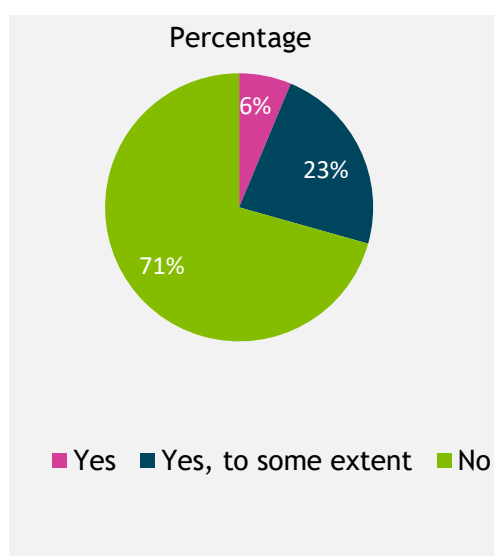
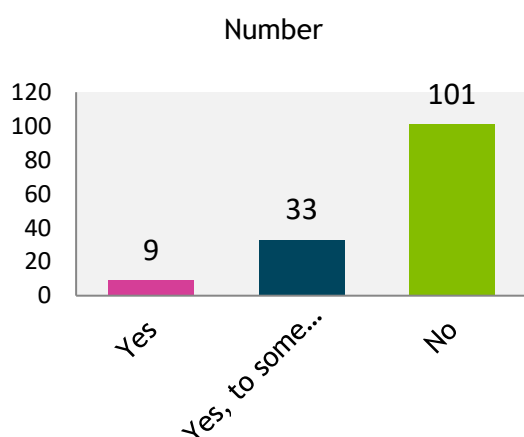
“There’s absolutely no support, it’s like people with Long Covid are invisible.”

“I was never diagnosed with Long Covid, even though I have long term affects after having Covid. So I wasn’t offered support.”

“I’ve had to research a lot of the stuff myself and then ask for tests.”

“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?



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

Long waiting lists for mental health support are reported.

Selected 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

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*
- *Uncertainty as to the nature and designated symptoms of Post-Covid-19 syndrome*
- *Confusion and frustration in access*
- *Distress and severe disease impact*
- *Unsure if the issues are worthy of medical attention (eg loss of smell for two years)*

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, but this is representative of the participants as a whole.

6.12 GP perspective

It was extremely difficult to find GP's who would be willing 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*
- *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.

8. Conclusions and Recommendations

The specialist provision for Post-Covid-19 syndrome is exceptionally well evaluated by service users. The multi-disciplinary nature of the team is especially 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 across primary care; fear of being disbelieved and in fact having symptoms dismissed during consultations; and a long wait for 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.

However, the interim findings of this report were shared with clinical colleagues both in primary care and in the Long Covid service and clinic. This led to immediate changes to the service, of a simplified referral system for GPs and a series of primary care webinars delivered to GP intranet portals within the survey window. 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 in patient interviews by increasing 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.'

In summary, our findings are:

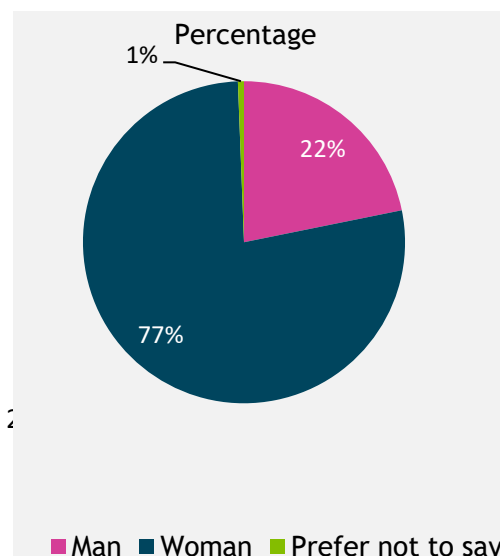
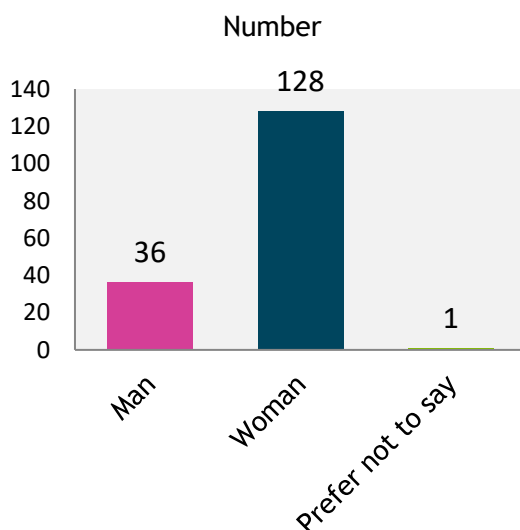
- *Although a 'niche' clinical area there is high disease impact*
- *Well-evaluated specialist clinical provision*
- *Extreme access difficulties are being experienced by service users, which is causing distress and exacerbating high levels of anxiety*

Recommendations:

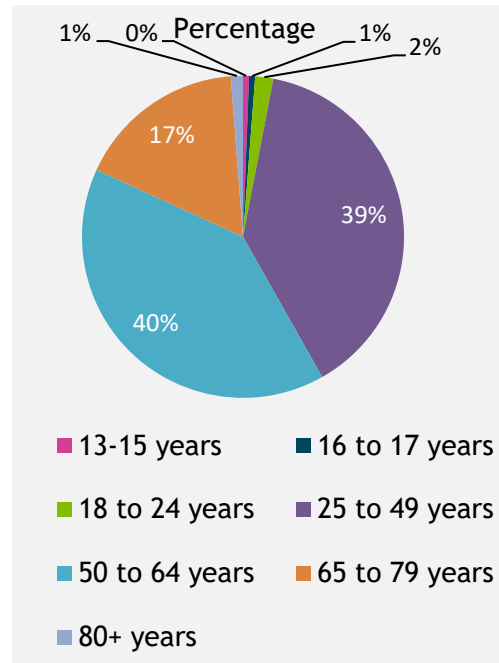
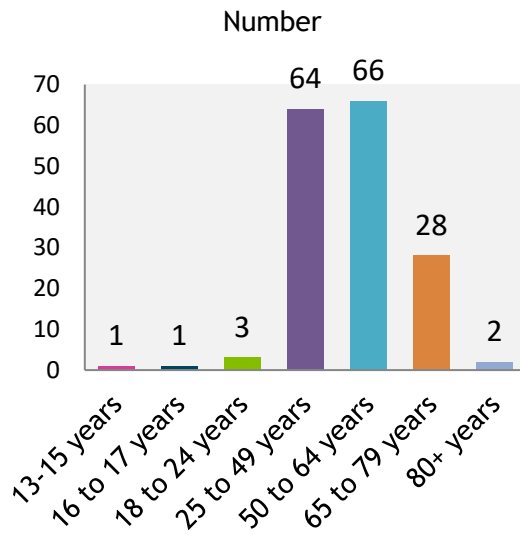
- *Referral structures continue to be simplified*
- *Community intelligence gathering across NEL to replicate the project - this is currently underway in City & Hackney and Newham*
- *Widen in-person GP access to assess impact*
- *Increase promotion of the Long Covid service in social media communications*

APPENDIX 1 DEMOGRAPHIC DATA

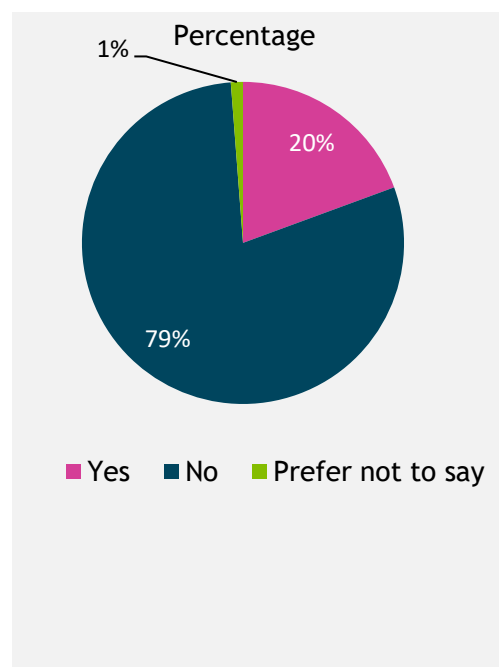
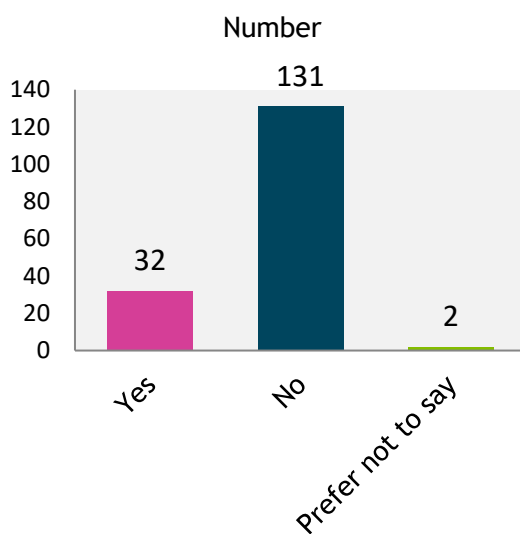
1. Gender



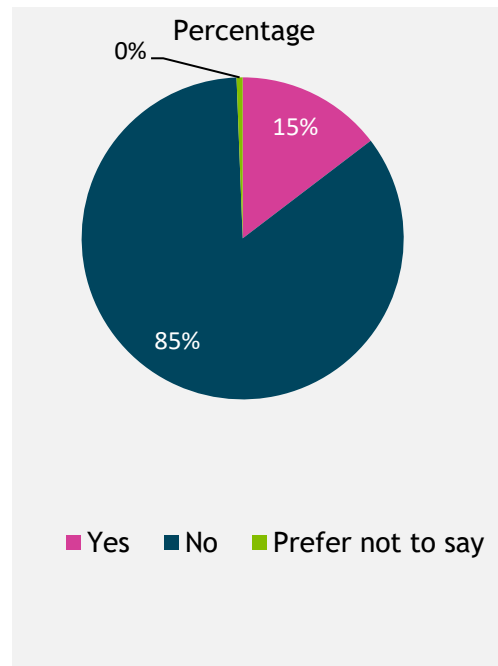
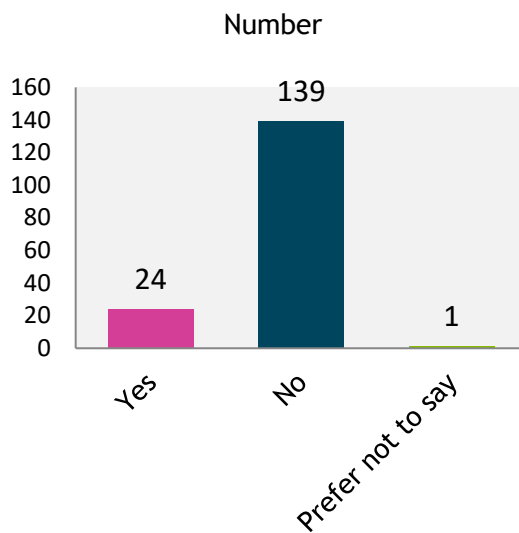
2. Age



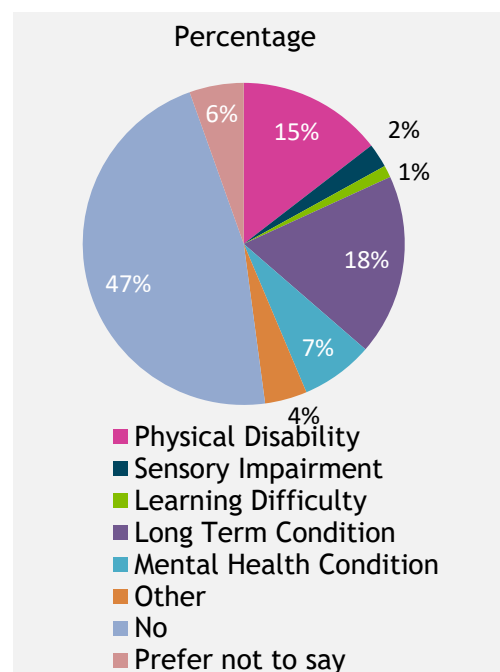
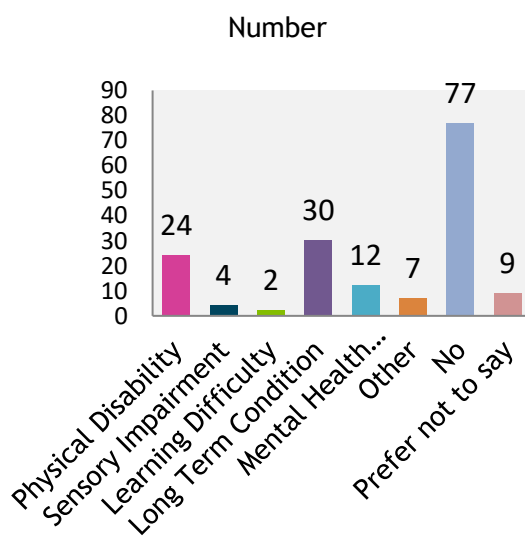
3. Are you a carer?



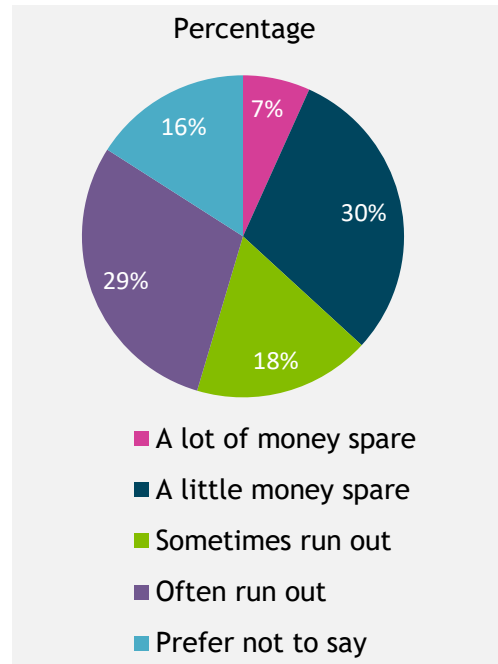
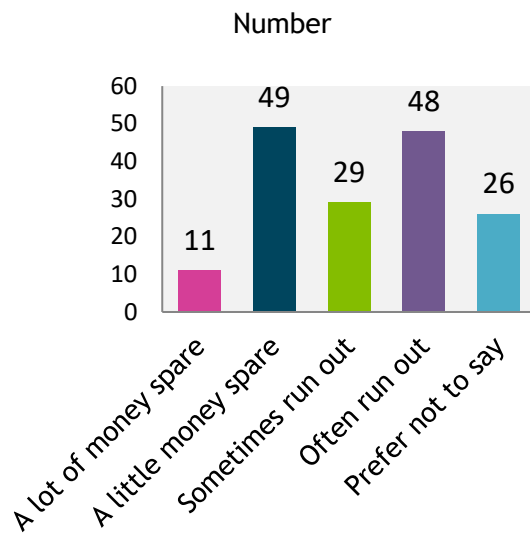
4. Are you a healthcare worker?



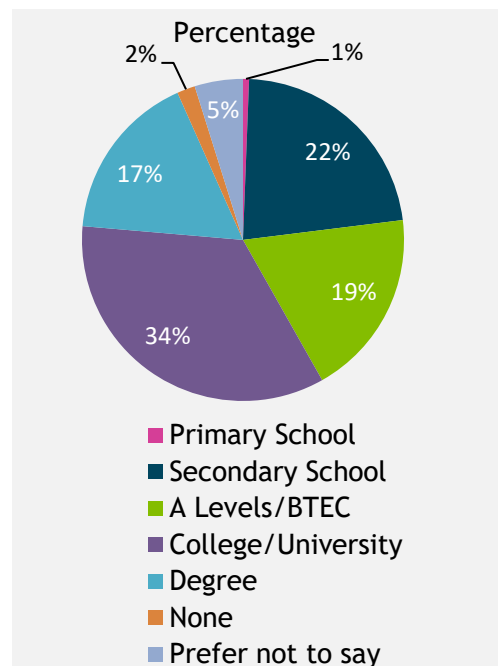
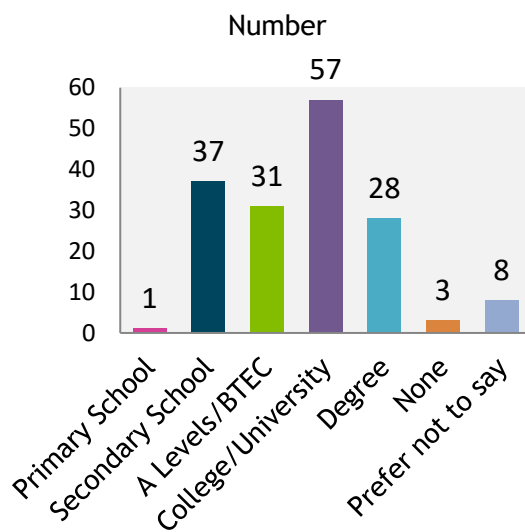
5. Do you have a disability or long term condition?



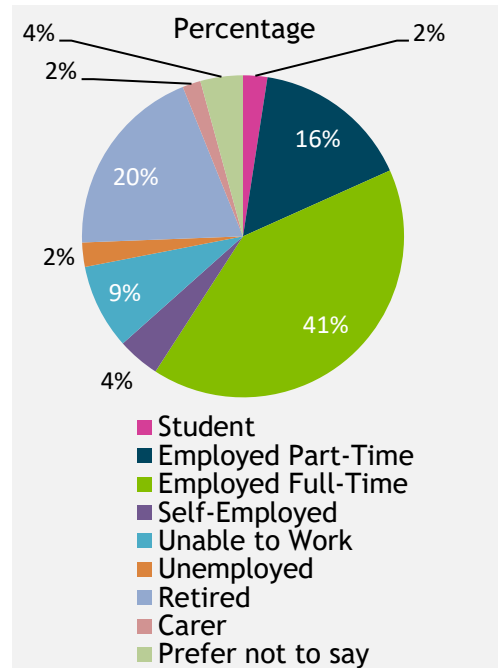
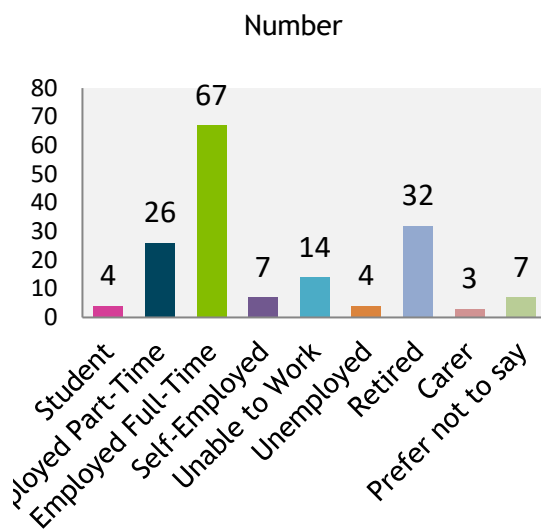
6. What is your money situation?



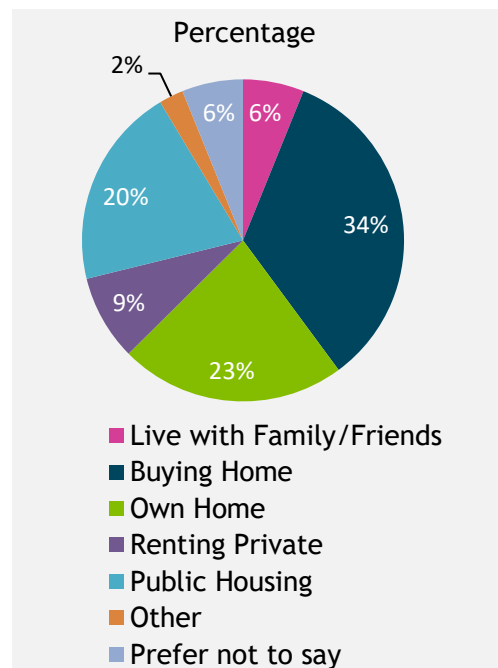
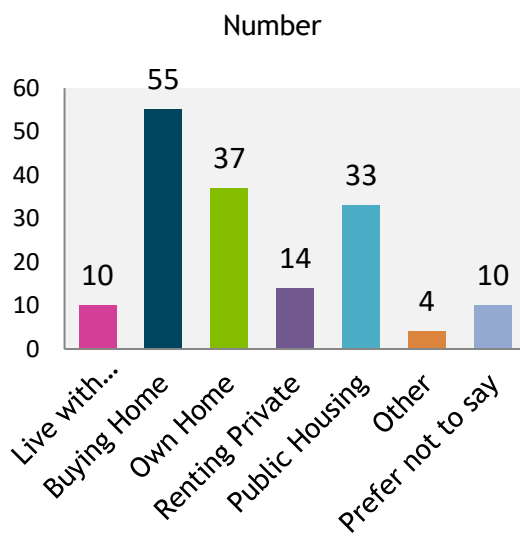
7. What is the highest level of education you have completed?



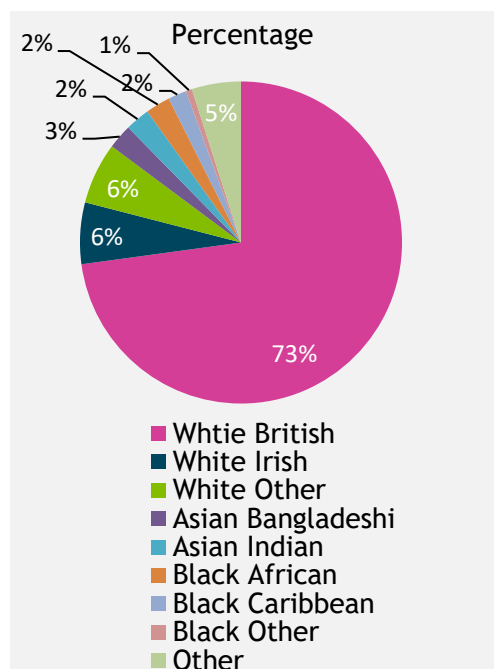
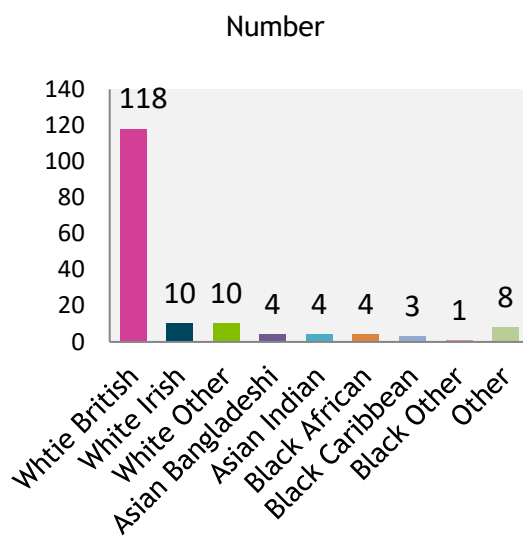
8. What is your employment status?



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



10. What is your ethnicity?



Glossary

NELFT

North East London NHS Foundation Trust

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.

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