



# **Insight Report** **Living through COVID-19** **with a respiratory condition**

---

November 2020





**Learning from 72  
experiences**

# Contents

Introduction	5
Methodology	7
Accessing help and support	9
Accessing GP services	13
Accessing medicine	16
Exploring inter-group disparities: avenues for further research and engagement	18
Conclusion from Healthwatch Central West London	19
Conclusion from Breathe Easy Westminster	20
Appendix 1: Demographics	21
Appendix 2: Survey Questions	26
Contact us	31





# Introduction

In January 2020, Healthwatch Central West London (HWCWL) launched our Small Grant, a first of its kind project for our organisation. We wanted to reach people in Westminster and Kensington & Chelsea who are under-represented in conversations about health and social care, and we awarded the recipients £500 to complete engagement with groups from these communities.

The five organisations who received the grant were selected in April, just as the national health conversation was turning towards the Coronavirus outbreak. We decided to offer an additional fund to the selected groups, so that they could conduct engagement work, with HWCWL, which focused on the COVID-19 outbreak and response.

In this report, HWCWL shares the main results from a membership survey carried out by the fifth group. The survey was conducted between July and September 2020 with members of Breathe Easy Westminster invited to respond.

Our first publication in this series, ‘Domino Effect: Discussing the knock-on effects of COVID-19 for parents with SEND in Westminster’ is available to view at [www.healthwatchcwl.co.uk](http://www.healthwatchcwl.co.uk)

## Healthwatch Central West London

Healthwatch Central West London (HWCWL) is an independent organisation for people who use health and social care services. We deliver the statutory Healthwatch projects in Kensington & Chelsea and Westminster. Through our research and local engagement, we make sure that local people’s views are always at the centre of decision making about health and social care.

## We make this happen by

- Listening to what people like about services and what could be improved
- Monitoring how changes in the health care system affect local people
- Helping to improve the quality of services by letting those commissioning, running, and making decisions about services know what people want from care

## Breathe Easy Westminster

Breathe Easy Westminster (BEW) is a British Lung Foundation support Group, whose primary aim is to provide support and information for people living with a lung condition and those who look after them. BEW promotes local community support groups, education for self-management, and empowerment. BEW has a strong local network which is ideal for this engagement work.



# Methodology

## What did we do?

To hear more about local people's experiences of living through the COVID-19 pandemic, we designed a survey for local people. Breathe Easy Westminster developed a survey that uses the same demographic questions that the Healthwatch, 'Your Experience Matters' survey uses.

This means that the quantitative data collected by Breathe Easy adds important information to what local people told us through our open answer survey questions, giving a breadth of understanding of what it has been like to live with a respiratory condition through the COVID pandemic.

BEW promoted and distributed the survey between July and September 2020. BEW also phoned members to verbally ask them the survey questions in June 2020. In total, we received 75 responses.

## The survey focused on:

- What type of support and care patients received during the COVID-19 pandemic;
- How easy it was for patients to get the help they need through their GP practice or hospital;
- How easy it was for patients to access their prescriptions and any necessary non-emergency treatment;
- What information was available to patients on available support and services; and
- How patients coped with the extraordinary measures imposed to deal with the COVID-19 pandemic

## Who did we speak to?

This report includes the views of 75 people either living with a respiratory condition or caring for someone who has a long-term respiratory condition in Westminster.

The ages of the people who engaged with us ranged from one person in the 13-17 age group to those above 80 years. Over four fifths of the people we spoke to were aged 65 years or older (81%); with just under half (43%) aged 75 years or older.

Over two thirds of the respondents to the survey stated that they were retired (67%). Half of the respondents (53%) said that they have a long-term health condition, while just under two fifths (19%) stated that they have a disability.

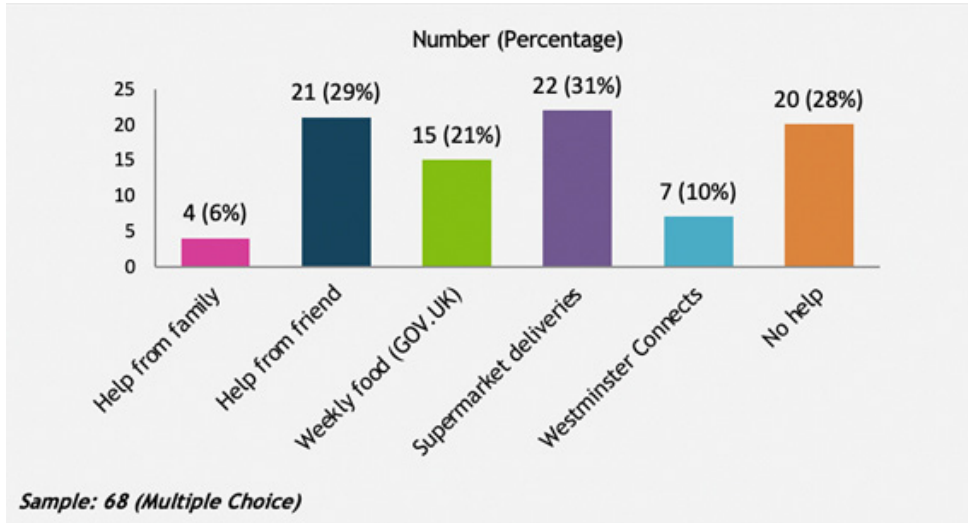
Over two thirds of the respondents stated that they identified as a woman (69%). Under one third of the respondents indicated that they identified as a man (31%).

More information about who we spoke to is included in Appendix 1: Demographics.

# Accessing health & support

## What help and support were patients able to access during the first wave of the pandemic?

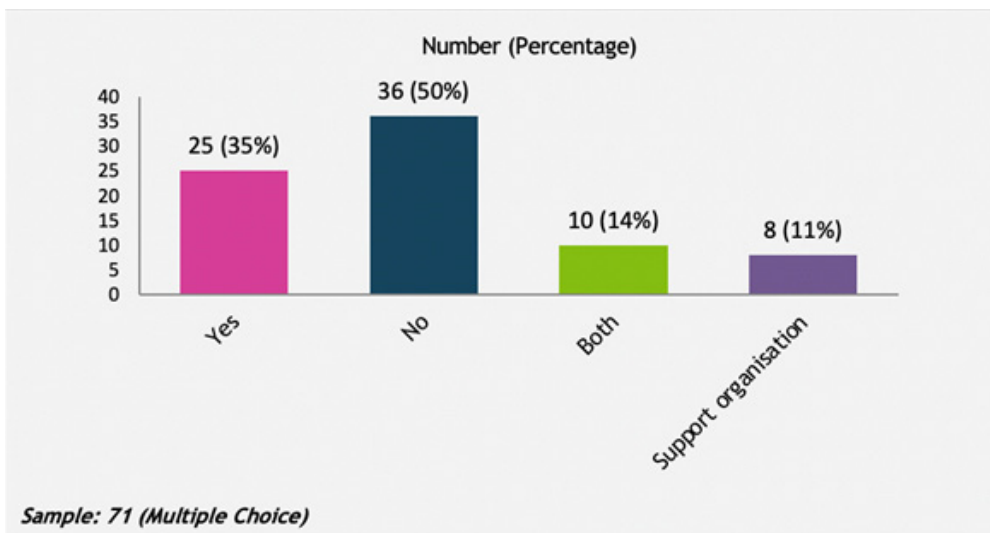
We asked respondents what help and support they received during the first lockdown



Supermarket deliveries, at 31%, were the most-used form of support, followed by help from friends (29%) and weekly free food from GOV.UK (21%). Lesser utilised options included Westminster Connects.

Most notably, over a quarter over all respondents indicated that they received no help from any source, and just 6% of respondents indicated that they received help from family.

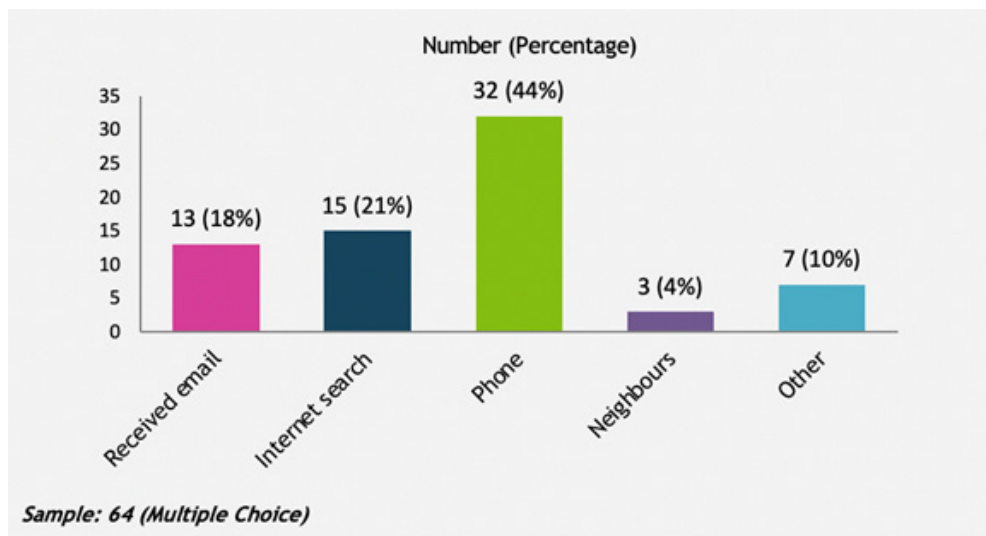
We asked respondents if they were contacted by their GP or hospital, or whether they were contacted by another support organisation





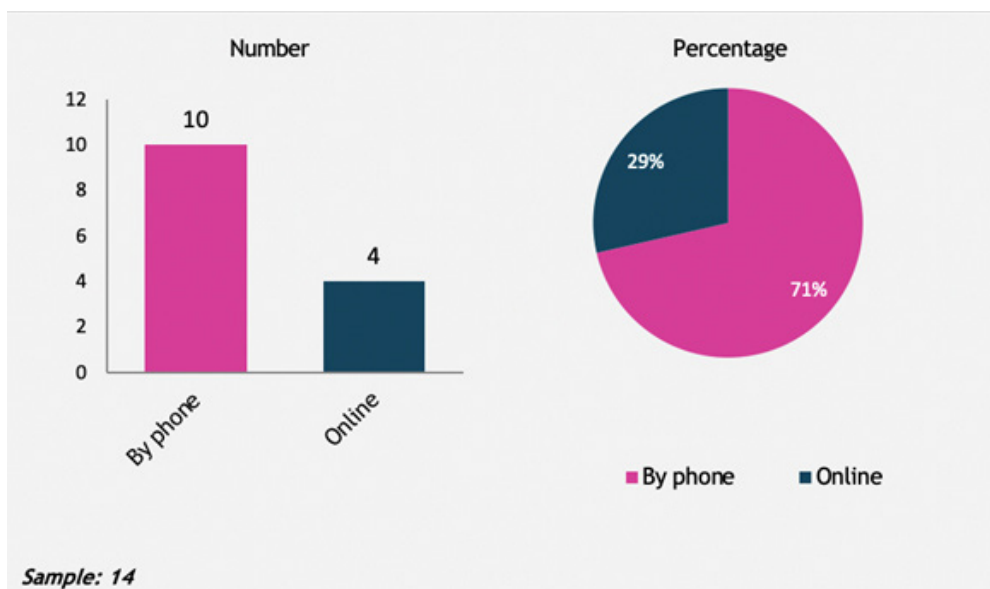
Half of all respondents were not contacted by their GP, hospital or other support organisation. Just 14% of respondents were contacted by both their GP and hospital or other support organisation, while over a quarter (35%) were contacted by just their GP or hospital. 11% of respondents were not contacted by their GP or hospital but were contacted by another support organisation.

### We asked patients how they found the support they needed

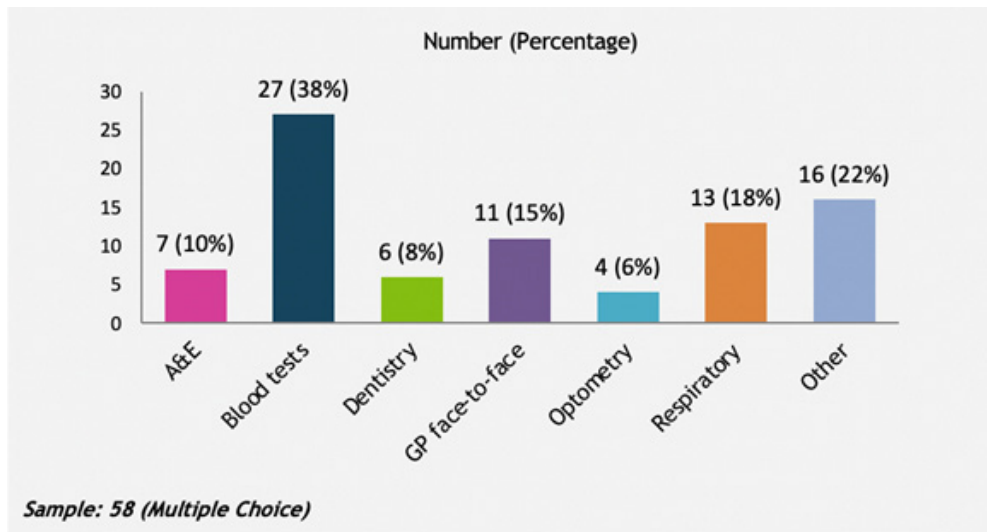


At 44%, the phone was significantly the most popular method of seeking support. Around a fifth of respondents (21%) searched the internet, while a similar number (18%) received emails. 10% also cited varied other methods.

**Significantly more** respondents used the phone for information than the internet. 57 respondents told us they used NHS 111 since March 2020. 14 respondents told us how they accessed the NHS 111 service. **Over two thirds** (71%) used the service by phone. **Just 29%** used the service online.



## We asked participants what services they have been able to use



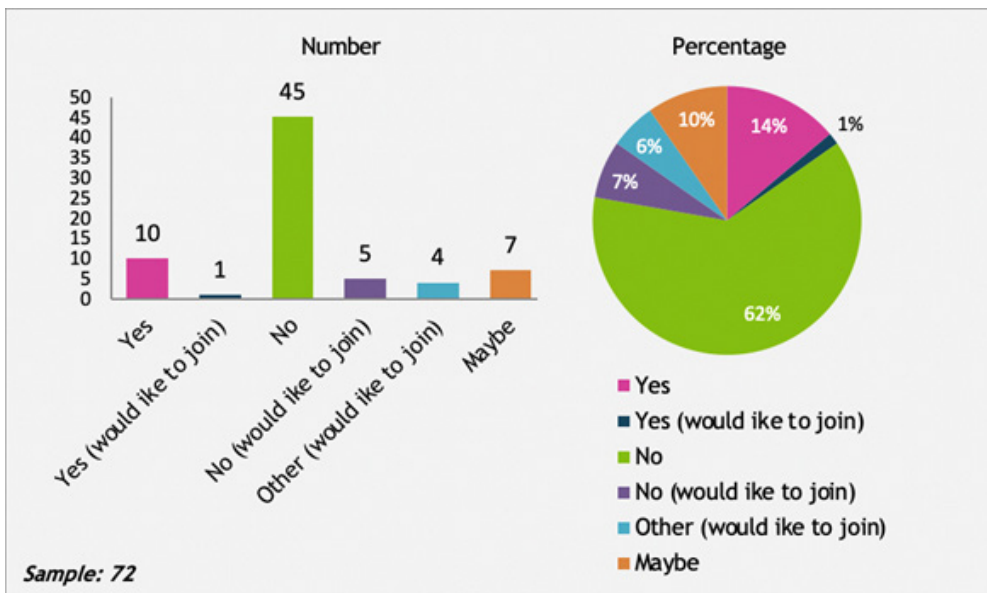
38% of respondents had been able to undertake blood tests, while 18% used respiratory services and 15% attended face-to-face GP appointments. Lesser utilised services included dentistry, A&E and optometry. A wide range of 'other' services was also mentioned, such as vaccination services.

These findings are consistent with other engagement work we have carried out over this period. Many service users have told us of their reluctance to go to hospital or A&E for treatment. Many service users have also told us of the difficulties they have faced accessing dentistry services.

## What other services are patients aware of?

We wanted to know what other health and social care services patients are aware of and if they are interested in accessing them. We asked respondents if they are aware of social prescribing, the Care Information Exchange and Coordinate My Care.

### We asked respondents if they are aware of social prescribing

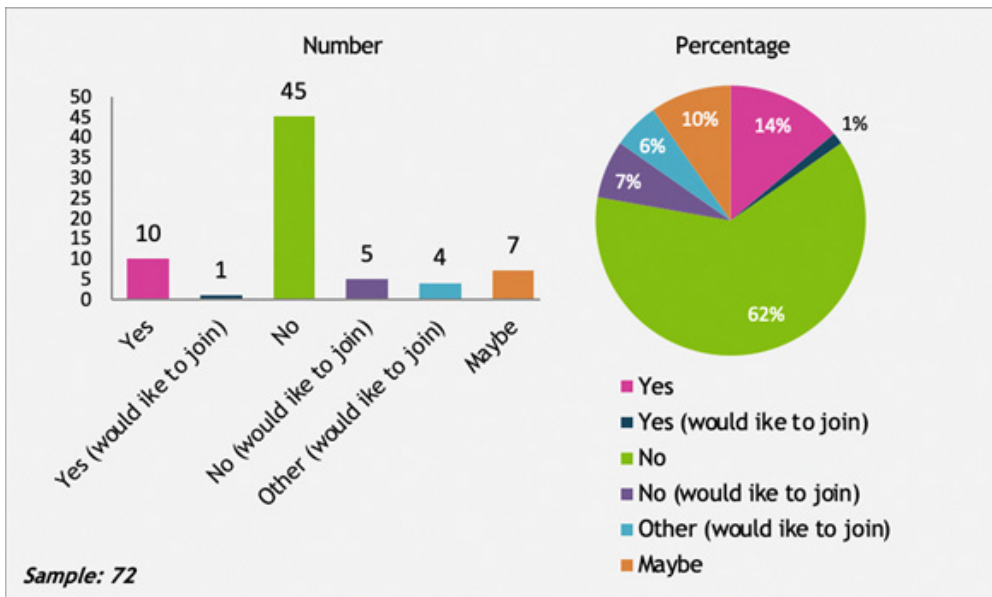


Social prescribing is a way for local agencies to refer people to a link worker. Link workers give people time, focusing on ‘what matters to me’ and taking a holistic approach to people’s health and wellbeing.

They connect people to community groups and statutory services for practical and emotional support.

**Over two thirds of respondents (67%)** had not heard of social prescribing. **Just over a quarter of respondents (29%)** had heard of social prescribing, while 17% said they would like to access social prescription.

## Care Information Exchange

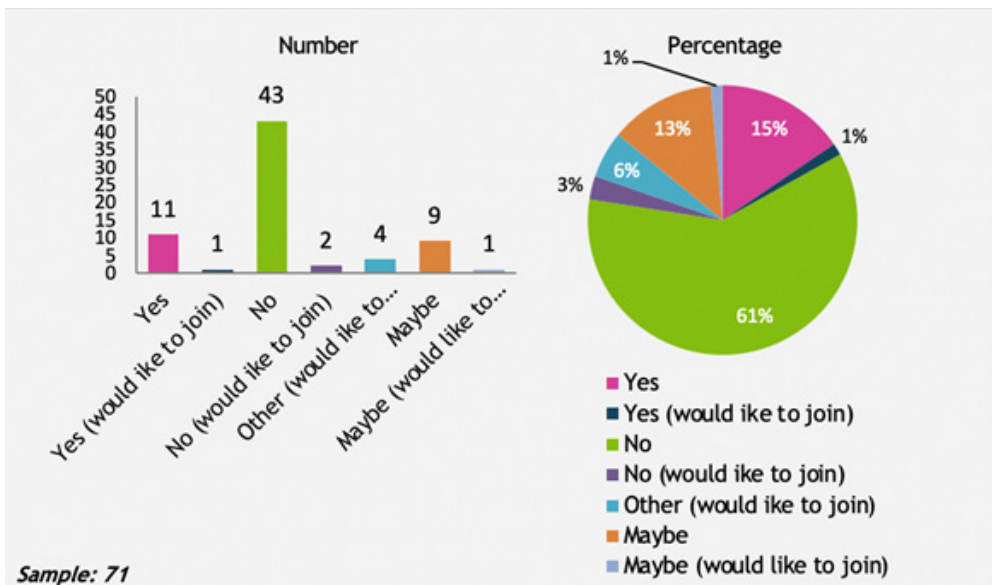


We asked respondents if they had heard of the Care Information Exchange (CIE). The CIE is the personal health record for patients and service users in north-west London. The goal of the service is to make sure you receive the best care and to help you feel more in control of your health.

It provides secure online access to medical records for you and the health and social care professionals who are involved in your care.

Over two thirds of respondents (69%) had not heard of the CIE, and 10% were unsure. Just 10% of respondents had heard of the service. 14% indicated that they would like to join.

## Coordinate My Care



We asked respondents if they had heard of Coordinate My Care (CMC). CMC is a clinical NHS service that supports patients in urgent care situations. Together with their clinicians, patients may record their preferences and wishes within an electronic personalised urgent care plan that also includes clinical information and relevant medical history.

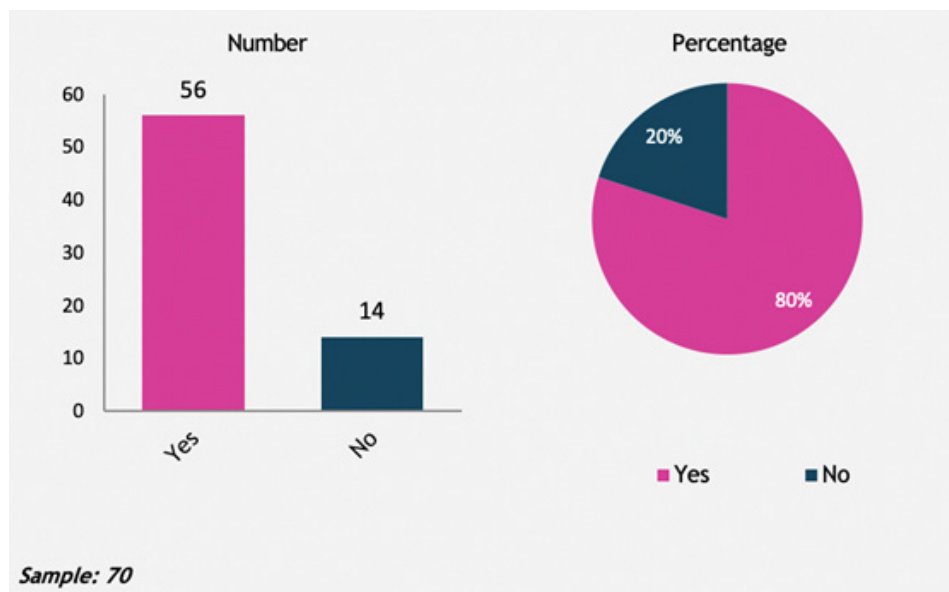
Nearly two-thirds of respondents (64%) had not heard of CMC, and a further 14% were unsure. Just 16% of respondents had heard of CMC. 5% said they would like to join.

The vast majority of respondents had not heard of social prescribing, the CIE or CMC, suggesting that visibility and awareness of these services is very low and that patients tend to not know of all the services that are available to them.

## Accessing GP services

### How accessible have GP services been to patients during the COVID-19 pandemic?

We asked respondents how easily they have been able to access their GP reception.



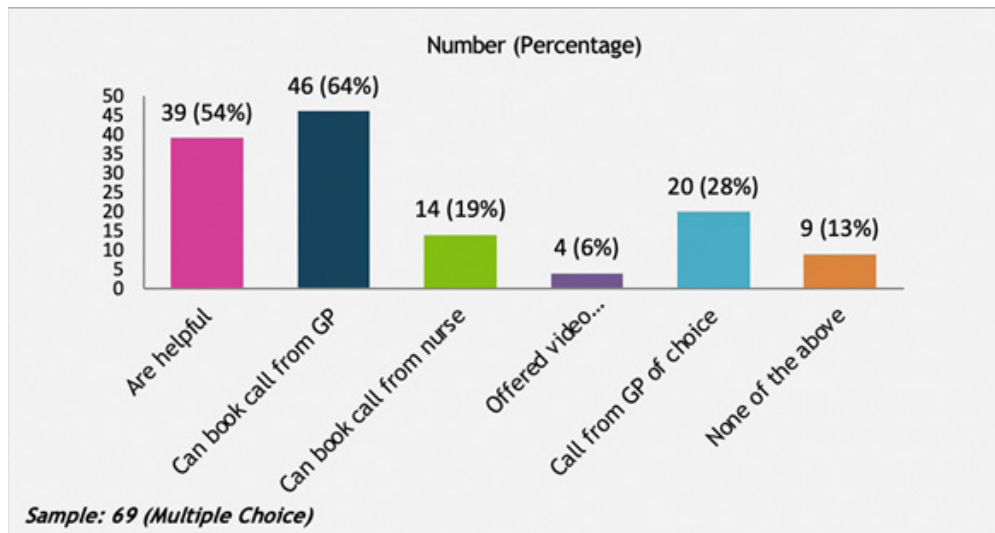
The majority of respondents (80%) were able to get through to their GP reception ‘easily’, while a fifth of respondents (20%) found it more difficult. This is encouraging: shifts in working and operating practices at GP surgeries have ensured that 80% of respondents could still contact GP services over this period.

However, one respondent told us that “My GP practice is de facto refusing service since I cannot use the telephone and need video consultation or email instead.

I am now searching for a GP practice which will take my disabilities into consideration.”

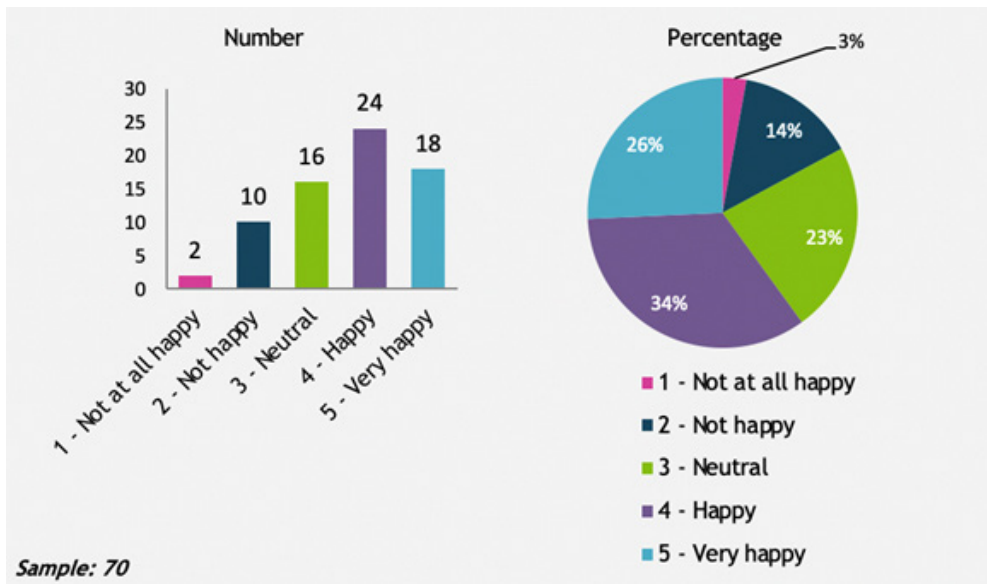
Digital exclusion remains an issue of prime importance across local health and social care services.

We wanted to know more about how patients have experienced GP services over the period. We asked respondents about their experiences when contacting their GP.



Over half of respondents (64%) were able to book a call from the GP, around half of which (28%) were able to secure their clinician of choice. 19% of respondents were able to book a nurse call and 6% were offered a video conference. Over half of respondents (54%) found the GP service to be helpful.

## We asked respondents how happy they are with their GP service



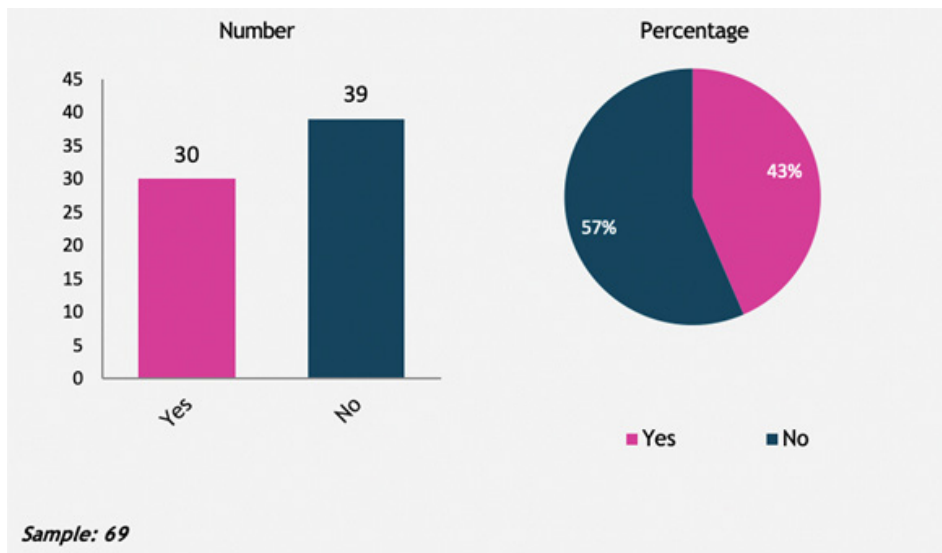
The majority of respondents (60%) gave their GP complimentary ratings of 4 or 5, while 17% were less satisfied, choosing the lowest options of 1 or 2.

## Accessing medicine

### How accessible were prescriptions and other medicine to patients during the COVID-19 pandemic?

The COVID-19 pandemic has altered standard processes. How patients obtain prescriptions and other medicine has changed. With many patients shielding during the first lockdown, alternative arrangements were put in place to ensure the accessibility of prescriptions and other medicine.

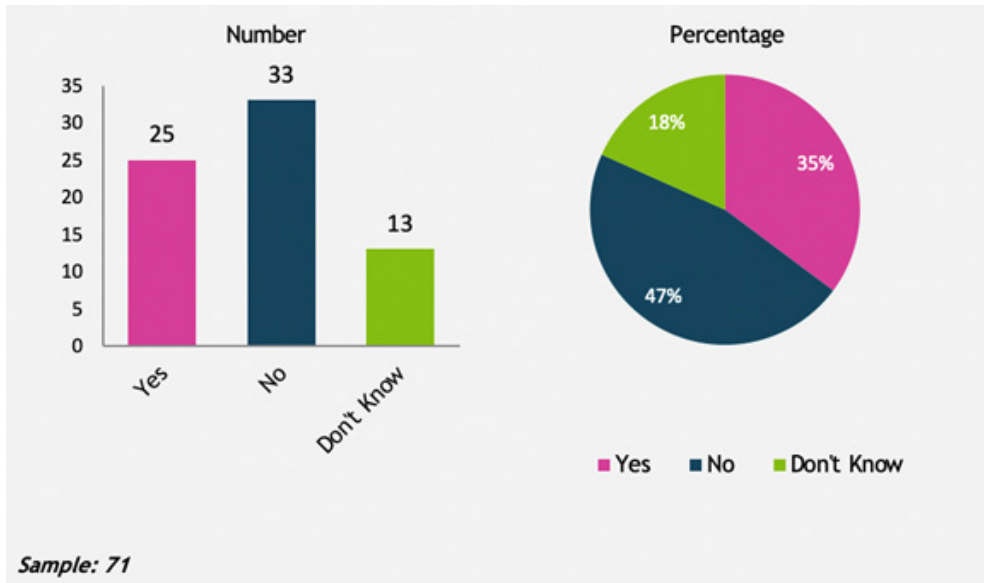
We asked respondents if they have been shown how to order their repeat prescriptions online



Just under half of respondents (43%) had been shown how to order repeat prescriptions online. The majority of respondents (57%), however, had not. Significant improvements can be made in this area.

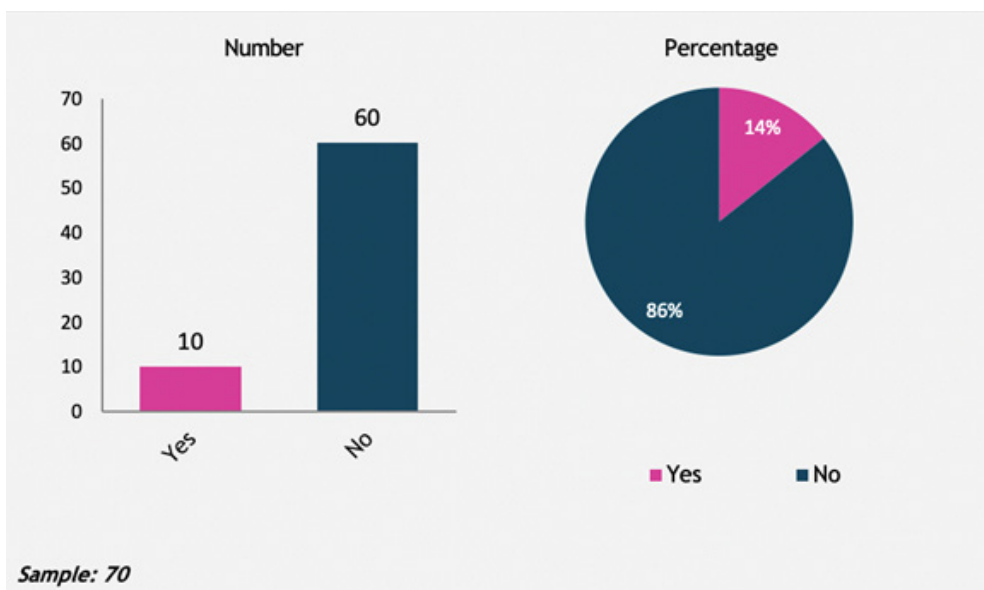


**We asked respondents if their pharmacy delivers their prescriptions to their home**



Almost half of respondents (47%) said their pharmacist does not deliver their prescriptions to their home. Just over a third (35%) said their pharmacist does deliver, while 18% were unsure. This is another area where improvements are needed and will be crucial in ensuring the ongoing accessibility of prescriptions and other medicine.

We wanted to know if patients have had trouble obtaining prescriptions. We asked respondents if they had faced difficulty obtaining regular medication from their local or hospital pharmacy.



Encouragingly, the majority of respondents (86%) indicated that they had no problem obtaining regular medication. However, over 10% of respondents had experienced difficulty, demonstrating that the accessibility of prescriptions remains a prevalent issue.

# Exploring inter-group disparities

## Avenues for further research and engagement

While this report has detailed top-level, inter-group findings, at just 72 the sample size is not large enough to draw any group-specific conclusions or insights. As the ongoing COVID-19 pandemic continues to alter processes, affect health and social care provision and impact communities, research exploring inter-group disparities is important to know where to focus attention, support and resources.

Although we can draw no group-specific conclusions from our research, we have identified some possible inter-group disparities within our results which may provide avenues for further research and engagement.

### Black, Asian and minority ethnic (BAME) communities

- BAME respondents to this survey were the least likely to have received help during the lockdown.
- BAME respondents were the least likely to have been contacted by their GP, hospital or other support organisation.
- BAME respondents tended to be less able to contact their GP easily, and tended to be less likely to find the GP service helpful.

### Carers

- Carers, along with BAME respondents, were least likely to have received help from an outside source during the lockdown.
- Carers were the least likely to have been shown online repeat prescriptions.
- None of the respondents to our survey who indicated they are carers were shown how to access their prescriptions online.

### People with disabilities

- Disabled respondents were the least able to contact their GP successfully.
- Disabled respondents were more likely to identify a fear of isolation.
- Disabled respondents were less likely than the baseline figure to be shown how to order repeat prescriptions online.

### LGBTQ+

- The survey did not receive enough responses from people who identify as LGBTQ+ to draw any group-level insight.

## Conclusion from Healthwatch Central West London

This report is the latest in a series detailing the results of engagement work HWCWL has carried out, alongside partner organisations, exploring the impact of COVID-19 on groups in the local community. A number of recurring issues and themes have emerged over the course of our work since March 2020. Many of the findings described here have also been echoed in our other engagement work over the period. These include:

- Issues of digital exclusion
- Awareness of available services
- Difficulties accessing non-essential services and prescription medication

The issue of digital exclusion has been frequently discussed across all our engagement work on COVID-19. As evidence in this report shows, the issue of digital exclusion is not binary: there are many ways people can be digitally excluded, and many levels to people's exclusion. People may be able to access their emails on their smartphone, for instance, whilst lacking the knowledge and support to be able to use the internet to find information or to communicate with healthcare providers or other people. The conversation around digital exclusion, and the solutions proposed to ensure all people are included, must take into account that having the appropriate technology is not the only factor in combatting this issue. The problems posed by digital exclusion are complex; a single solution is not adequate.

Another recurring issue throughout our engagement concerns patients' awareness of available services. A high number of participants across all our recent work have been unaware of all the services and care options which are available to them. Healthcare providers must do more to raise patient awareness of the available services and their own individual care options.

Although the vast majority of patients have been able to access prescription medication during this period, we have still heard from many people who have had trouble receiving the medicine and support they need. While extraordinary measures remain in place to combat the ongoing pandemic, measures need to be in place to ensure that all patients are able to access the medicine and treatment that they need at any time.

As we move into a new phase of measures to contain and treat COVID-19, listening to patients' voices, learning from their experiences and adapting process accordingly remains as important as ever. It is vital that the voices of patients and carers are kept central to considerations of new ways of working, and when commissioning and evaluating services. We have heard from patients and carers about their experiences of living with, or caring for someone with, a long-term health condition during this period and their aspirations of how the health care and support they receive could be improved that can help this to happen.

## Conclusion from Breathe Easy Westminster

More thought and action needs to be taken to support people who are more vulnerable to catching COVID-19 because of a long-term respiratory condition. This includes not only those who are shielding, but also those with little or no English language skills, those that are digitally excluded, and those that live alone. A particular issue that needs addressing is the impact of this period on people's mental health. As the first lockdown came to an end, for instance, many of those who were shielding were worried about leaving their homes.

Offering fair employment and rights for healthcare staff is vital in tackling the virus. A respondent with a parent in a care home commented that while care home staff work without sick pay and are low paid, they have no option to but to work, even when they are ill. This increases the risk of virus transmission, as staff are incentivised to work while they should be at home. This could also apply to key workers in other areas, too.

Some people with progressive incurable conditions were only designated as moderately at risk by the government and were therefore not asked to shield. This did not take into consideration escalating symptoms. Some members of Breathe Easy Westminster needed to be redesignated in order to receive supermarket food deliveries and other support. Inconsistencies in determining who needs to shield has in many cases led to a lack of continuity of care.

The findings detailed in this report highlight the importance of telephone contact and stress the need of members to be part of an active organisation which is aware of their needs. Before the pandemic took hold, Breathe Easy Westminster monthly meetings were lively and well-attended. Members felt free to express their opinions and compare details of their medical treatments. Guest speakers from all branches of the NHS were always happy to answer questions and give up-to-date, relevant information. The need to maintain a high level of communication is important for this extremely vulnerable group of patients.

We hope that virtual meetings and remote health consultations become widely available in the future. They will help members encourage each other and will aid in self-management.

**Tessa Jelen**

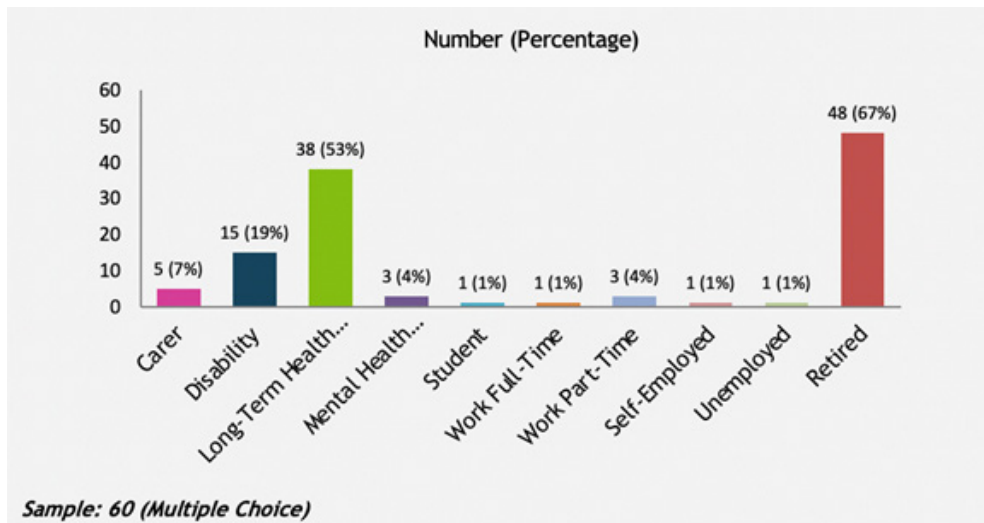
Breathe Easy Westminster

# Appendices

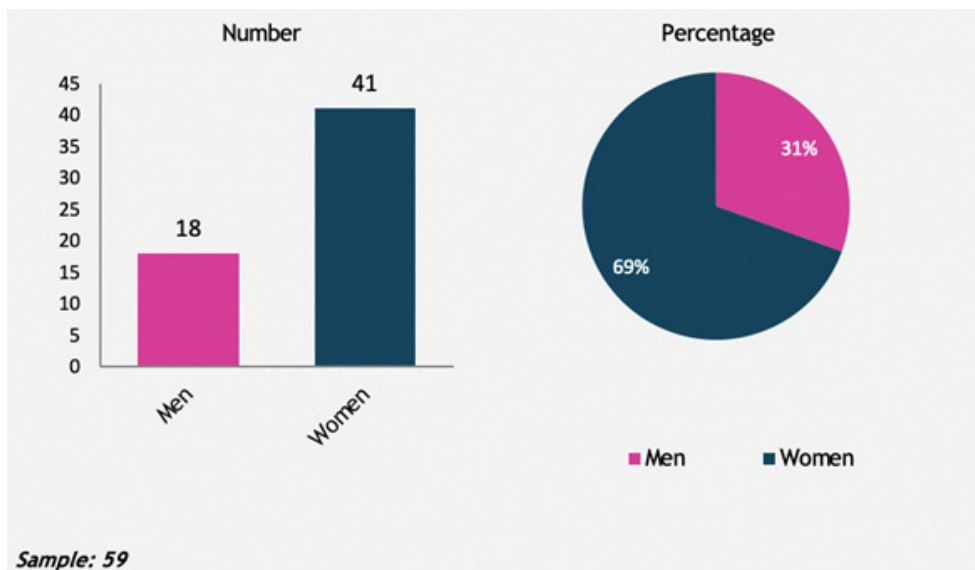
## Appendix 1: Demographics

The stated demographics of participants are as follows:

Which best describes you?

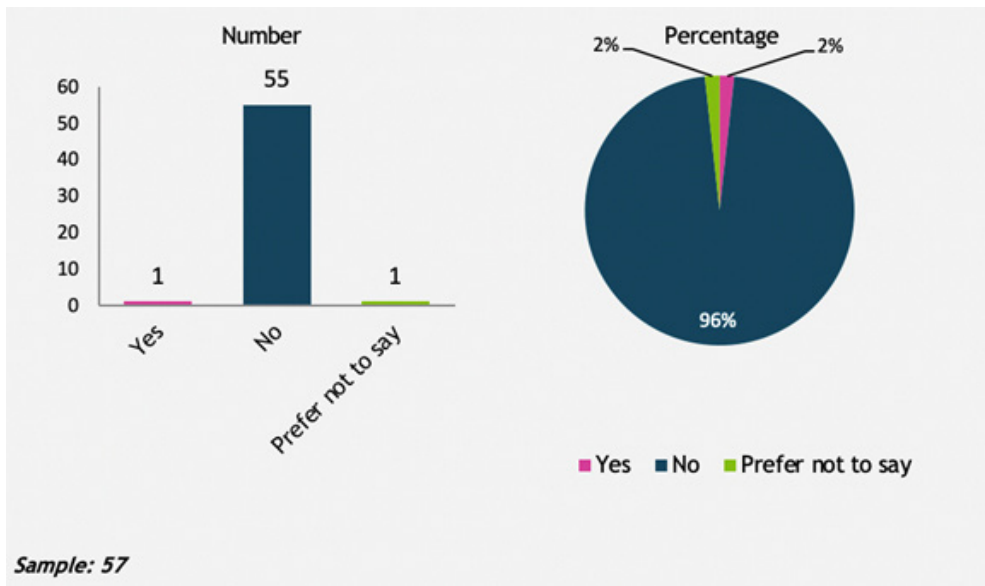


What gender do you identify with?

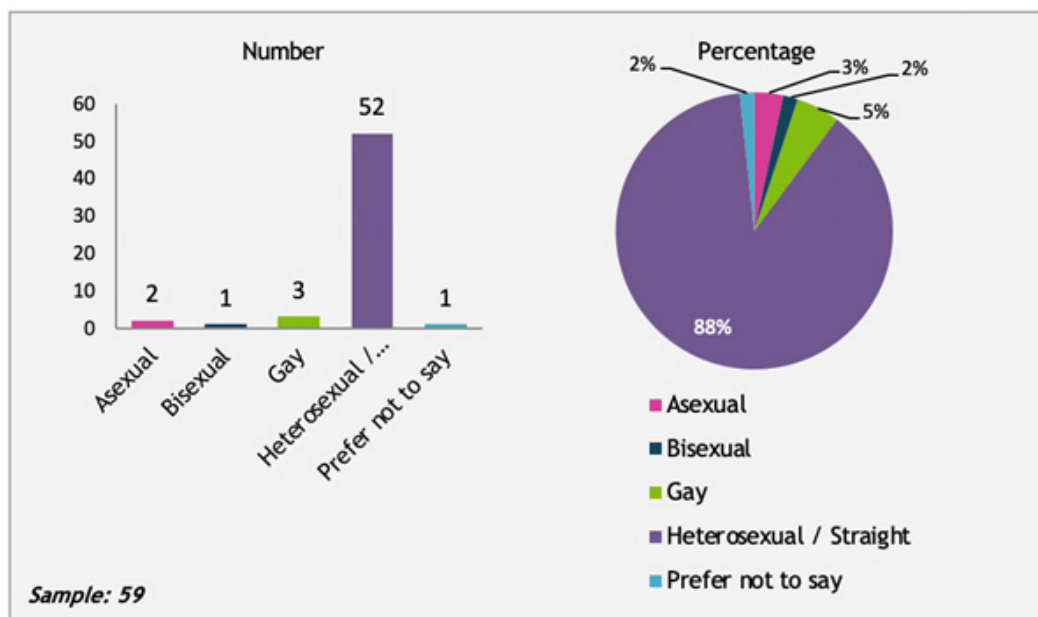


## Appendix 1: Demographics

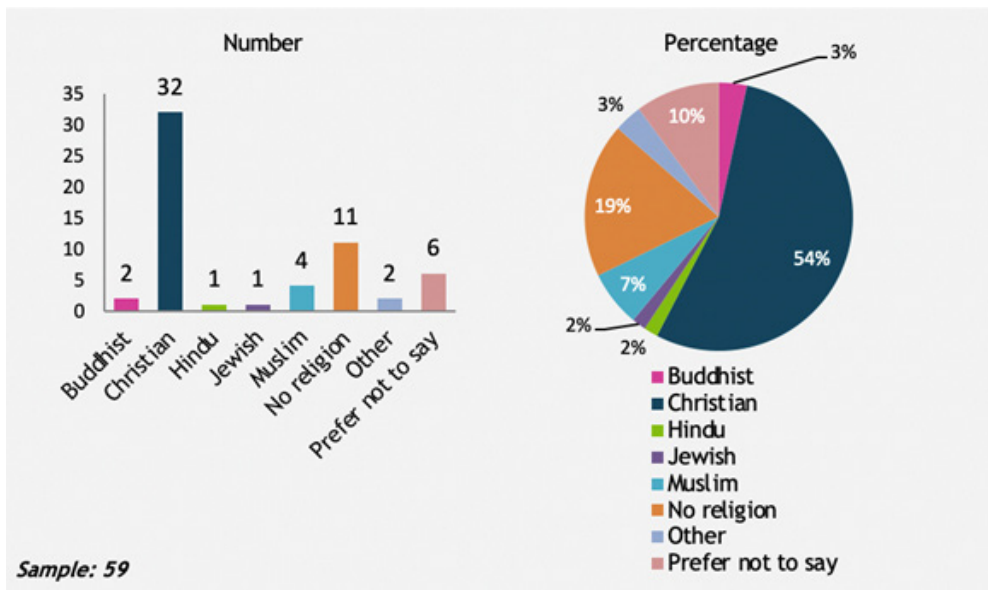
Is your gender different from that assigned at birth?



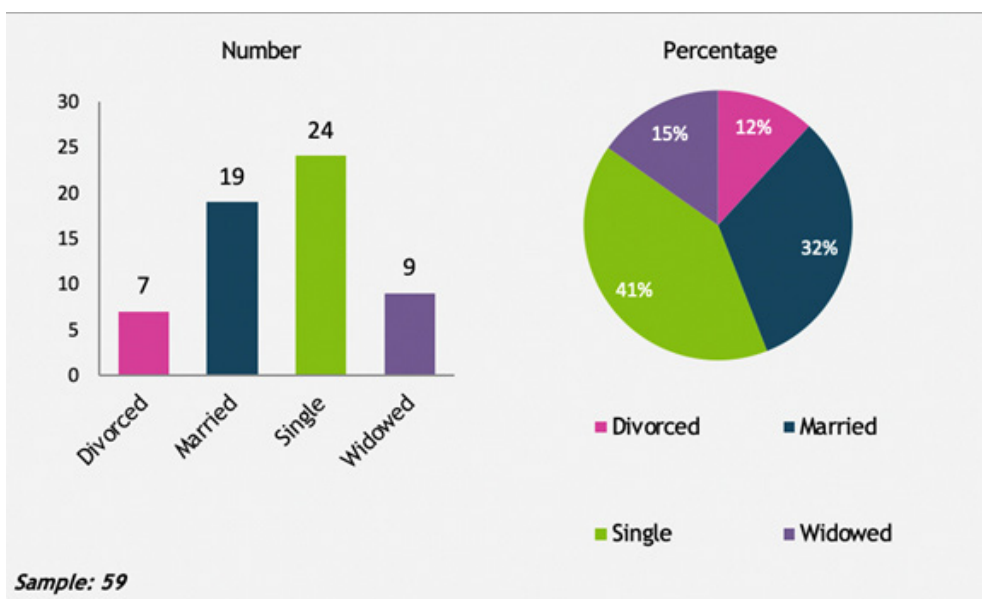
Please tell us which sexual orientation you identify with?



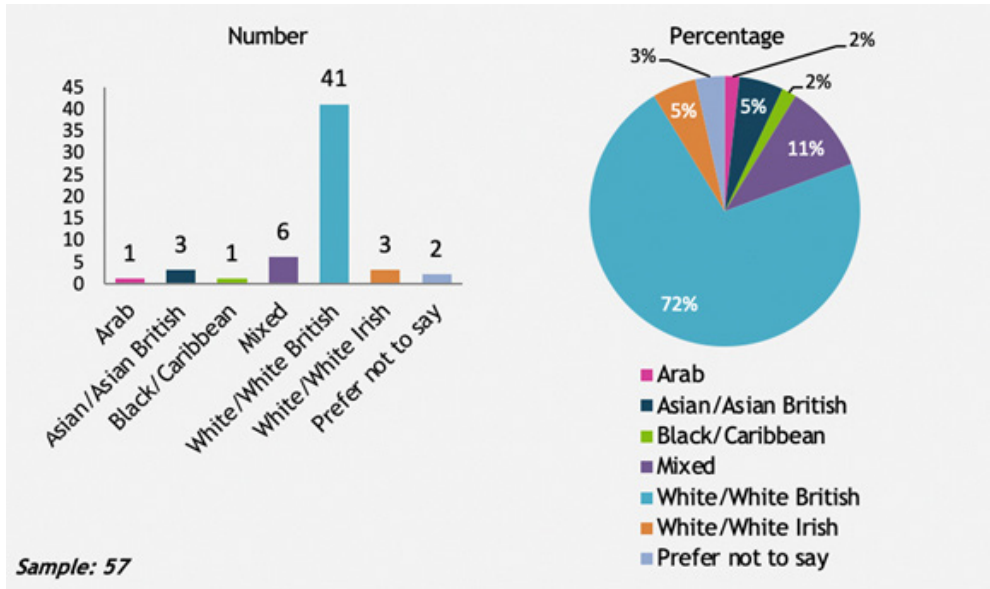
What is your religion or belief?



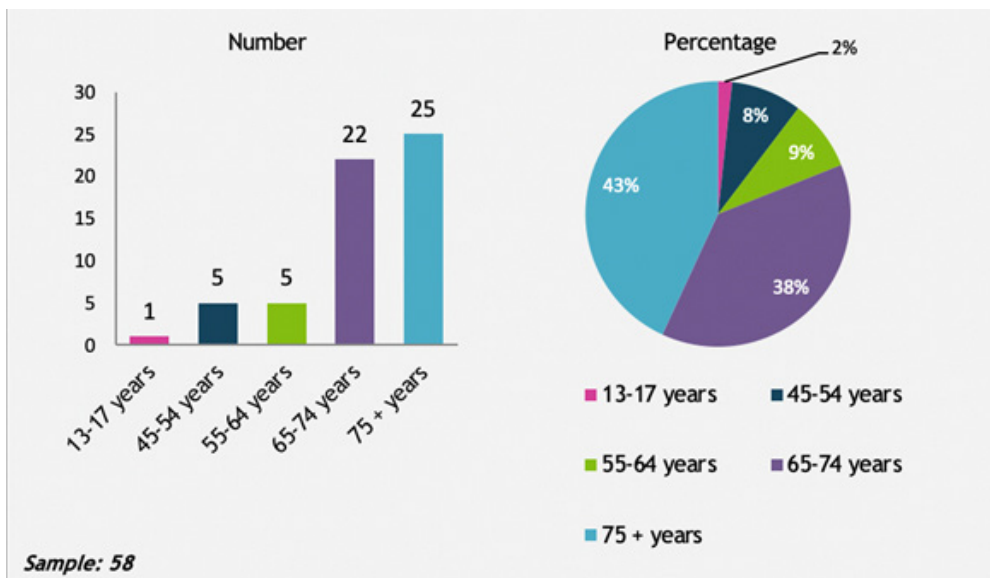
What is your marital or civil partnership status?



What is your ethnic background?

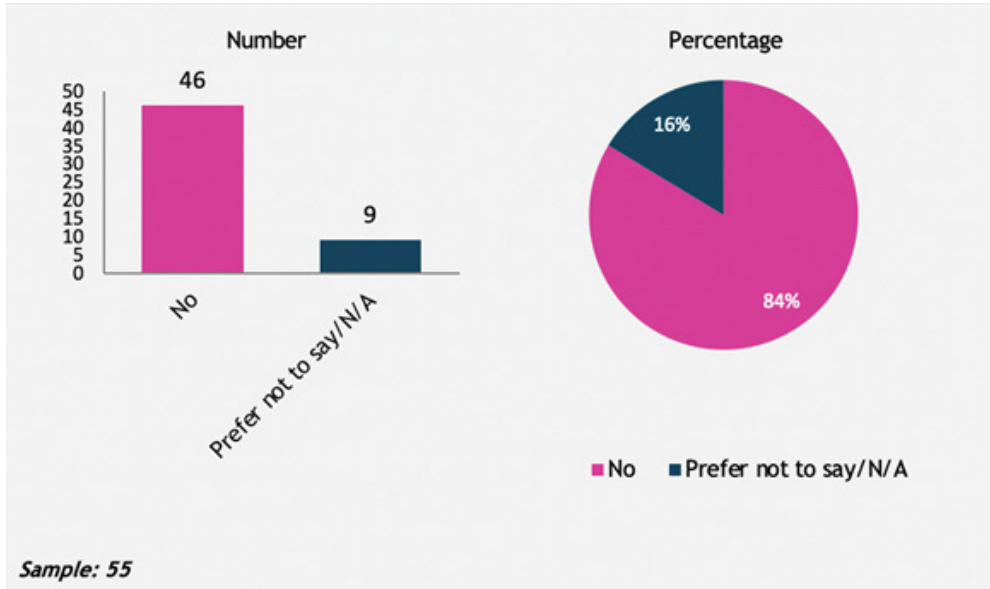


Please tell us which age category you fall into?





Are you currently pregnant or been pregnant in the last year?



# Appendices

## Appendix 2: Survey Questions

1. Have you had a letter saying you are shielded?
  - a. Yes
  - b. No
  - c. No, but should have
  - d. Not applicable
  
2. How did you adhere to the lockdown requirements?
  - a. Fully
  - b. Partially
  - c. Not at all
  
3. In lockdown, did you receive?
  - a. Help from family
  - b. Help from friends
  - c. Weekly food (GOV.UK)
  - d. Supermarket deliveries
  - e. Westminster Connects
  - f. No help
  
4. Were you contacted by your GP, hospital or other support organisation?
  - a. Yes
  - b. No
  - c. Both
  - d. Support organisation
  
5. How did you manage to find the support needed?
  - a. Received email
  - b. Internet search
  - c. Phone
  - d. Neighbours
  - e. Other
  
6. Have you used 111 for advice?
  - a. Yes
  - b. No
  
7. How did you contact them?
  - a. By phone
  - b. Online
  
8. Was 111 helpful?
  - a. Yes
  - b. No
  
9. What services have you been able to use?
  
10. What services were not able to provide support?
  
11. Can you get through to your GP reception easily?
  - a. Yes
  - b. No

12. When you contact your GP (tick all that apply)...
- a. Are helpful
  - b. Can book call from GP
  - c. Can book call from nurse
  - d. Offered video consultation
  - e. Call from GP of choice
  - f. None of the above
13. Which specialist contact do you have at your GP?
- a. Care Navigator
  - b. Phlebotomist
  - c. Respiratory nurse
  - d. None of the above
  - e. Other
14. Has a care plan been discussed with you?
- a. Yes
  - b. No
  - c. Maybe
15. Do you know if you have had a frailty test?
- a. Yes
  - b. No
  - c. Maybe
16. Have you heard of Social Prescribing?
- a. Yes
  - b. Yes (would like to be prescribed)
  - c. No
  - d. No (would like to be prescribed)
  - e. Other (would like to be prescribed)
17. Have you heard of Care Information Exchange?
- a. Yes
  - b. Yes (would like to join)
  - c. No
  - d. No (would like to join)
  - e. Other (would like to join)
  - f. Maybe
18. Have you heard of Coordinate My Care?
- a. Yes
  - b. Yes (would like to join)
  - c. No
  - d. No (would like to join)
  - e. Other (would like to join)
  - f. Maybe
19. Have you been introduced to any of the above by your GP?
- a. Yes
  - b. No
  - c. Maybe
  - d. Other

20. Have you been shown how to order your repeat prescriptions online?
  - a. Yes
  - b. No
  
21. Does your pharmacy deliver your prescriptions to your home?
  - a. Yes
  - b. No
  - c. Don't know
  
22. Have you had any problems with obtaining regular medication from your local or hospital pharmacy?
  - a. Yes
  - b. No
  
23. How happy are you with your GP service?
  - a. 1 - Not at all happy
  - b. 2 - Not happy
  - c. 3 - Neutral
  - d. 4 - Happy
  - e. 5 - Very happy
  
24. Would you like to join your GP's Patient Participation Group (PPG)?
  - a. Yes
  - b. No
  - c. Maybe
  
25. Do you think you have had COVID-19?
  - a. Yes
  - b. No
  
26. If you have been tested for COVID-19, what were the results?
  - a. Positive
  - b. Negative
  
27. Would you like to have an antibody test?
  - a. Yes
  - b. No
  
28. What are your main causes of stress?
  - a. Fear of virus transmission
  - b. Isolation
  - c. Money worries
  - d. Other

## Demographic questions

1. What best describes you?
  - a. Carer
  - b. Disability
  - c. Long-term health condition
  - d. Mental health condition
  - e. Student
  - f. Work full-time
  - g. Work part-time
  - h. Self-employed
  - i. Unemployed
  - j. Retired
2. Which gender do you identify with?
  - a. Men
  - b. Women
3. Is your gender different from that assigned at birth?
  - a. Yes
  - b. No
  - c. Prefer not to say
4. Please tell us which sexual orientation you identify with?
  - a. Asexual
  - b. Bisexual
  - c. Gay
  - d. Heterosexual/Straight
  - e. Prefer not to say
5. What is your religion or belief?
  - a. Buddhist
  - b. Christian
  - c. Hindu
  - d. Jewish
  - e. Muslim
  - f. No religion
  - g. Other
  - h. Prefer not to say
6. What is your marital or civil partnership status?
  - a. Divorced
  - b. Married
  - c. Single
  - d. Widowed
7. What is your ethnic background?
  - a. Arab
  - b. Asian/Asian British
  - c. Black/Caribbean
  - d. Mixed
  - e. White/White British
  - f. White/White Irish
  - g. Prefer not to say
8. Please tell us which age category you fall into?
  - a. 13-17 years
  - b. 45-54 years
  - c. 55-64 years
  - d. 65-74 years
  - e. 75+ years
9. Are you currently pregnant or have been pregnant in the last year?
  - a. Yes
  - b. No
- c. Prefer not to say/N.A.



## Contact Us

### Healthwatch Central West London

5.22 Grand Union Studios,  
332 Ladbroke Grove,  
W10 5AD

Tel: 020 89687049

Email: [info@healthwatchcentralwestlondon.org](mailto:info@healthwatchcentralwestlondon.org)

[www.healthwatchcwl.co.uk](http://www.healthwatchcwl.co.uk)

Company no. 08548208

Charity no. 1154777

© Copyright Healthwatch Central West London 2020