

# Long Covid - The Experience of Local People

A report by Healthwatch Enfield



April 2022

“I feel too tired to exercise, I try and walk to work each morning as it’s only 10 minutes away but seldom manage - and end up on the bus.”

Local Resident

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## 1. Introduction

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.

## 2. Background

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. 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 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.

University College London Hospitals (UCLH) provides the Post-COVID Specialist Clinic service for residents across North Central London (NCL).

## 3. Methodology

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.

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.

## 4. Limitations (Disclaimer)

While a good number of people completed our local survey, it is by no means representative of residents experiences as a whole.

## 5. Executive Summary of Findings

During October and November 2021, 53 local people completed our survey on Long COVID.

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

### Key Findings

#### General

- Two thirds of respondents (66%) had tested positive for COVID-19 prior to experiencing Long COVID symptoms. 7% had tested negative.
- 42% have been living with Long COVID for over year, while many others - who are close to this milestone are also likely to do so.
- Few people (just 2) indicate they have recovered.
- A clear majority of respondents (92%) have received at least one vaccine dose.

#### Impact on Health and Wellbeing

- 87% of respondents cite an impact on their physical health. We receive numerous accounts of tiredness and fatigue, a lack of energy and sleep, aches and pains, a loss of smell and taste, and inability to perform once routine tasks.
- 74% say their mental health has been affected. Many people describe feeling tense, anxious, nervous or depressed.
- Over half of respondents (60%) feel they are less able to do the things they enjoy and 53% have difficulty in undertaking daily tasks, such as home chores.
- 42% experience problems with work. Some employees taking days off sick are fearful of facing 'disciplinary action'.
- Just 6% of respondents feel that Long COVID has not affected their daily lives.

#### Services and Support

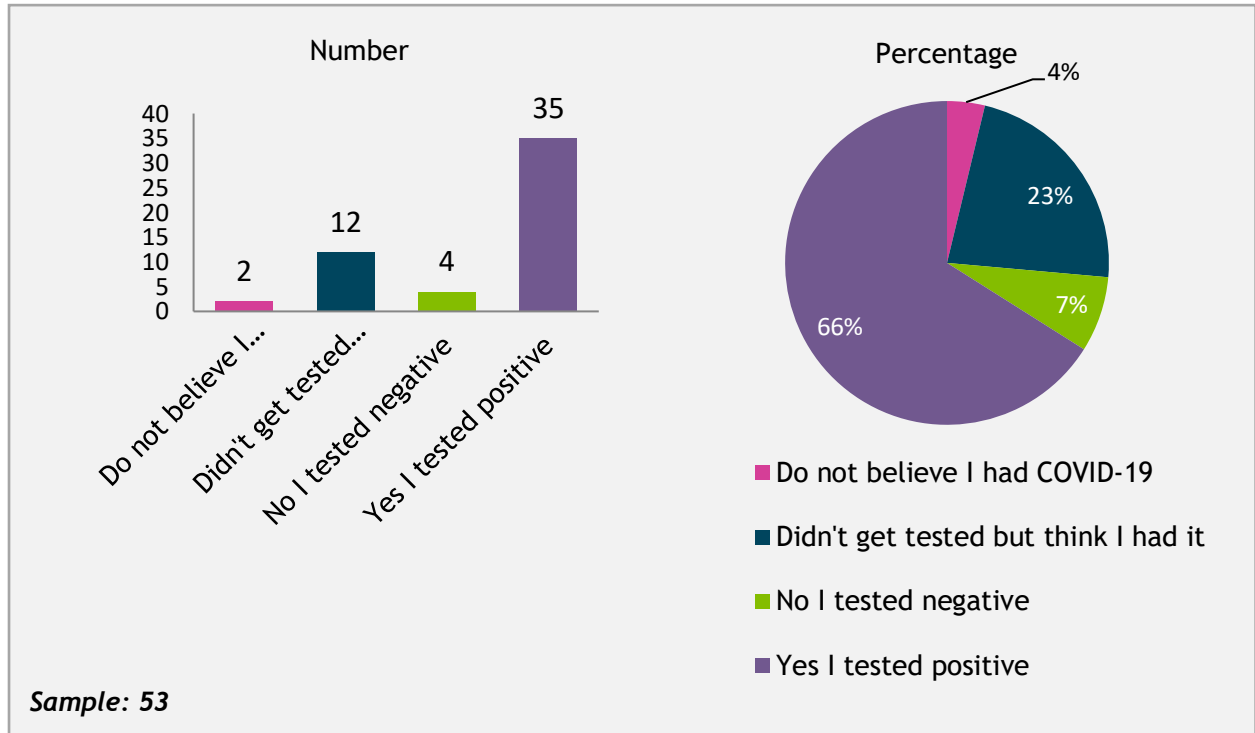
- A marginal majority of respondents (54%) have consulted with health professionals.
- Of these, almost two thirds (62%) have been formally diagnosed - with diagnosis times ranging from less than one month (40%) and over four (also 40%).
- For those not seeking support from their GP, over half (52%) feel they were not a priority and 43% are not confident that their GP could help.
- Just 12% of respondents feel that their GP or clinician have 'a great deal' or 'a lot' of knowledge on the condition.
- A significant number (40%) have experienced difficulty in accessing healthcare support. A lack of information and follow-up is reported. Some also feel 'a burden'.
- Just 2 respondents have been referred to receive support and just 2 are satisfied with the health service support offered.
- 79% of respondents have felt the need to conduct their own research.
- Self-management (such as exercise, pain relief and peer support) has been notably more effective than support from services.

## 6. Analysis of Feedback

During October and November 2021, 53 local people completed our survey on Long COVID.

This report is based on their collective feedback.

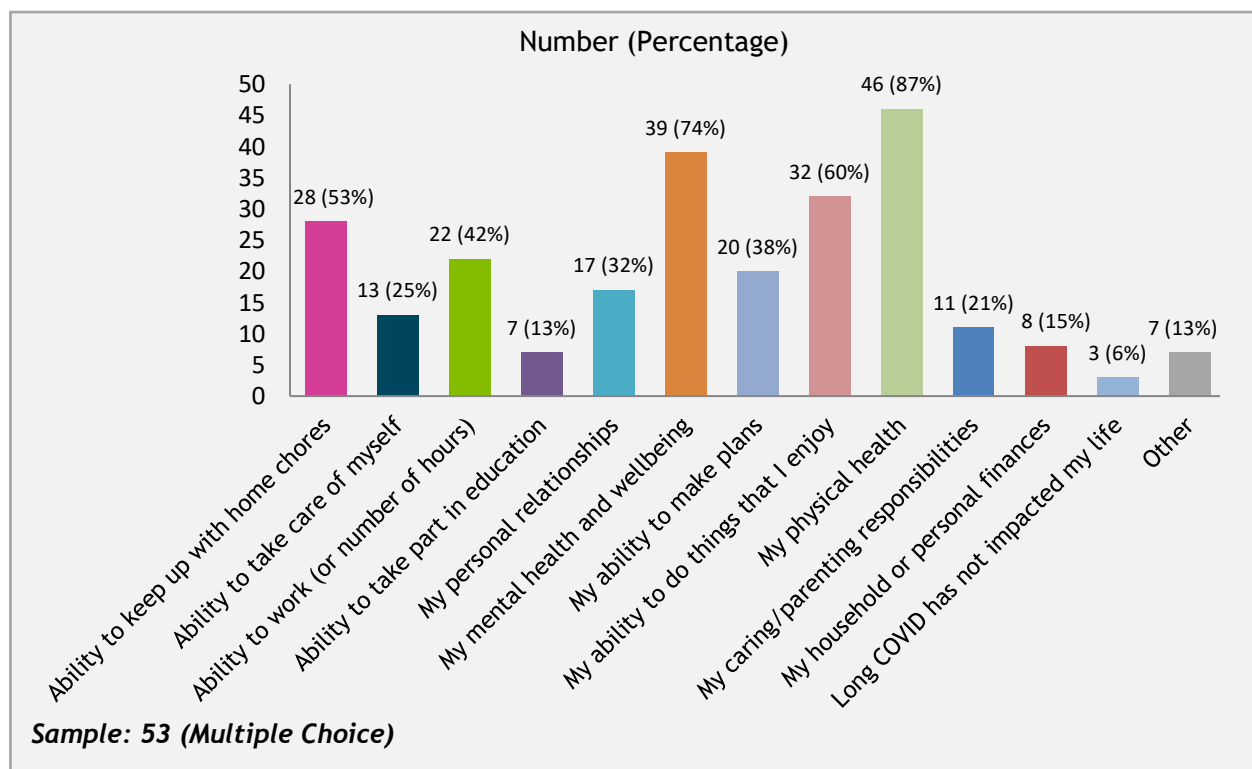
### 6.1 Did you test positive for COVID-19 prior to experiencing Long COVID symptoms?



Two thirds of respondents (66%) had tested positive for COVID-19 prior to experiencing Long COVID symptoms, while a further 23%, who did not get tested believe they had contracted the virus. 7% tested negative.



## 6.2 What has been the impact of Long COVID on your life? Choose the areas it has negatively affected.



When asking people how Long COVID has affected them, a broad majority (87%) cite an impact on their physical health, while three quarters (74%) say their mental health has been affected.

Over half of respondents (60%) feel they are less able to do the things they enjoy. The ability to undertake daily tasks, such as home chores (53%) or work (42%) are also widely mentioned.

Lesser but still significant areas include the ability to plan ahead (38%), personal relationships (32%), looking after personal needs (25%) or caring for others (21%).

Just 6% of respondents feel that Long COVID has not affected their daily lives.

On reviewing feedback, we hear numerous accounts of tiredness and fatigue, a lack of energy and sleep, aches and pains, a loss of smell and taste, and inability to perform once routine tasks - a common cause of frustration. Many people describe feeling tense, anxious, nervous or depressed.

### Selected Feedback

*"I cannot smell and taste which affects my enjoyment."*

*"Extreme fatigue daily and long bouts of anxiety."*

*"I have fluid around the heart, back and joint pains, some depression."*

*"I feel too tired to exercise, I try and walk to work each morning as it's only 10 minutes away but seldom manage and end up on the bus. I feel drained after a few hours and supplement this with energy drinks to keep me alert."*

*"I had COVID symptoms including extreme tiredness, shortness of breath, fever, sore throat, loss of taste, weakness in my muscles, aches all over my body, confusion, unable to sleep and many more."*

*"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 - this is making me feel useless as I can't do anything anymore."*

*"Not being able to physically do the things I used to has also impacted my mental wellbeing."*

When asking people about impact on their job security, some indicate they are less able to perform usual duties, and those taking days off sick are fearful of facing 'disciplinary action'. One person has felt the need to resign, and those no longer working highlight depression.

#### **Selected Feedback**

*"It has affected me as my anxiety prevents me from doing jobs I think I can do."*

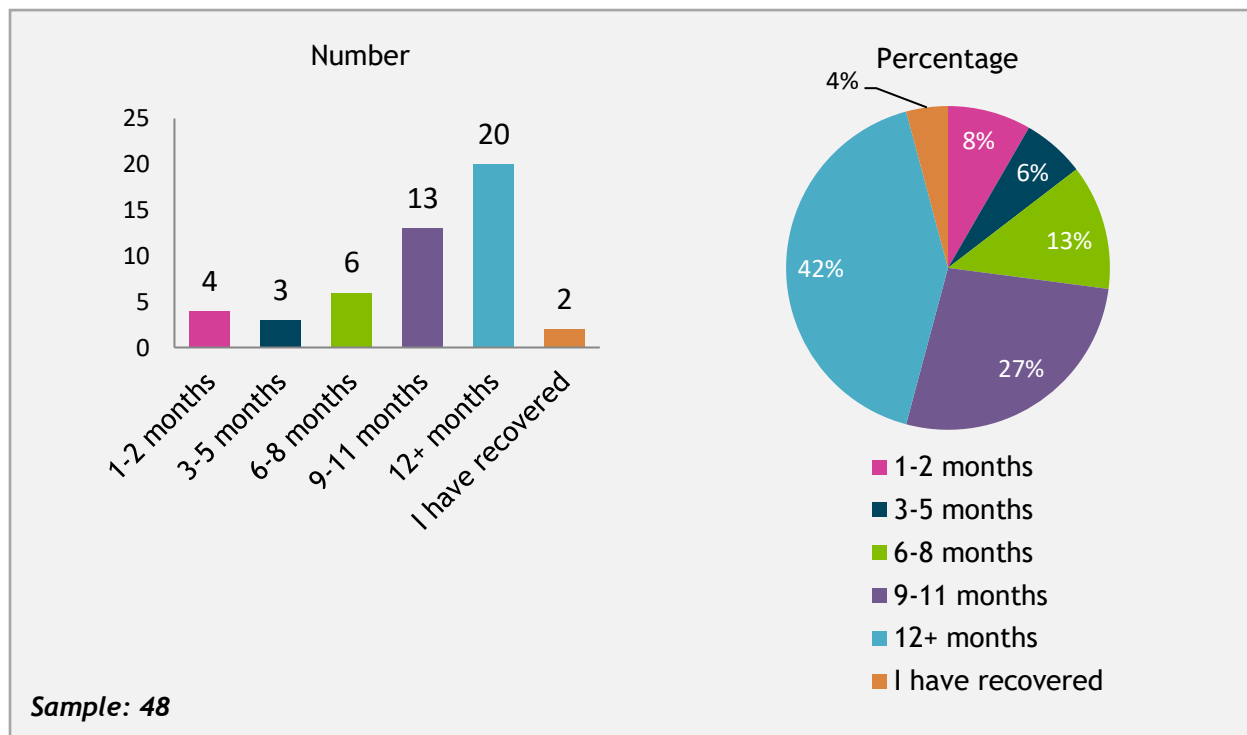
*"Due to having episodes of fatigue, breathlessness, brain fog and many other symptoms I worry about the number of days I have off sick."*

*"I have had too many absences which could result in a disciplinary."*

*"I ended up quitting my job as I was constantly tired."*

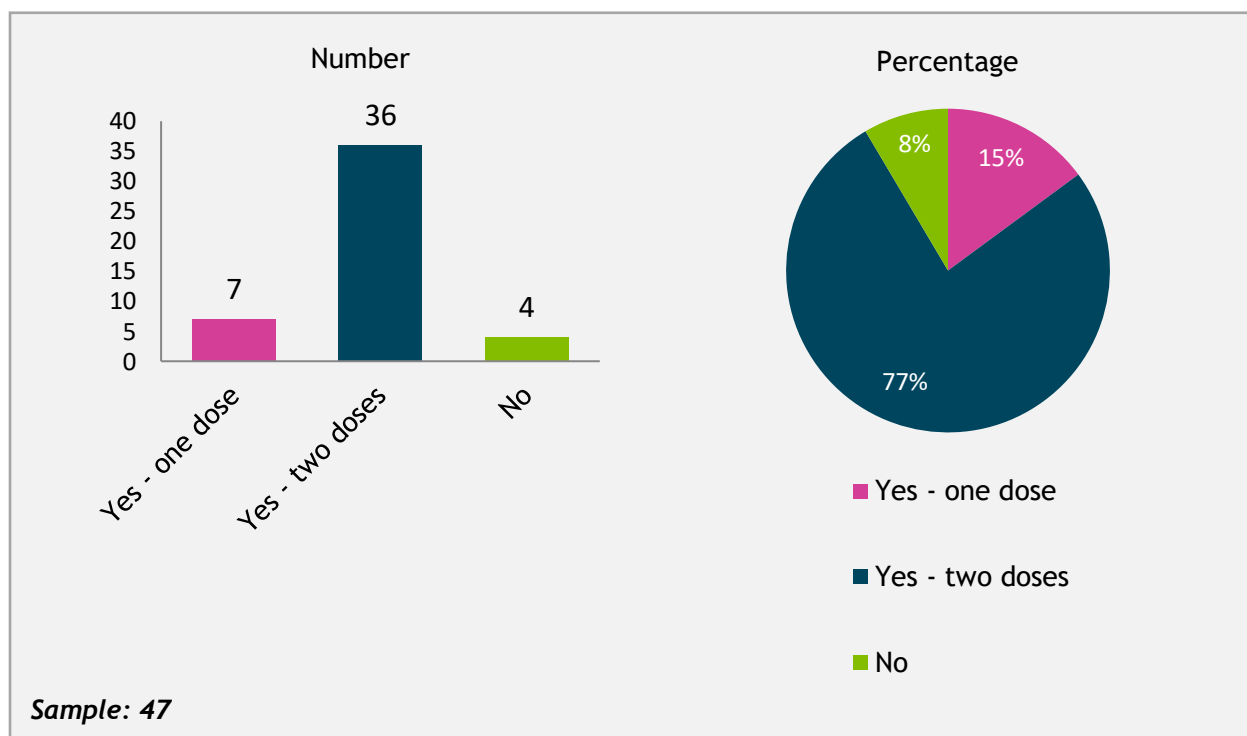
*"Due to the effects Long COVID has on my body I have to have time off work. I also feel depressed as I am unable to do things that I had no difficulties with prior to Covid."*

### 6.3 How long have you been living with Long COVID?



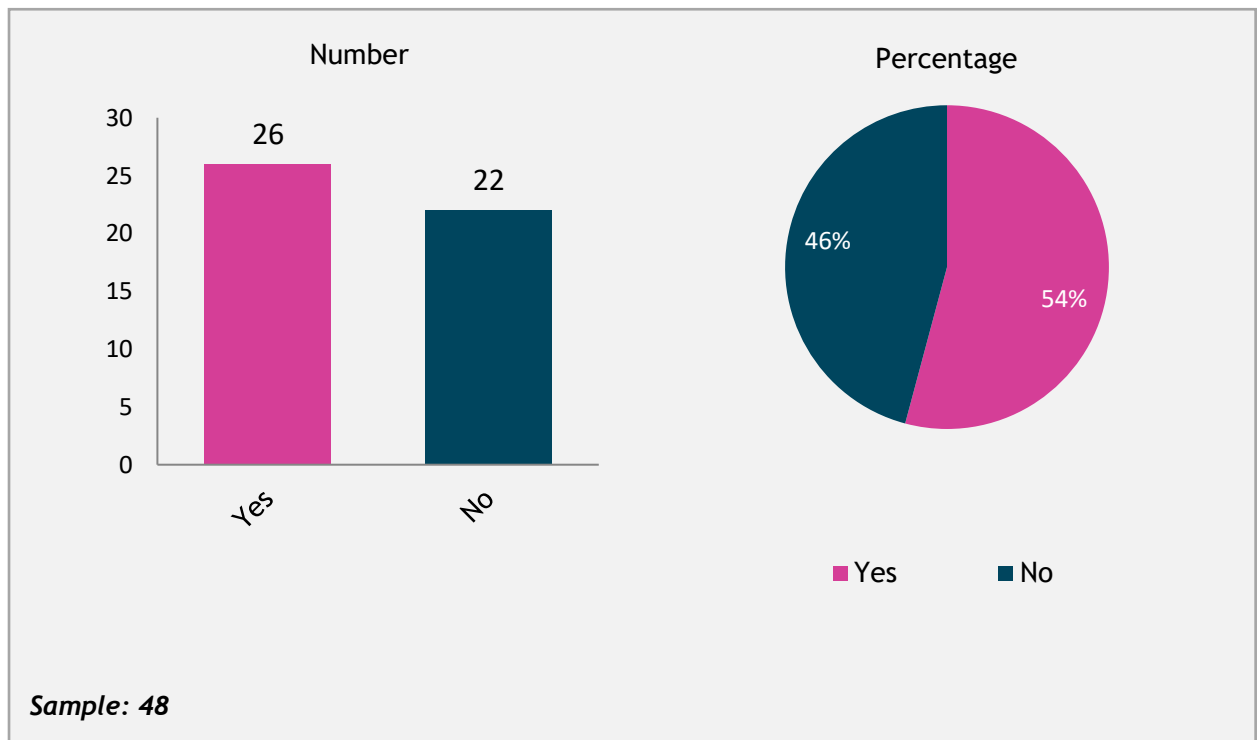
A significant number of respondents (42%) have been living with Long COVID for over a year, while many others - who are close to this milestone are also likely to do so. Few people (just 2) indicate they have recovered.

### 6.4 Have you been vaccinated against COVID-19?



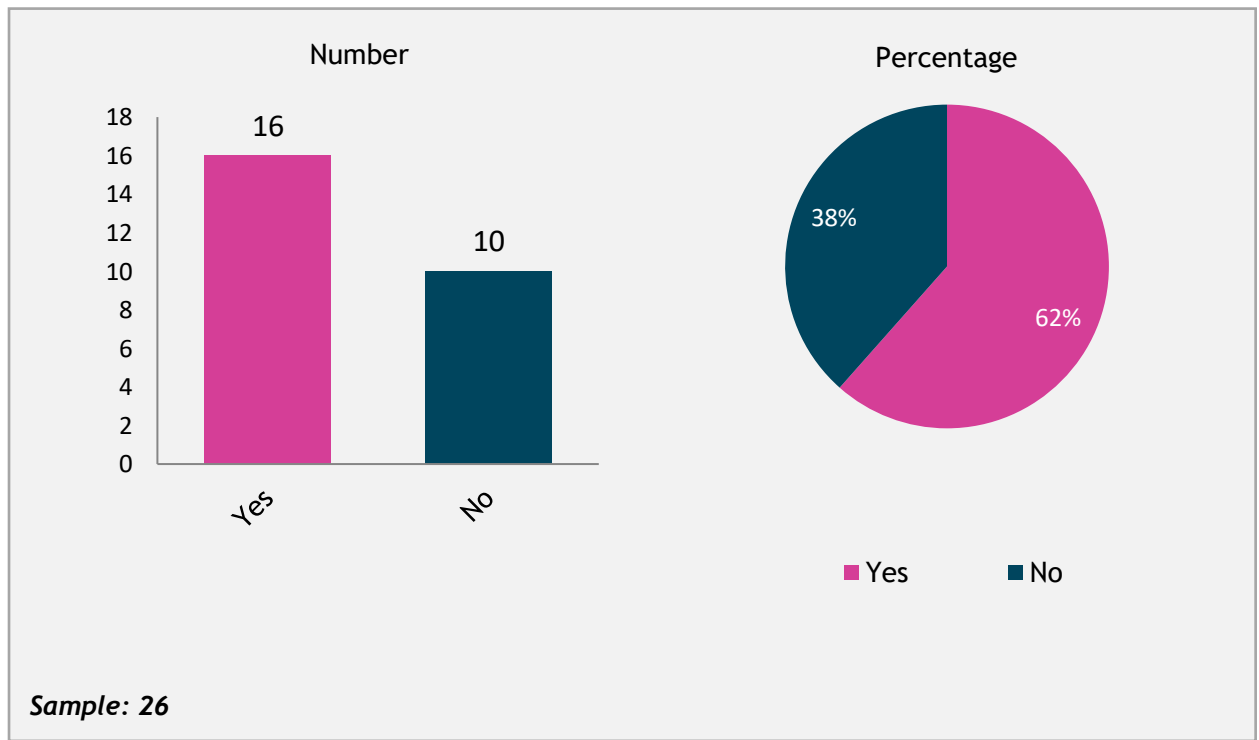
A clear majority of respondents (92%) have received at least one vaccine dose.

**6.5 Have you seen your GP or other health care provider about your Long COVID symptoms?**



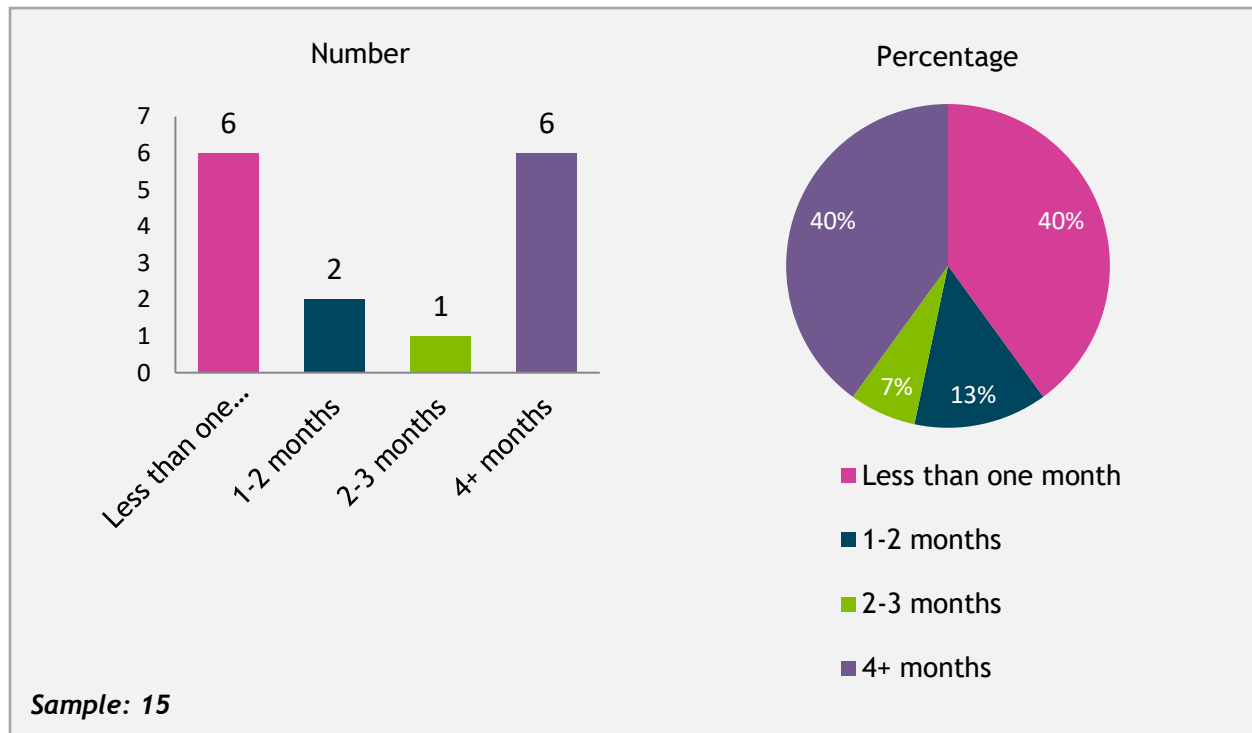
A marginal majority of respondents (54%) have consulted with health professionals.

**6.6 If yes, have you formally been diagnosed with Long COVID by a GP/Clinician?**



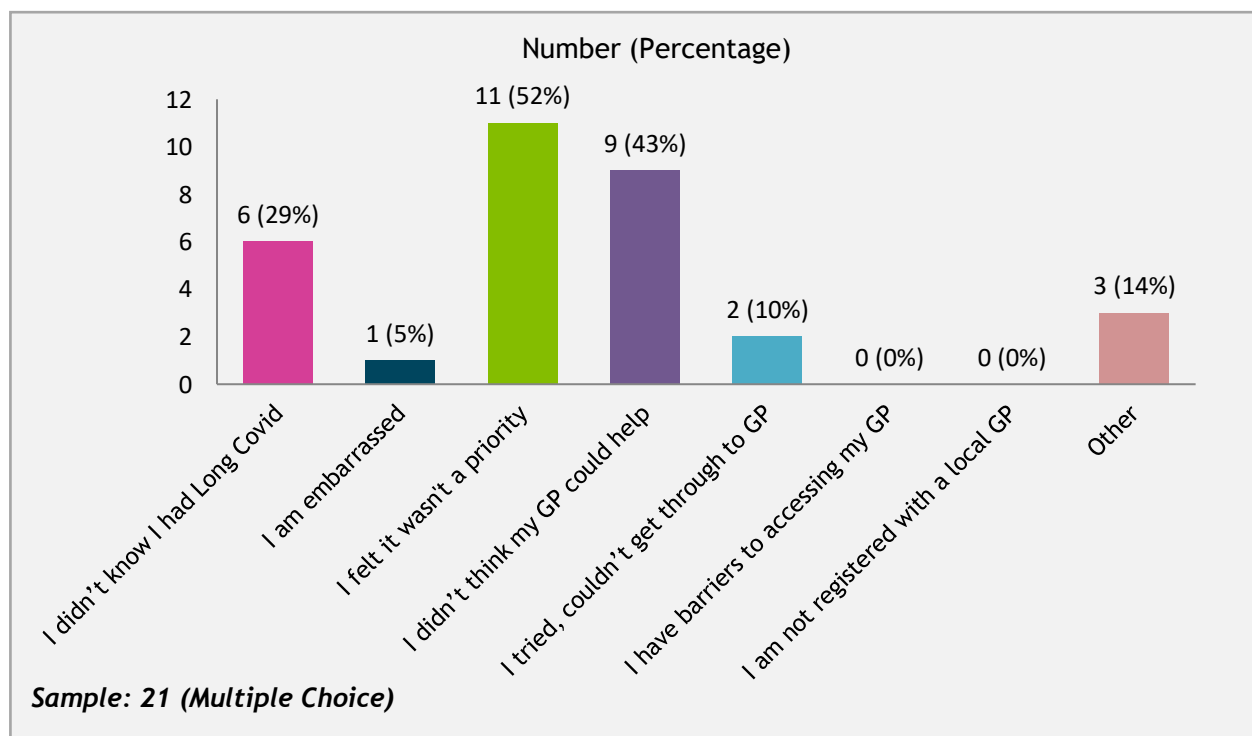
Of these, almost two thirds (62%) have been formally diagnosed with Long COVID. Nobody says their symptoms were attributed, by clinicians, to another condition.

## 6.7 If yes, how long did it take for you to receive a diagnosis of Long COVID?



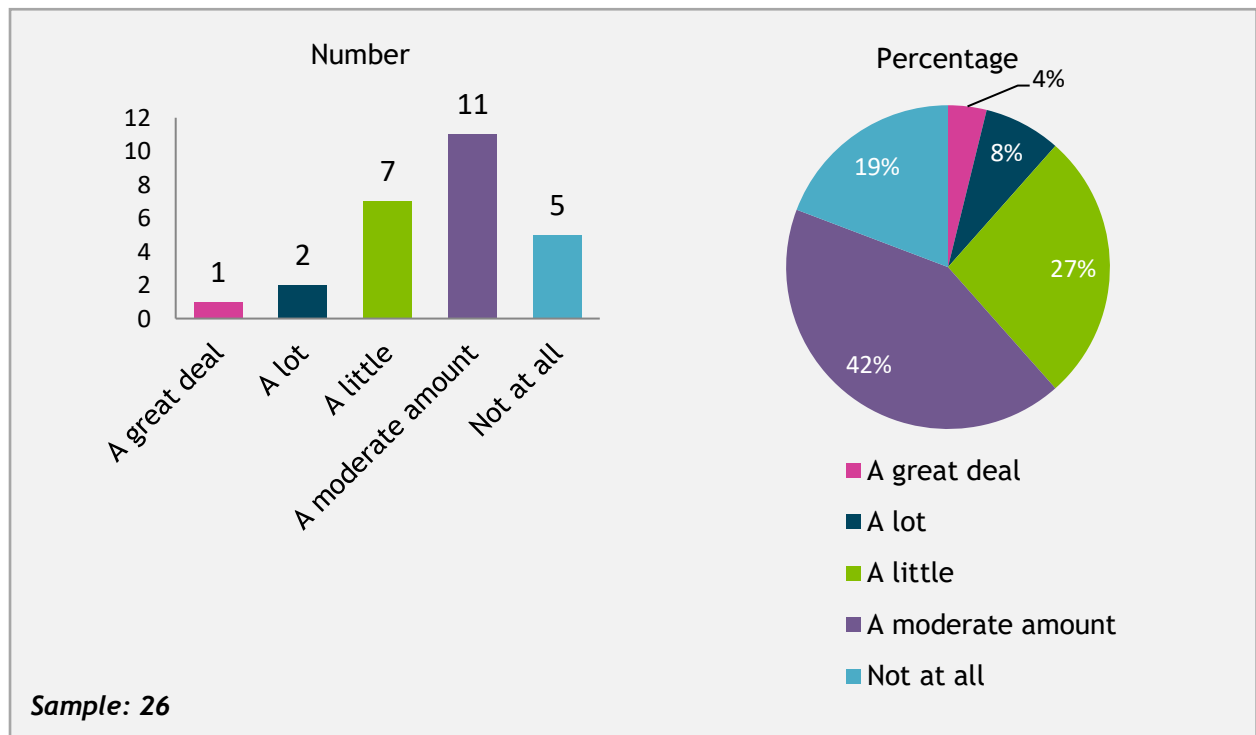
While 40% of respondents were diagnosed in less than a month, for an equal number it has taken over four months.

## 6.8 If you haven't contacted your GP about your symptoms, why not?



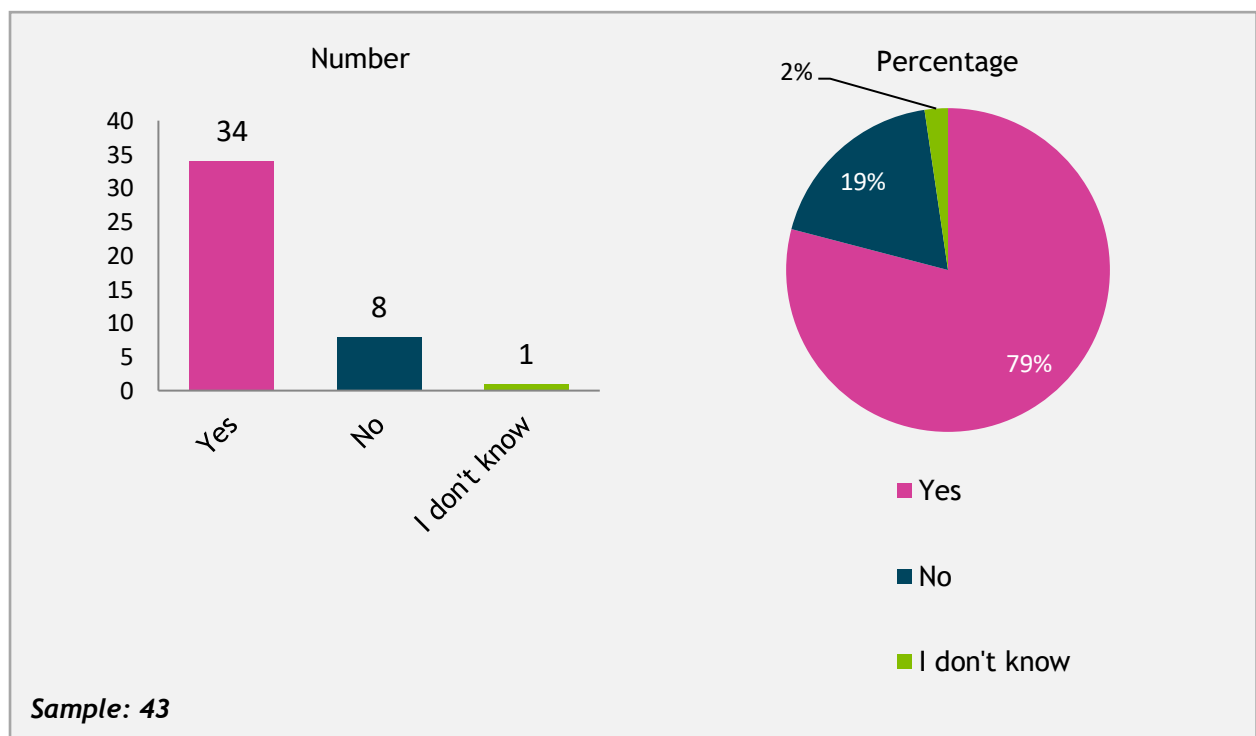
For those not seeking support from their GP, over half (52%) feel they were not a priority and a similar number (43%) are not confident that their GP could help.

### 6.9 How knowledgeable do you think your GP/clinician was on the symptoms and effects of Long COVID?



Just 12% of respondents feel that their GP or clinician have ‘a great deal’ or ‘a lot’ of knowledge on the condition.

### 6.10 Have you felt the need to conduct your own research on Long COVID?



Over three quarters of respondents (79%) have felt the need to conduct their own research.

Of these, many feel their GPs are not sufficiently knowledgeable on the condition - partly as it's a new development, while others doubt they would be 'taken seriously'. Those with ongoing symptoms express a general desire to find out more about the condition and its effects - one person cites the benefits of peer support.

#### Selected Feedback

*"Because earlier on, doctors may not have known the long-term effects of Covid."*

*"GPs don't seem to know the answers, so I have to research myself."*

*"Because it was only talked about in the media. I didn't think the GP would take it seriously."*

*"Felt I was not getting support on how I could try to deal with Long Covid."*

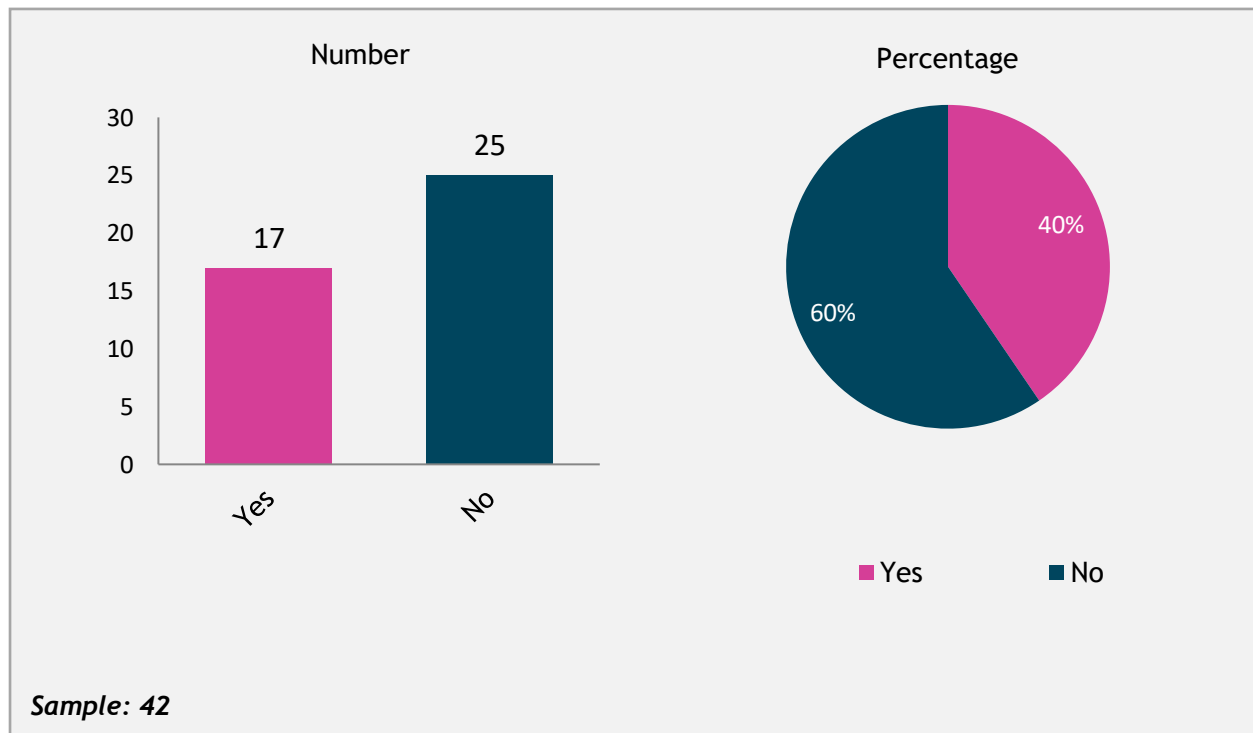
*"Because I'm still having trouble with my memory, taste and anxiety."*

*"Because I didn't understand why I was feeling so rough for so long."*

*"Because I wanted to know exactly what was happening to me."*

*"The loss of smell and taste has been horrible. I joined a group to be able to talk to other people suffering the same."*

**6.11 Have you had any difficulties in getting the appropriate healthcare support for Long COVID, such as referral to the Specialist University College London Hospitals Long COVID clinic, Community Teams, tests from primary care etc.?**



A significant number of respondents (40%) have experienced difficulty in accessing healthcare support.

Several say they are unaware of support for Long COVID, and those interacting with services describe a lack of follow-up contact, and waits of months for referrals. On GPs specifically, there is criticism on access (inability to book appointments) and while some have been referred for further treatment, others have felt 'brushed aside'.

Some people are weary of being a burden on an 'overstretched NHS' and there is also doubt that services will be effective.

### Selected Feedback

*"I hadn't realised I could get specialist help with Long COVID."*

*"I was first sent to the Whittington who after only a phone call added me to a new list, 3 months for hospital."*

*"I've had 1 phone call from a Long Covid clinic back in December 2020 where they just asked me about my symptoms."*

*"I have not been able to get through to my doctor."*

*"I had called my GP to seek advice specifically about my lack of sleep and my breathing issue and they did not seem to care."*

*"I received nothing from primary care and was told off for calling GPs too many times!"*

*"Doctor did refer me but nothing came of it."*

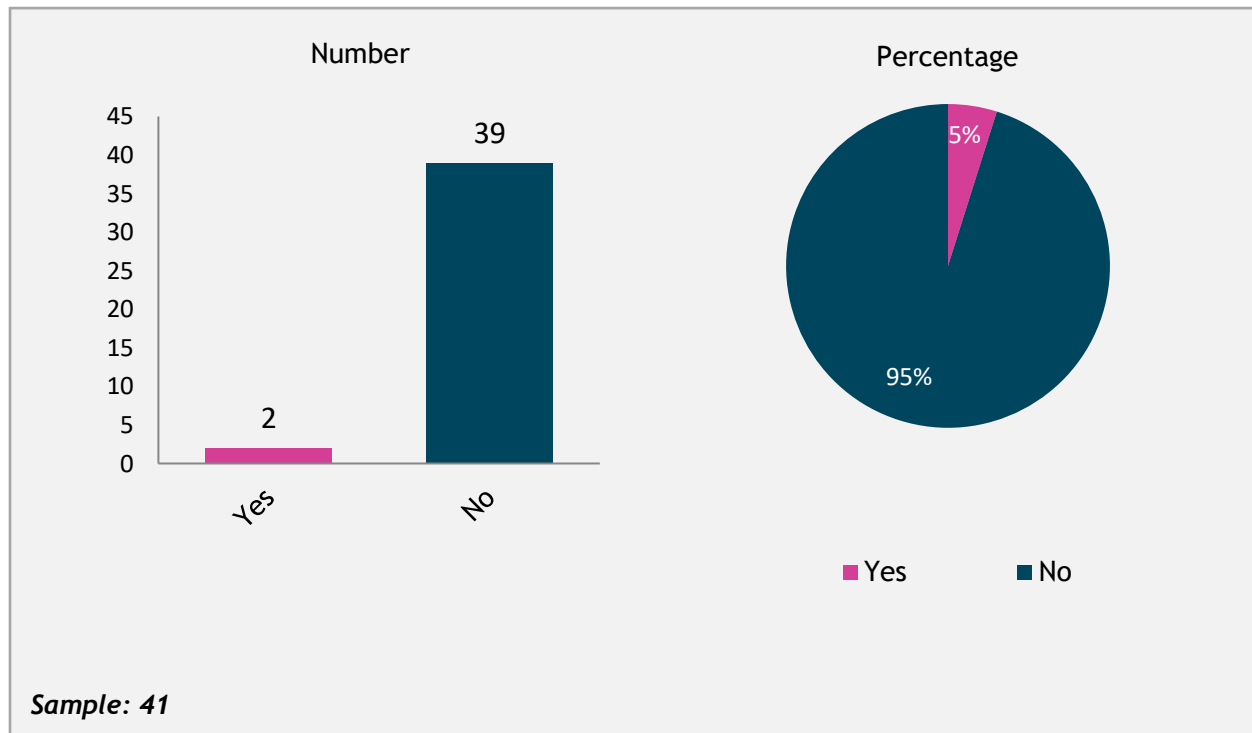
*"I haven't asked because I feel bad taking up their time."*

*"The NHS is completely over-run. It has been a struggle to get my usual appointments such as my annual diabetes check-up and, more recently, see a hepatic specialist following several days in hospital."*

*"Nothing they can do."*

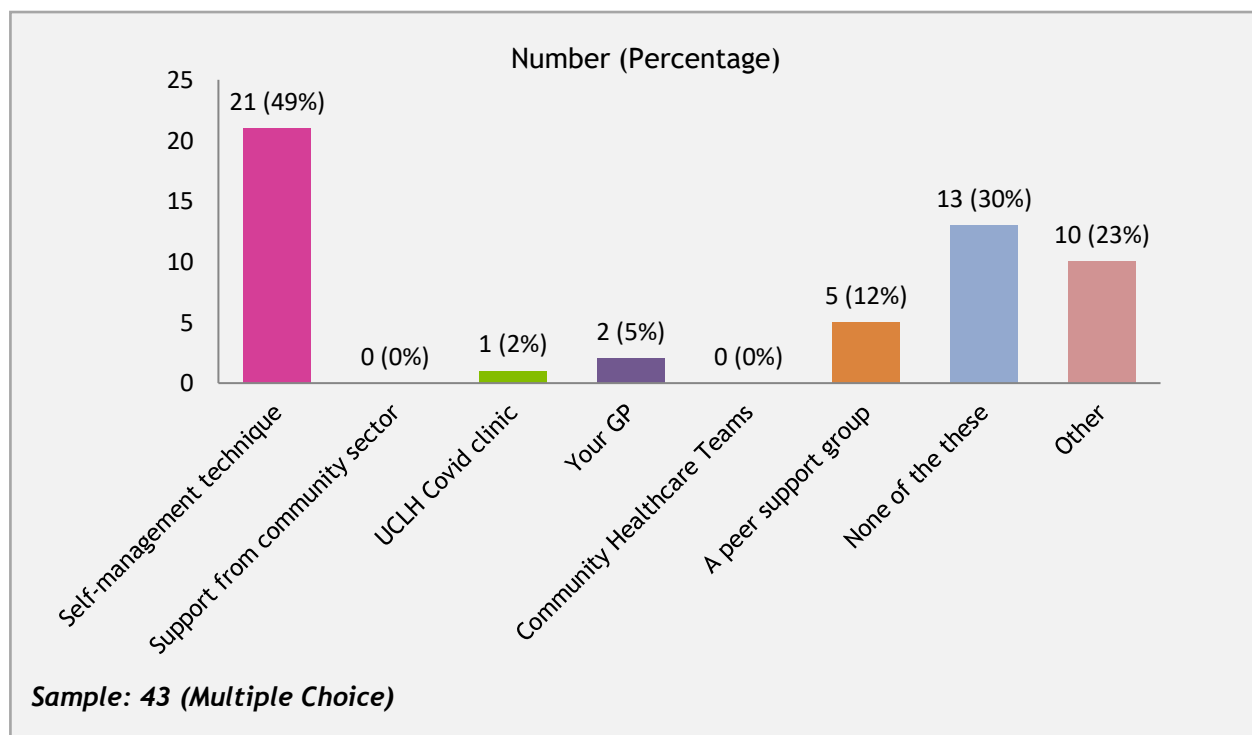


## 6.12 Have you been referred anywhere else for support for Long COVID?



Just 2 respondents (5%) have been referred to receive support.

## 6.13 What interventions do you feel have helped the most with your Long COVID recovery?



By some margin, respondents feel that self-management (such as breathing technique or physical exercise) has been most effective.

Measures adopted include exercise, physiotherapy, taking pain relief and vitamin supplements, good sleep, and routines including social contact.

Selected Feedback

*“Just exercising, eating and sleeping well.”*

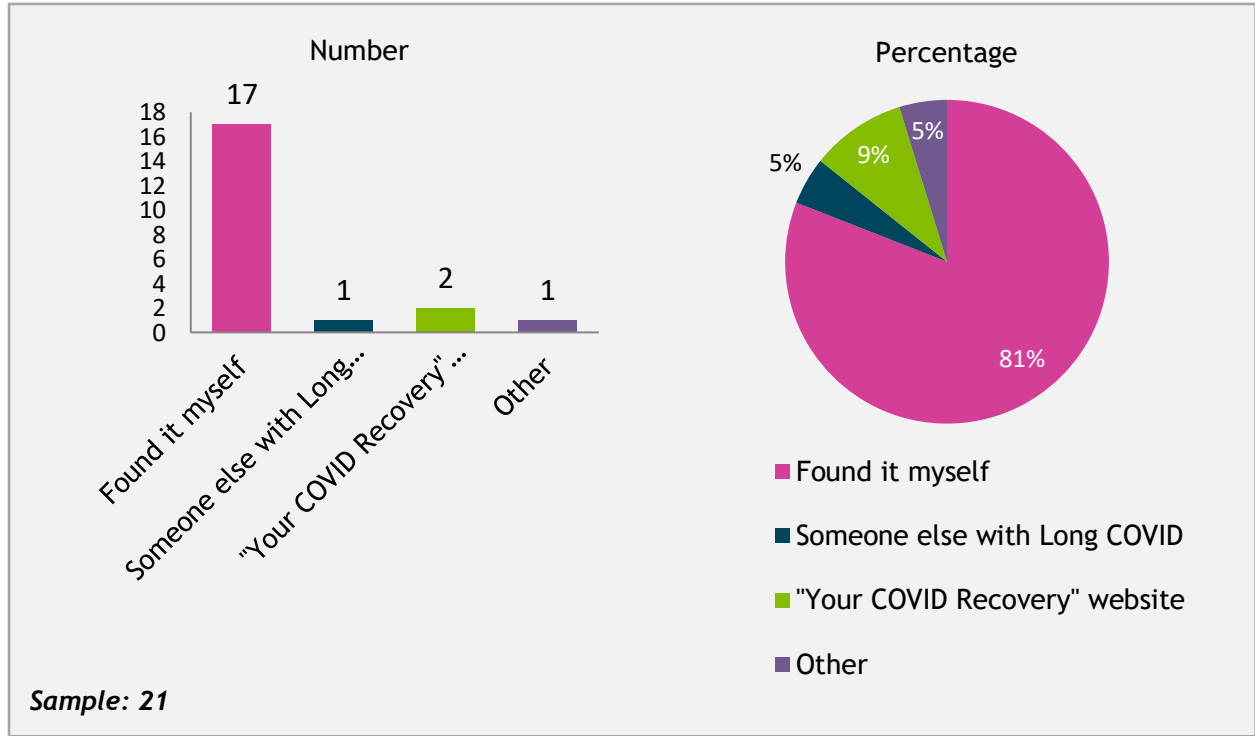
*“Physiotherapy.”*

*“Healthy routine with pain killers when required.”*

*“Taking vitamins.”*

*“Friends and church community.”*

6.14 How did you access and learn about self-management techniques?



A broad majority of respondents (81%) have conducted their own research into self-management techniques.

6.14.1 What did you find most helpful?

We asked people what they found to be most helpful following their research. Many comment on the emotional relief of ‘not being alone’, feeling understood and having opportunities to interact with - and learn from peers.

The benefits of practical support, such as videos on breathing is also mentioned.

## Selected Feedback

*"Realising that I wasn't alone."*

*"Understanding that my symptoms were known about and others were experiencing similar symptoms."*

*"It enabled me to understand how I can help myself."*

*"Helped with my anxiety."*

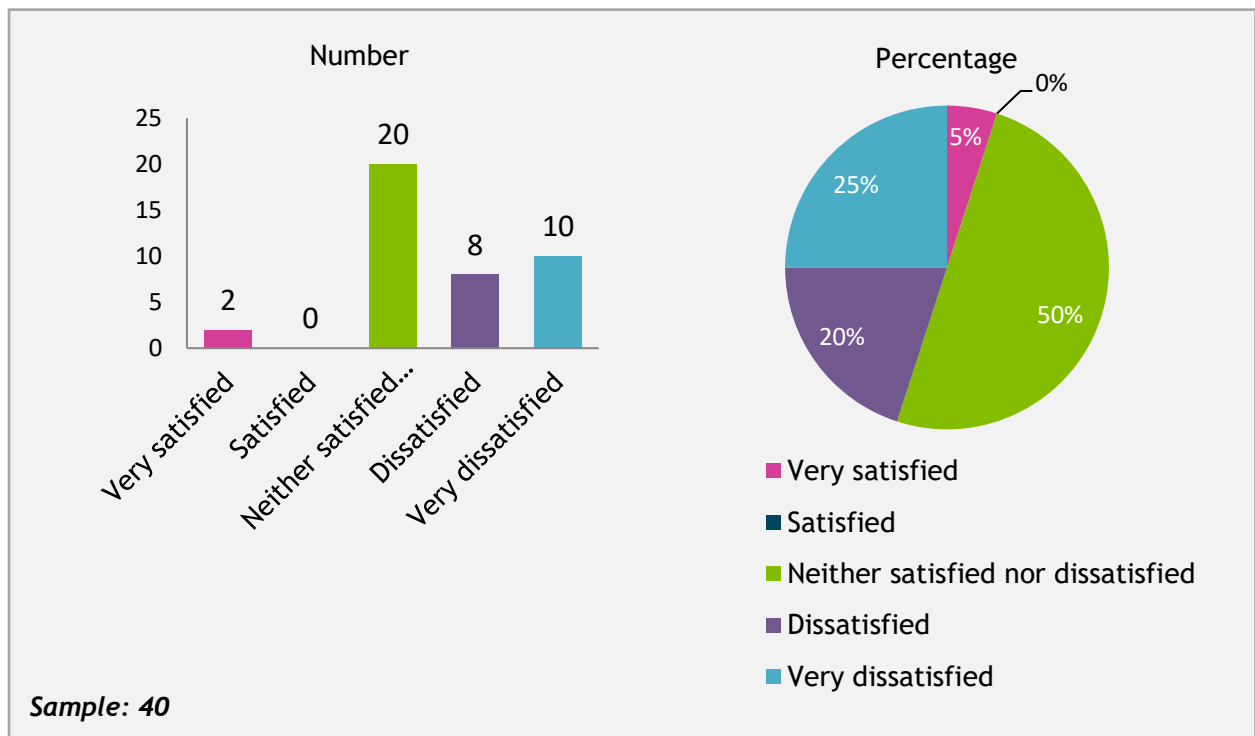
*"Being able to talk about how my symptoms were making me feel depressed."*

*"Gave me a bit of hope, reading stories in the press and trying ideas others found useful."*

*"Emotional and practical support."*

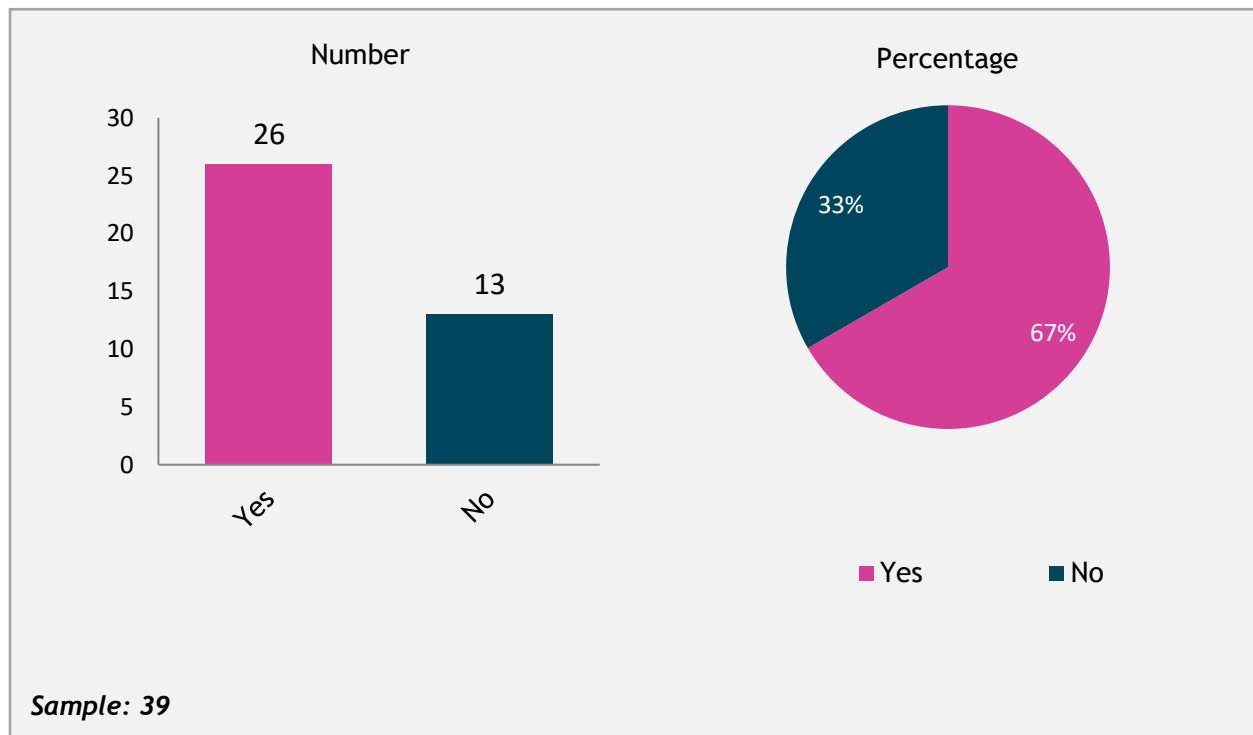
*"I watched videos on how to improve my breathing and lung exercises."*

### 6.15 Overall, how satisfied were you with the Long COVID support offered to you?



Just 2 respondents (5%) feel satisfied with the Long COVID support offered.

## 6.16 Do you have suggestions that could improve your experience and/or recovery?



Two thirds of respondents (67%) have suggestions on how to improve the experience and/or recovery.

We list them (in full below) and detect themes on GPs and Health Services, Information, Peer Support and Involvement, and Self-Help.

### Respondents' Suggestions

#### GP Services

*"Being able to get a GP appointment would be helpful."*

*"GP should be more aware."*

*"Easier to be referred to Long Covid team."*

*"GP to have more information on symptoms, recovery and make suggestions."*

*"A referral or specialist knowledge to support me. I had one group GP appointment and blood tests but no support for Long Covid thereafter."*

*"GP training and more clinics locally."*

*"I registered with a new GP during my illness and used the track and trace but there's been no follow-up from anyone and I haven't seen any general information about it."*

*"For GPs to take it more seriously. I was just given a mental health initial screening for depression and anxiety (this was not made explicit just done over the phone and sent for blood tests)."*

*"I'd have liked to be seen by a doctor after the first two weeks but I never was."*

*"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."*

### **General Health Services**

*"Contact from my local healthcare providers informing myself and others that the condition is real and that help is available. But to do so the NHS would need much greater resources, especially staffing."*

*"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."*

*"Someone with medical experience and the time to listen and advise on the best option going forward."*

*"Those with a diagnosis should have been offered a health check to monitor any changes and be given advice on how to improve general wellbeing."*

### **Information**

*"Would have been good to know help is available."*

*"I didn't know that any of these things were available."*

### **Peer Support and Involvement**

*"Try and keep in touch with people suffering. It feels very lonely trying to deal with it on your own."*

*"We should be made aware that we are not alone and we are not pretending the symptoms."*

*"There is a thing we used to call "Listening". used to be quite effective."*

*"More understanding/practical help with education."*

*"Treat young people with Long Covid as seriously as anybody else."*

*"Having a friend to talk to or go out for a gentle walk however it is difficult to do this on your own. People are not available all of the time due to commitments so local groups aimed at specific age groups would be helpful."*

### **Self-Help**

*“self-monitoring of oxygen levels, would need equipment as this would allow the confidence to get on with my life, knowing what my limits are.”*

*“I contacted the local leisure centre hoping they would offer classes tailored to suit recovery of LC (Long Covid) such as swimming, yoga, meditation.”*

#### Other

*“Make it aware to employers as a reason why performance may not be 100% as I struggle with short term memory as a result.”*

## 7. Recommendations

Based on the analysis of all feedback, Healthwatch Enfield would like to make the following recommendations:

We make 2 recommendations on GP services.

### 7.1 GP Services

It is generally felt that clinicians have limited knowledge and awareness of Long COVID. We hear that during consultations, some patients have felt ‘brushed off’, with symptoms undiagnosed and little, or no information received.

Related to this, a significant number of people have not sought help from their GP or other services, as they feel they would not be taken seriously.

*7.1.1 Given that Long COVID is relatively widespread, and there is now a body of learning and research, we hope that in future clinicians will be better placed to diagnose, and to refer to specialist testing and support. We hope that patients will have the reassurance that they need - while not commenting on clinical decisions, we suggest that at the very least, information and signposting is given on the condition and what support may be available locally.*

It is commented that once referred for treatment or support, waiting times can be considerable.

*7.1.2 Long COVID has affected people’s lives in many ways & often dramatically, with consequences for working and social life. The impact on mental health is also cited often. We hope that referral pathways are as effective as possible in order to minimise waiting, and that meaningful supplementary support may be offered in the interim, again that may include information and signposting.*

We make 4 recommendations on general health services.

## 7.2 General Health Services

A lack of local support options is reported.

*7.2.1 The condition has a severe impact on physical health and mobility - we hear that some people are housebound, while others are using public transport to travel very short distances. With this in mind, we urge that support is as local as possible, to avoid discomfort and to maximise uptake.*

*7.2.2 In addition, the supply of home testing equipment (such as to monitor oxygen levels) would be a practical solution for many who are less mobile.*

We also hear that patients have been contacted by services, and have heard nothing since the initial call.

*7.2.3 Not only is this confusing for patients, some have waited for treatment or support that is not forthcoming. We urge that if contacting patients, services have a robust follow-up mechanism and act timely on next steps. The provision of clear information is crucial and those making contact to check on status need an easy route to get help (such as a dedicated number or email contact).*

Many people are not aware of the support or services on offer.

*7.2.4 There needs to be much greater awareness of what is available locally and more generally, therefore services with a Long COVID offer should ensure that information and literature is shared widely within the health service, and targeted within the community.*

We make 2 recommendations on wider community support.

## 7.3 Wider Community

It is clear that peer support - this could be attending groups, or participating in online forums, has been most effective in helping people to learn about and manage their conditions.

*7.3.1 As this is the case, we recommend that such groups and online platforms are advertised widely, and signposted to as appropriate. This may also serve to reduce service footfall in the near and longer term.*

Some people tell us that discounts for exercise classes may incentivise them to attend.

*7.3.2 Given that many discounts are already available, we urge that information is disseminated widely, to maximise awareness and uptake.*

## 8. Glossary of Terms

LC	Long COVID
NCL	North Central London

## 9. 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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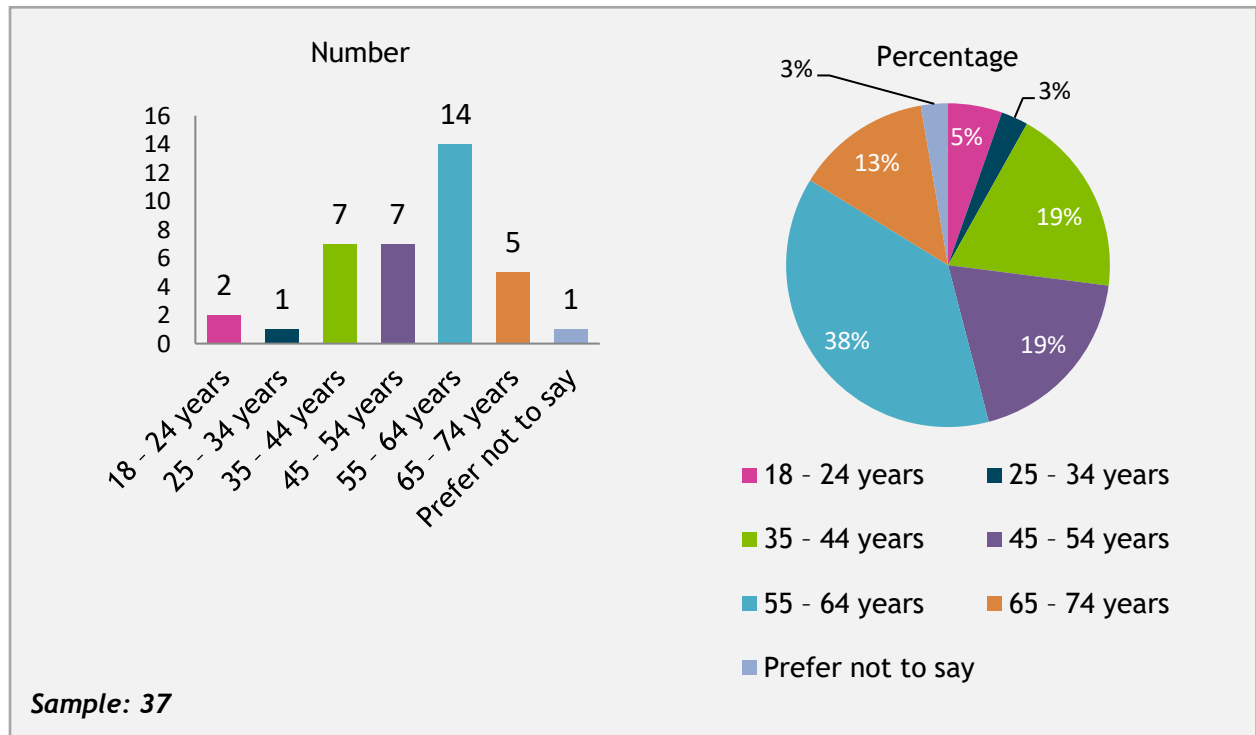
[www.healthwatchenfield.co.uk](http://www.healthwatchenfield.co.uk)



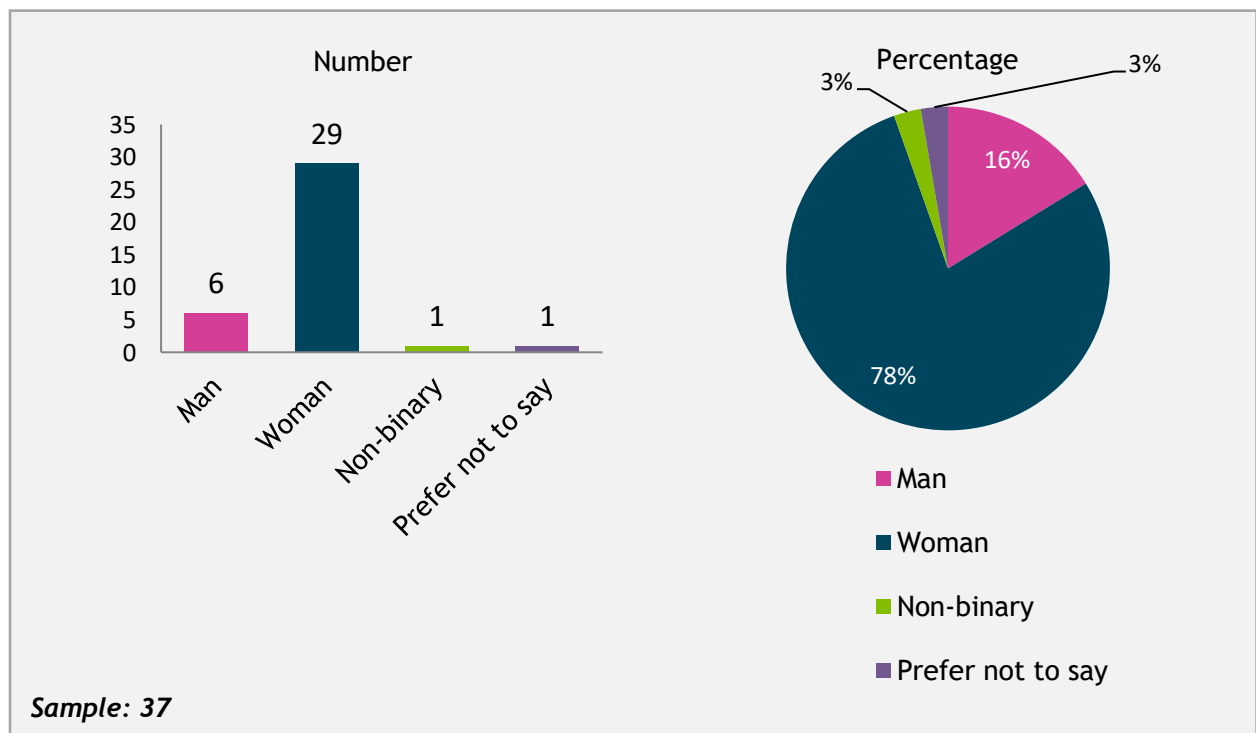
## Appendix - Demographics

The demographics of participants are stated as follows:

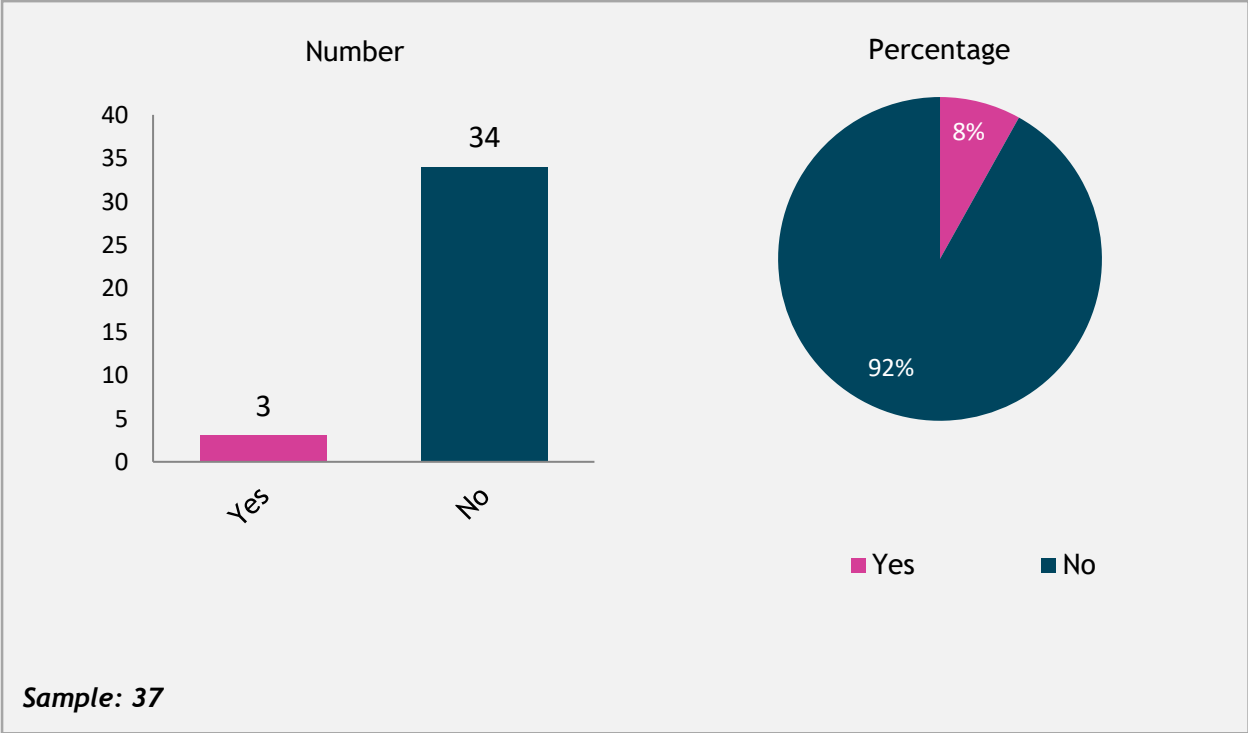
Please tell us which age category you fall into:



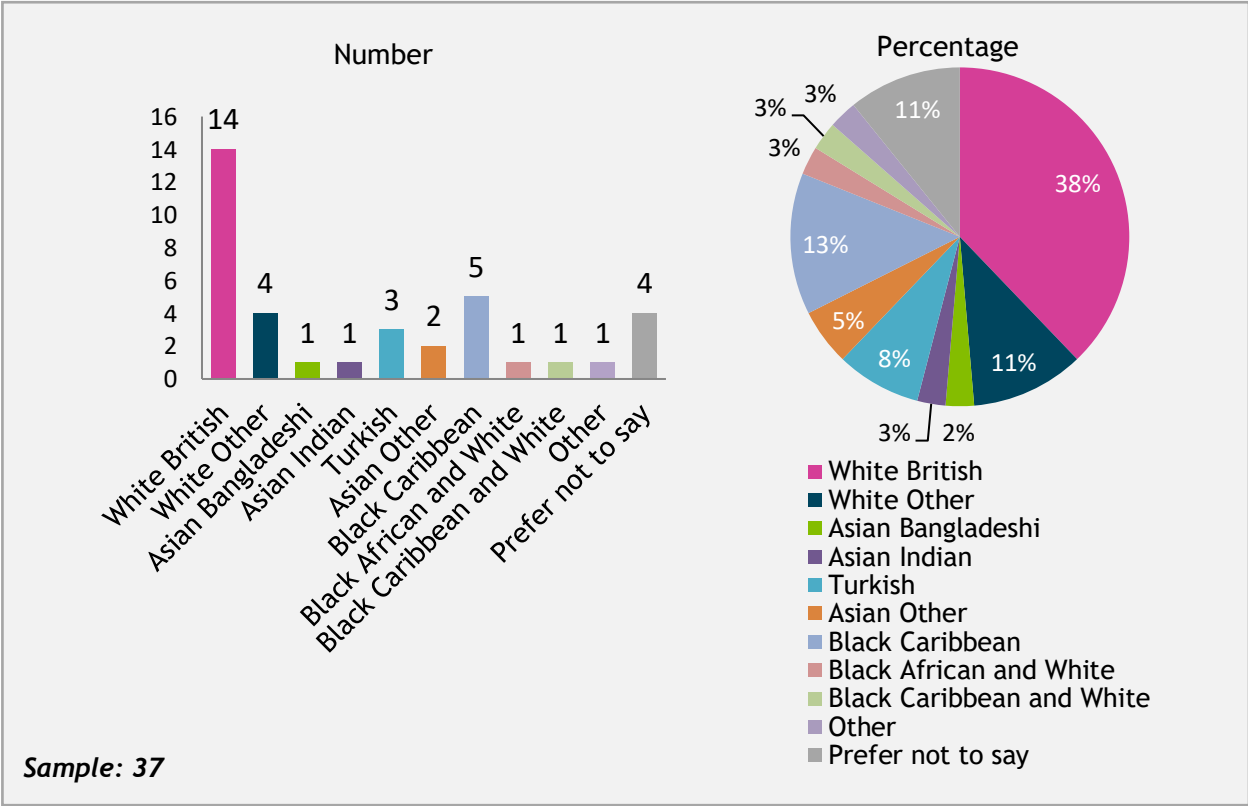
Please tell us which gender you identify with:



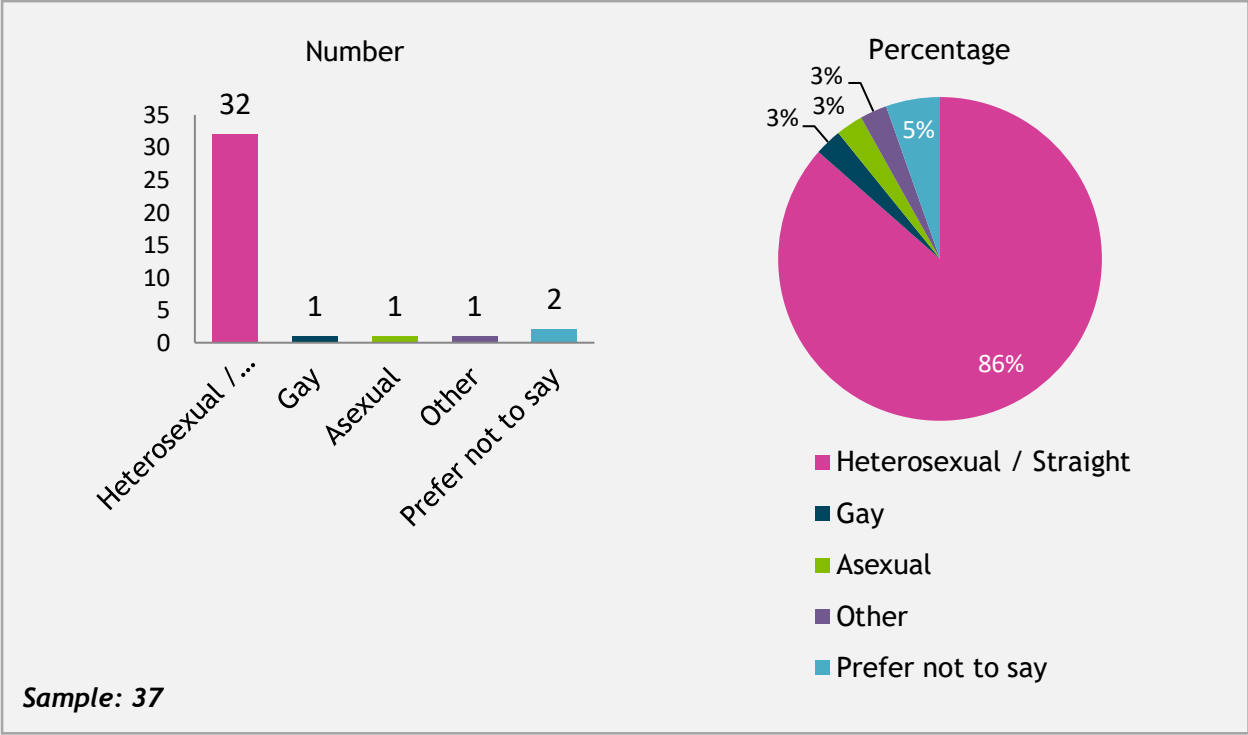
Is your gender different from the one assigned at birth?



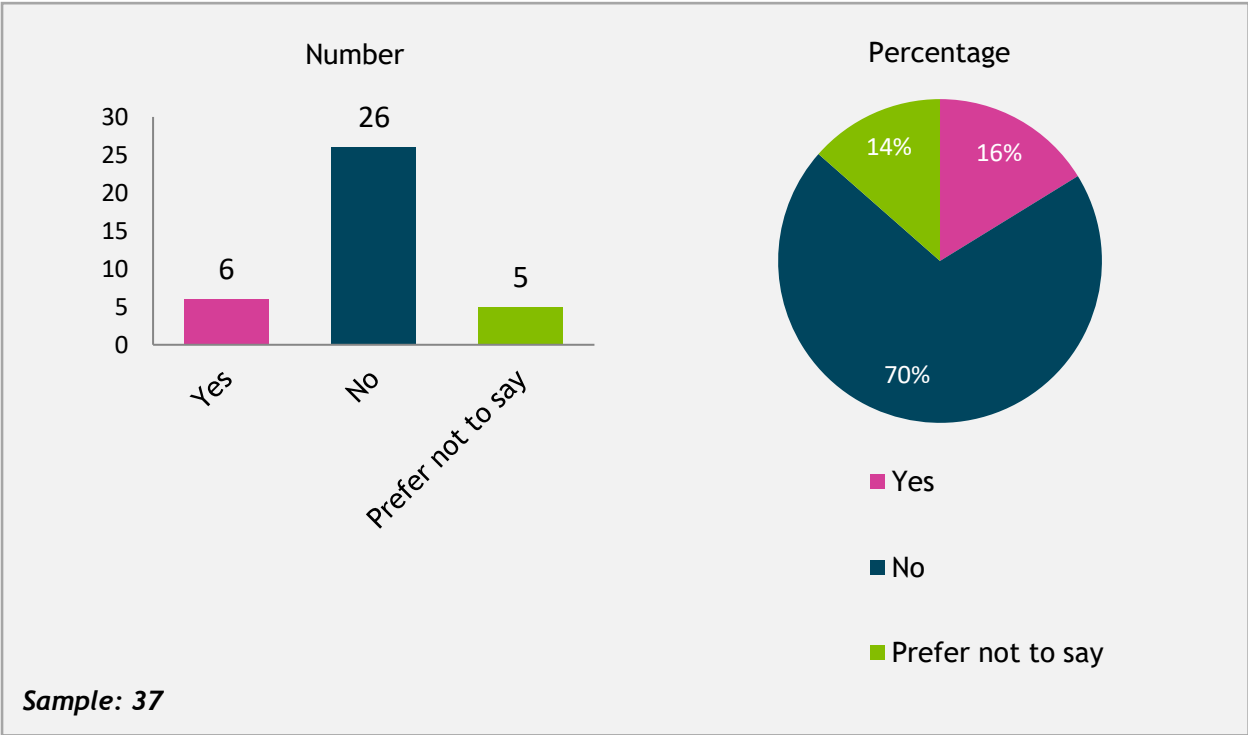
Please select your ethnic background:



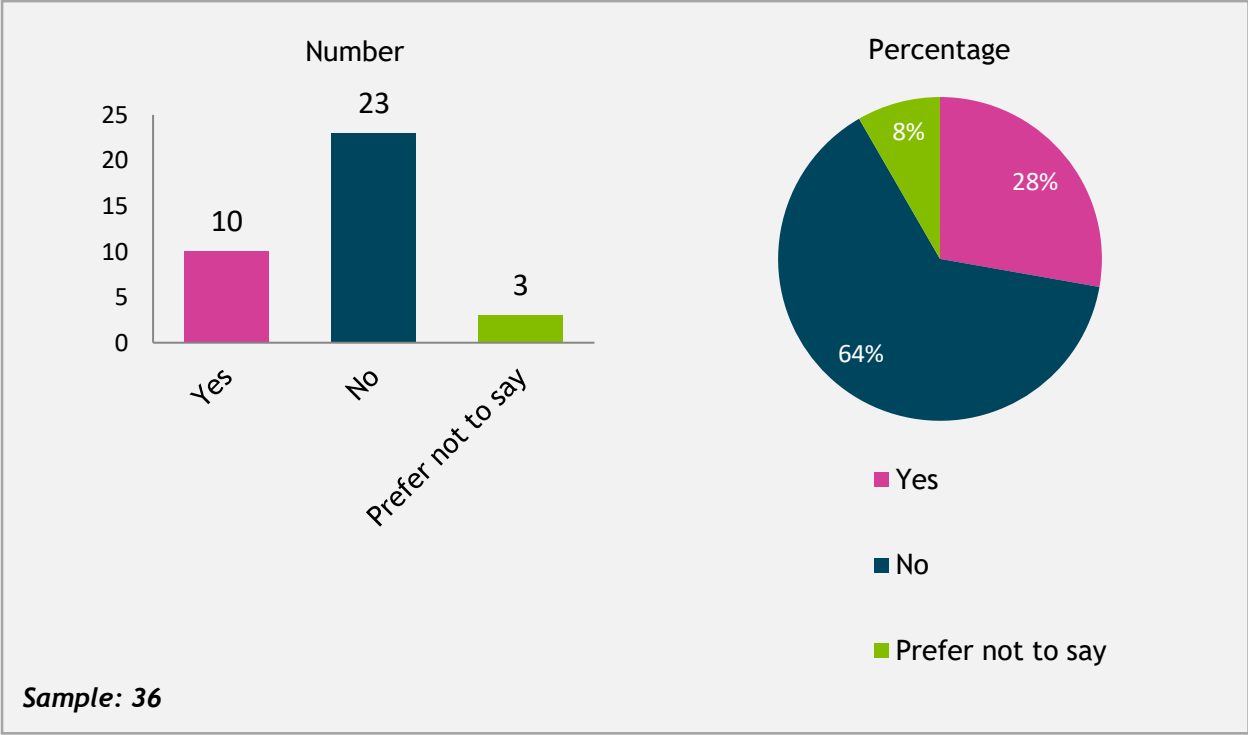
Please tell us which sexual orientation you identify with:



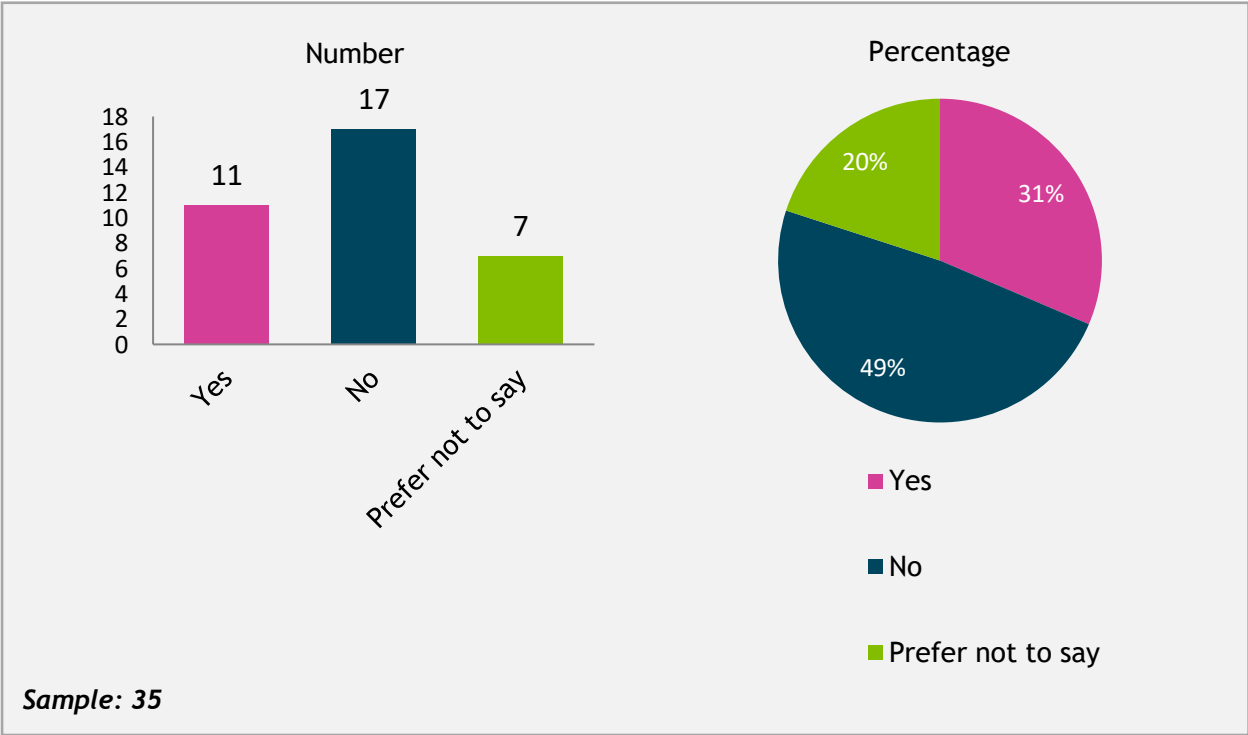
Do you consider yourself to have a disability?



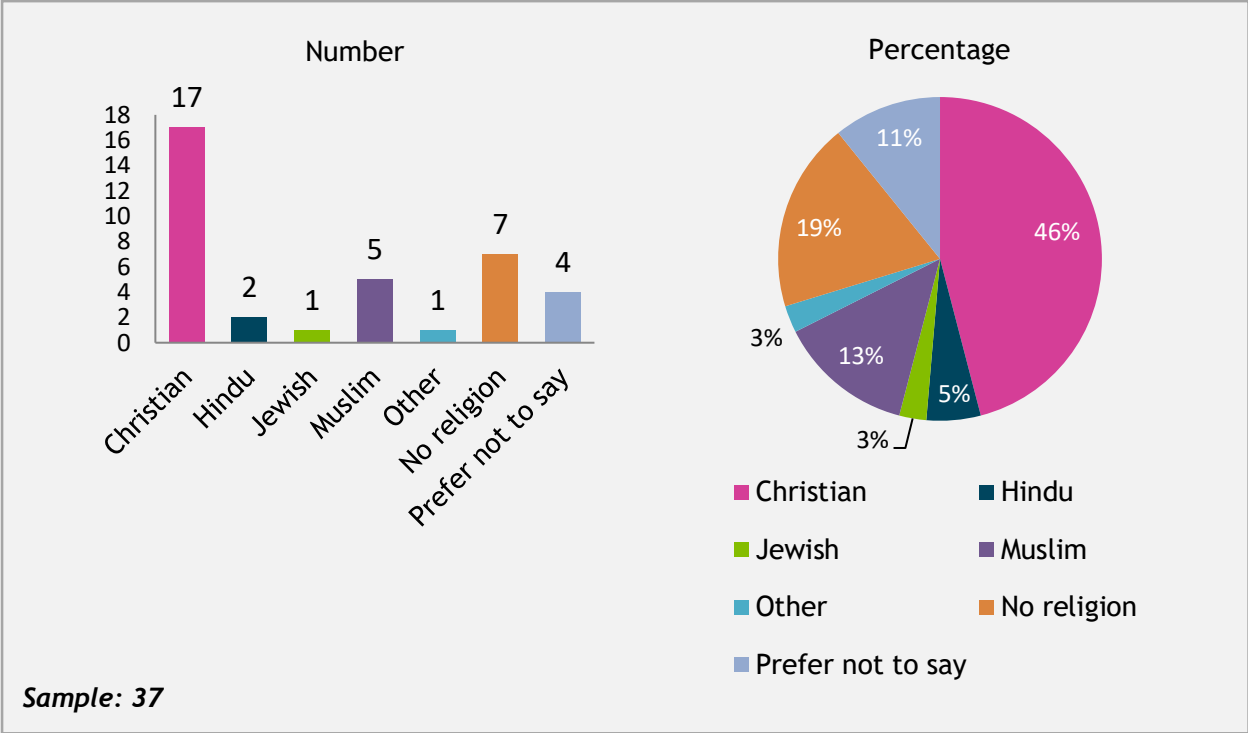
Are you a carer?



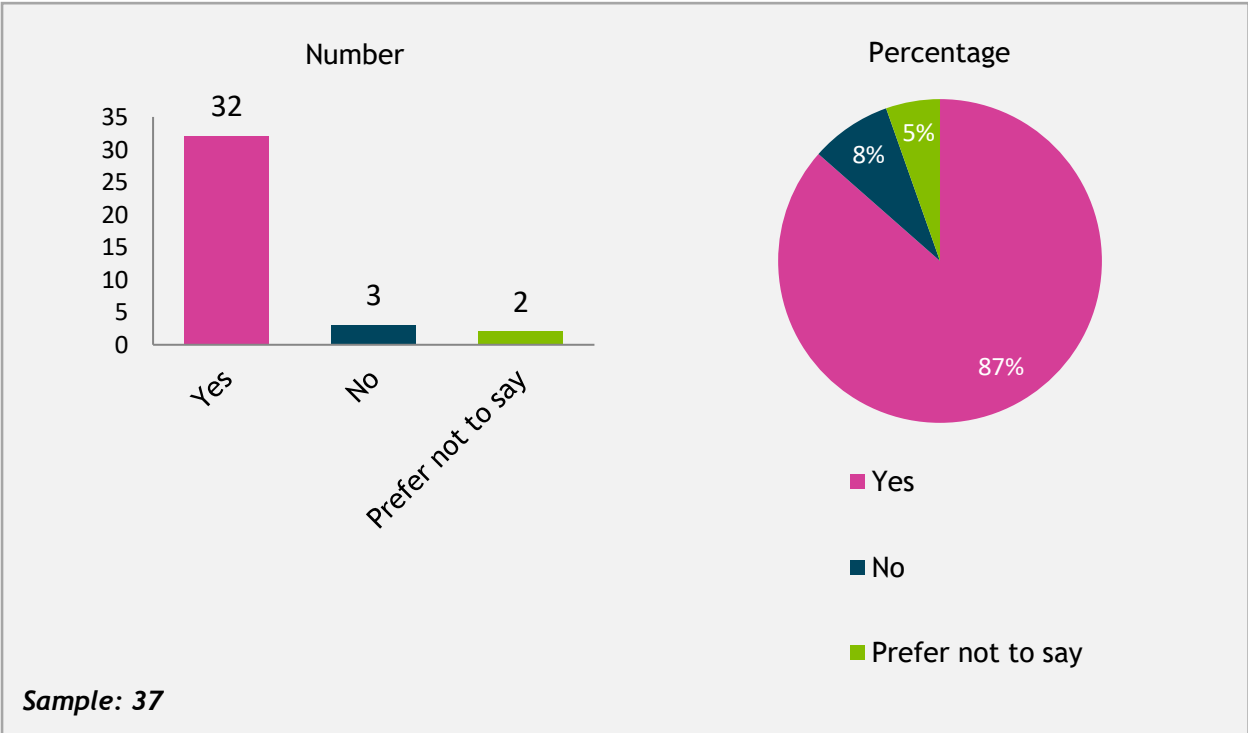
Do you have a long term health condition?



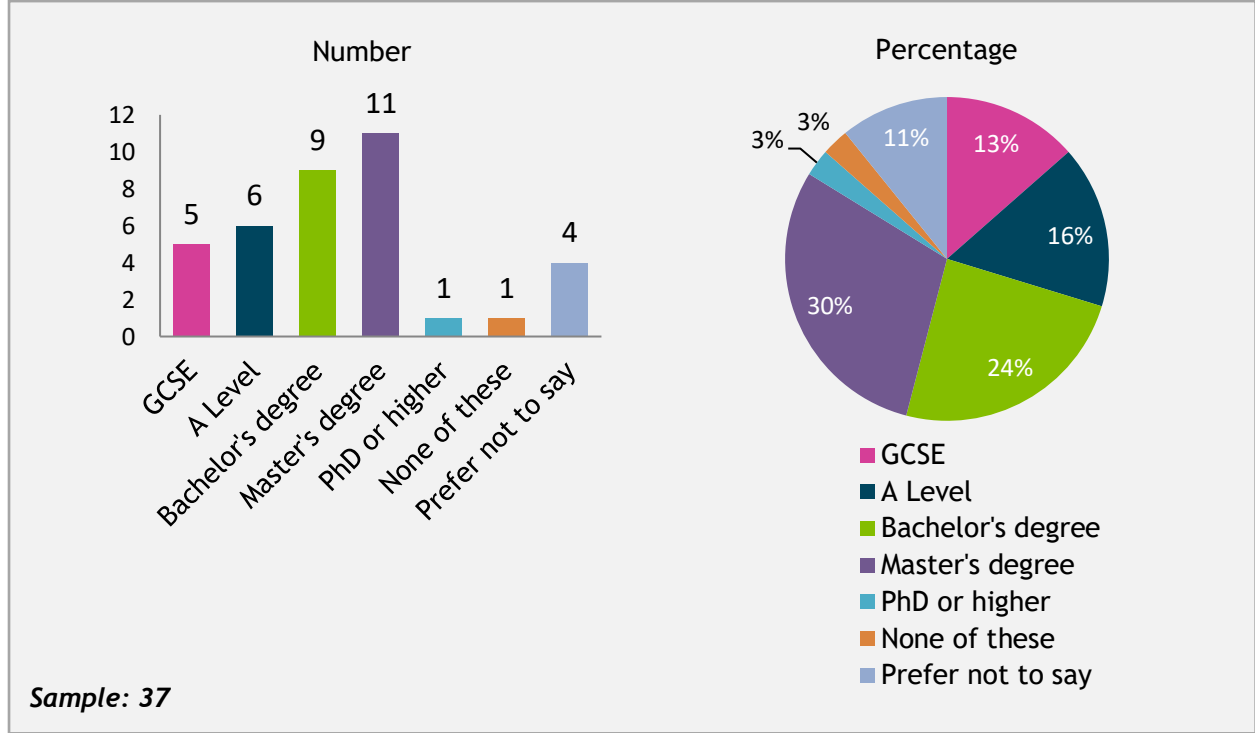
Please tell us about your religion or beliefs:



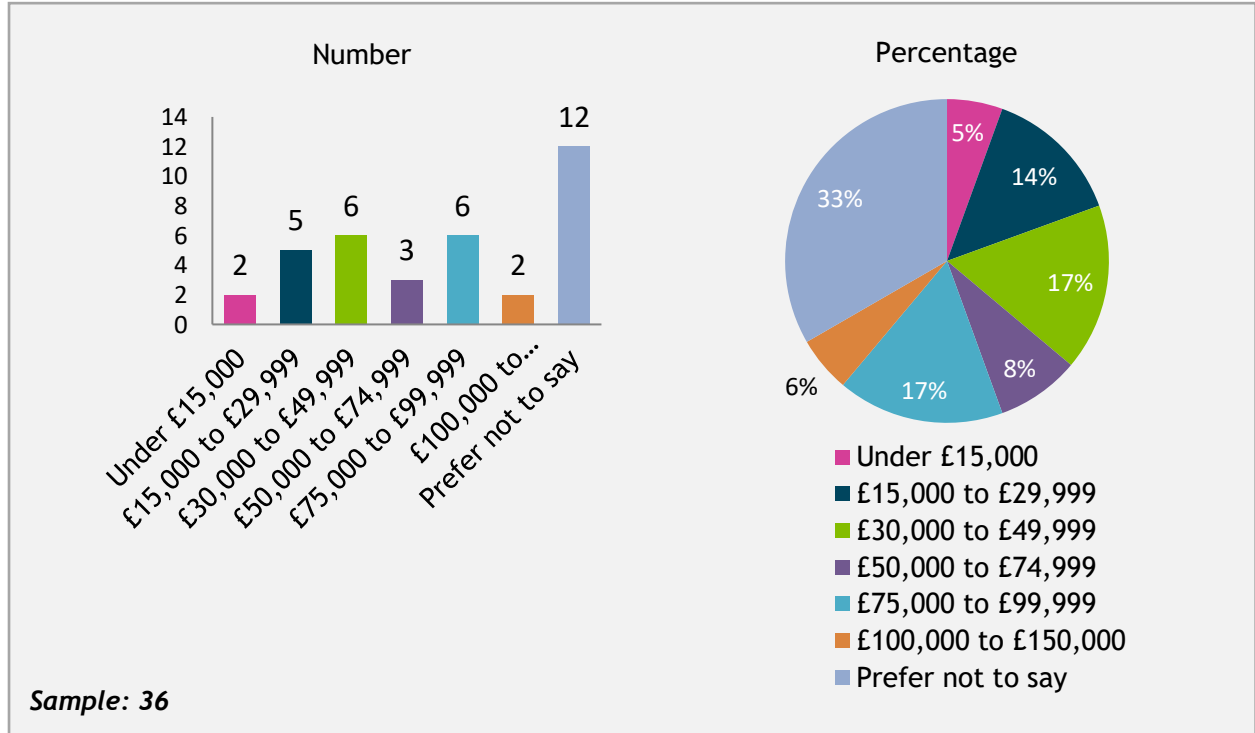
Is English your first language?



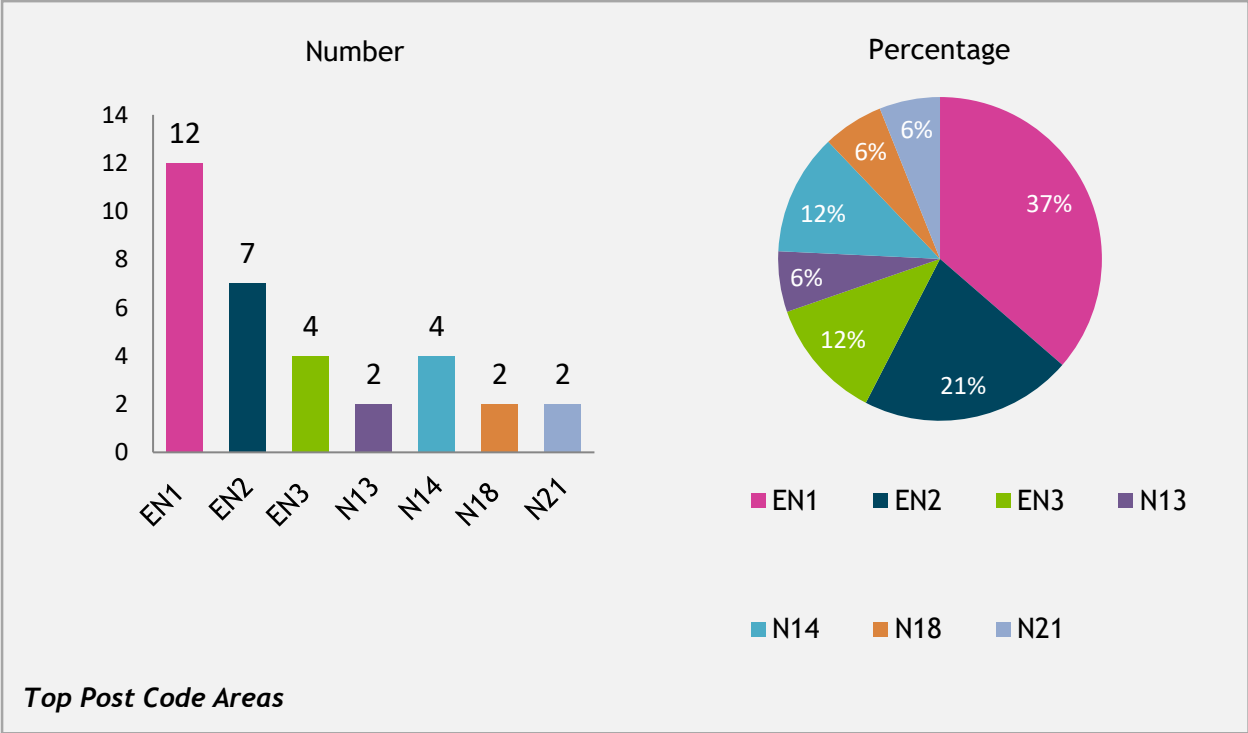
What is the highest level of qualification you have completed?



Please indicate your annual household income:



What are the first three digits of your post code?



“Not being able to physically do the things I used to has also impacted my mental wellbeing.”

Local Resident