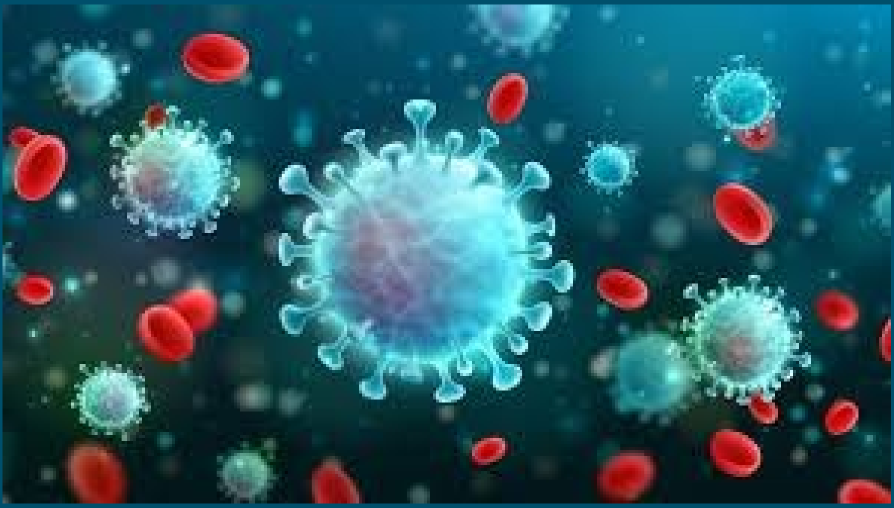


Croydon residents' experiences of living with Long Covid

June 2022

Findings in brief

Nearly 1 in 4 had symptoms but not a diagnosis.

33% still experienced symptoms 12 months later and 54% had symptoms between 6 and 11 months.

Fatigue, anxiety, and headaches were most severe symptoms.

74% said Long Covid negatively impacted their mental and emotional health.

53% had not received any help and the same number relied on friends & family.

75% felt their quality of life was affected.

Recommendations in brief

Develop a better screening process.

Create better pathways between GPs, consultants, and wider teams.

Deliver dedicated community support for those with Long Covid.

Focus on supporting family and friends.

Ensure those living on their own get the care they need.

Gather more insight by age, gender, and ethnicity.

Executive Summary

Long Covid is an informal term that is commonly used to describe signs and symptoms that continue and develop after an acute infection of Covid-19. It usually presents with varied symptoms that can change over time commonly respiratory and cardiovascular symptoms, as well as fatigue, fever, and pain. There can also be neurological, gastrointestinal, musculoskeletal, psychological, and psychiatric symptoms, and issues concerning ear nose and throat symptoms and skin conditions that continue for longer than 12 weeks. As a new condition, there is no test or clear pathway for Long Covid. This makes the condition difficult to identify and treat and there is a variation in diagnosis between clinicians. Many of the symptoms can be like other conditions, but research is developing to suggest that Long Covid is a condition in its own right. Healthwatch Croydon undertook a survey between July and November 2021 to ask those who had experienced Long Covid symptoms to share their experience. This survey was aligned with similar surveys undertaken by Healthwatch in South West London within this period.

These are our findings based on 62 responses from the survey:

Despite having the symptoms of Long Covid for some time, 1 in 4 had not had a diagnosis: 37% respondents had been diagnosed with Long Covid, and 23% had Long Covid symptoms but had not yet been diagnosed. Others had had Covid confirmed by a test **(see 2.3, page 14).** 43% had not had health conditions before contracting Covid illustrating the impact that Long Covid can have on previously healthy people **(see 2.4, page 15).**

While most started the patient journey with a GP it was a clinic, hospital, or consultant where they got diagnosed and where patients received a better response: Only two respondents were diagnosed by a GP and had a positive experience. Eight were diagnosed by the hospital, three at a clinic and two by a consultant. It is likely GPs are not able to give a diagnosis but will refer therefore accounting for the negative or neutral experience felt by the patients here **(see 2.5, page 17).**

Most respondents had symptoms for a considerable time and were still experiencing these at the time of the survey: 34% of respondents had Long Covid symptoms for 12 months or more, 31% had experienced symptoms for 6-8 months, 23% for 9-11 months. Patients have waited to see if their symptoms have improved and for a majority – whether diagnosed or not, they have not **(see 2.6, page 21).** 85% of respondents were still experiencing Long Covid symptoms with 11% unsure, and just 3% stating they were not experiencing symptoms **(see 2.7, page 22).**

Fatigue, anxiety, and headaches were the most severe symptoms and muscle pain was the highest recorded moderate symptom along with fatigue, breathlessness, memory, and concentration: 40% experienced severe fatigue, 31% had severe anxiety, and 19% experienced severe headache. 45% reported moderate muscle pain, with 44% reporting moderate fatigue. 41% experienced moderate breathlessness with 35% with moderate problems with memory and concentration **(see 2.8, page 23).**

For some anxiety and insomnia got consistently worse, most experience fluctuating problems with fatigue, muscle pain and brain fog: 13% experienced worsening anxiety and 11% experienced worsening insomnia and trouble sleeping, For many fluctuating symptoms were the highest reported, with 44% with fatigue, 39% with muscle pain, 35% with problems with memory/brain fog, 28% with memory loss and anxiety, and 28% experienced chest tightness/palpitations **(see 2.9, page 26).**

Most had their emotional wellbeing or mental health affected by Long Covid: 74% said living with Long Covid negatively impacted their emotional wellbeing or mental health. 24% participants reported anxiety, and 22% reported depression and 11% reported both anxiety and depression **(see 2.15, page 39).**

Most have not had a referral for support: 53% respondents have not had referral to support, 20% had to wait more than two months, 13% waited less than two weeks, 8% waited between one and two months **(see 2.11, page 30).**

When receiving support, most got this from friends and family: 53% had not received any help except from friends and family. The GP scored most highly with 27% reporting that they received help from their doctor. Outpatient care at a hospital was reported by 21% **(see 2.12, page 31).** When they have received support, the experience has been mixed with slightly more having negative than positive experiences. Just one mentioned a dedicated Long Covid clinic with a positive experience **(see 2.13, page 33).** 69% had been in touch with services, 19% had not **(see 2.10, page 29)** 10% got support from a community or voluntary organisation, 8% got support from another unspecified service – just 5% got support from NHS mental health care providers, GP, or online app. 36% did not need any support at all **(see 2.16, page 42).** Five respondents (8.6%) received support from services to manage their daily living, 91%) said they did not **(see 2.18, page 47).** 47% said yes that they did have a carer, and 53% said no. This suggests over half of those responding did not previously need care support **(see page 2.19, page 48).**

Most felt their quality of life was impacted: 75% felt that their quality of life was impacted with 37% reported that their work/school life was affected, 32% of respondents felt that their relationships were affected and 20% said caring or parenting roles were impacted. **(see 2.17, page 45).**

More women responded than men: Most surveys of this kind tend to have higher response rate from women but not as much as 72%. Even with relatively small sample, it may be that Long Covid affects women more than men **(see demographics page 51)** or that men under report via this method.

These are our recommendations which are relevant to providers and commissioners:

Develop a better screening process: Low and inconsistent levels of diagnosis compared with symptoms point to the need for a better and more consistent screening process.

Create better pathways between GPs and consultants and build wider multi-disciplinary teams: Most patients begin their patient journey with a GP but need to see a consultant to get diagnosed. Better pathways need to be developed to refer patients swiftly and easily which can involve a wider range of health professionals to support patients from physical conditions to mental health.

Deliver dedicated community support services for those with Long Covid: People who were previously well have been affected by this long-term condition, usually with little formal support. A package of support needs to be created, to enable people to manage their conditions and improve their quality of life including peer-led support groups to help those on their diagnosis and care journey.

Focus on supporting family and friends: Since many have relied on family and friends for support, focus support packages to help family and friends.

Ensure those living on their own get the care they need: Those living on their own may not have any access to care from family and friends and can be suffering alone. There is a need to ensure this information is collected at the screening process to support them with recovery and give them enhanced support.

Gather more insight about who is most affected by age, gender, and ethnicity: Our survey small was small, but suggests certain demographics were affected more than others, create regular insight through surveys. focus groups and interviews to create continued conversations with patients to ensure services meet patient need.

1 Background

1.1 Context

About Healthwatch Croydon

Healthwatch Croydon works to get the best out of local health and social care services responding to the voice of local people. From improving services today to helping shape better ones for tomorrow, we listen to people's views and experiences and then influence decision-making. We have several legal functions, under the 2012 Health and Social Care Act.

Context

Long Covid is an informal term that is commonly used to describe signs and symptoms that continue and develop after an acute infection of Covid-19. It usually presents with varied symptoms that can change over time commonly respiratory and cardiovascular symptoms, as well as fatigue, fever, and pain. There can also be neurological, gastrointestinal, musculoskeletal, psychological, and psychiatric symptoms, and issues concerning ear nose and throat symptoms and skin conditions that continue for longer than 12 weeks.[1]

There is no test or clear pathway for Long Covid. This makes the condition difficult to identify and treat and there is a variation among GPs confidence to diagnose.

New research now shows that Covid is associated with brain shrinkage, the study showed that compared with a control group, the Covid infected group showed

---

[1] NHS (2021) *Your Covid recovery:* https://www.yourCovidrecovery.nhs.uk/what-is-Covid-19/long-Covid/

greater tissue loss in specific regions of the cerebral cortex, the wrinkled outer surface of the brain affecting memory and emotions.[2]

As an emerging condition that is yet to be fully understood Healthwatch Croydon worked with Healthwatch across South London to gather patient experience across the boroughs to identify themes and commonality around this new illness and how those experiencing Long Covid can best be supported.

1.2 Rationale and Methodology

Healthwatch Croydon ran an online survey from 30 July to 27 November 2021 online where we received 62 responses, 54 from across the borough of Croydon and eight from outside the borough.

1.3 Method

The survey was set up on Smart Survey. Healthwatch Croydon promoted the survey across our social media platforms and used paid advertising on social media. This was also shared with Croydon Council using e shots.

Information and survey were presented like this:

In the last year, have you had signs and symptoms lasting more than 12 weeks after an infection from a virus? If so, tell us about your experience. Common symptoms include breathlessness, ‘brain fog’ and fatigue.

This may have been due to Coronavirus (sometimes it is called ‘Long Covid' or 'Post-Covid' Syndrome) or you may not have had a test to know what the virus was. You may not have been very ill from the virus itself but have experienced symptoms afterwards.

---

[2] Douaud, G et al: SARS-CoV-2 is associated with changes in brain structure on UK Biobanks Nature 21 February 2022 https://www.nature.com/articles/s41586-022-04569-5_reference.pdf

We'd like to hear about your experiences of managing symptoms and long-term effects. Your feedback will help us to understand what support is needed for people living with Long Covid and long-term effects of a virus.

Questions:

1. Which borough do you live in?
2. Are you completing this survey about yourself, or on behalf of someone you care for?
3. Have you been diagnosed with Covid-19 or Long Covid?
4. Tell us about any other health conditions you have other than the Long Covid type symptoms:
5. Please give us more details about getting or being unable to get your Long Covid type symptoms diagnosed?
6. For how long have you been experiencing/ did you experience Long Covid symptoms?
7. Are you still experiencing longer term symptoms?
8. What are the main symptoms that you experienced or are still experiencing?
9. How have your symptoms changed since you started experiencing them?
10. Have you been in touch with your GP or with a hospital about your symptoms and support needed?
11. How long have you had to wait before receiving support, after your first referral to support?
12. Have you received any other help and how has it made a difference to your health?
13. Do you have anything more to tell us about the support you have accessed?
14. Do you feel your personal preferences were respected (such as your lifestyle, culture, and beliefs)?

15. Has living with Long Covid negatively impacted your emotional wellbeing or mental health?

16. Have you received any support for your emotional wellbeing or mental health and from where?

17. Has living with long term symptoms had an impact on the rest of your life or those around you?

18. Have you received support to manage daily living or ongoing care needs?

19. Do you have someone (a friend, relative, neighbor, or other type of carer) who helps you with your daily living (not as part of their paid profession)?

20. Is there any other support or information for your Long Covid like symptoms that you're not currently getting that you think would help you?

21. Is there anything else you would like to share with us or that we should have asked you?

22. Demographic Information: - Name, Age, gender, sexuality, religious belief, ethnic background, disability status?

1.4 Limitations of the study

Partial responses: We did receive 62 completed surveys and also 107 partial responses which were not included in this survey. Most were experiencing Long Covid symptoms which may have affected their ability to complete the survey.

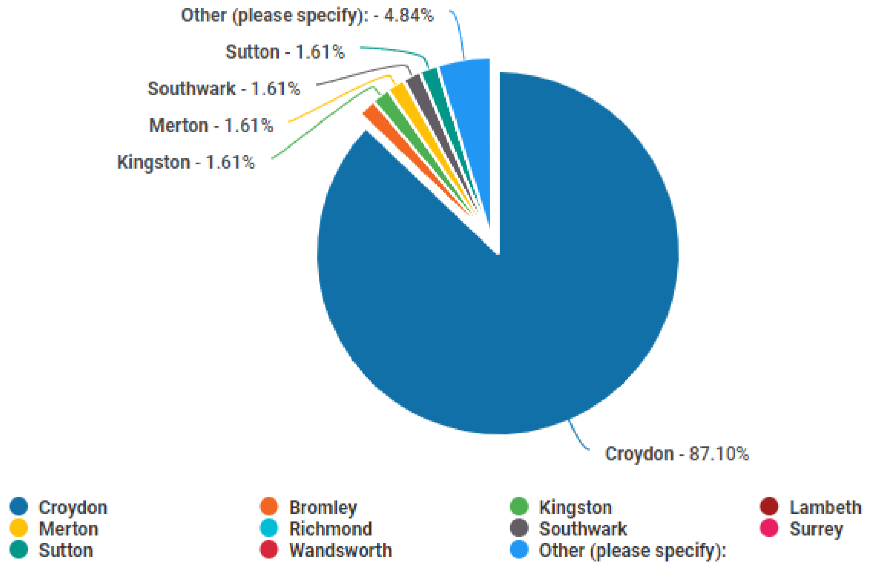
Online only reach: Few in person services and activities were operating at the time of our survey. So, we had to run an online survey meaning we did not hear from people who were digitally excluded unless a friend or carer completed it.

Length of the survey: The survey was agreed across six Healthwatch and while there was the opportunity to diverge it may have moved away from having a wider South West London dataset. The survey on reflection was long and detailed which may have discouraged participation. Focus groups and interviews may be a better way of collating insight.

2 Insight results

These are our findings based on the survey responses we received, each new space or new line is a separate comment. Please note we have not edited comments, so typos, grammar and phrasing are intentional.

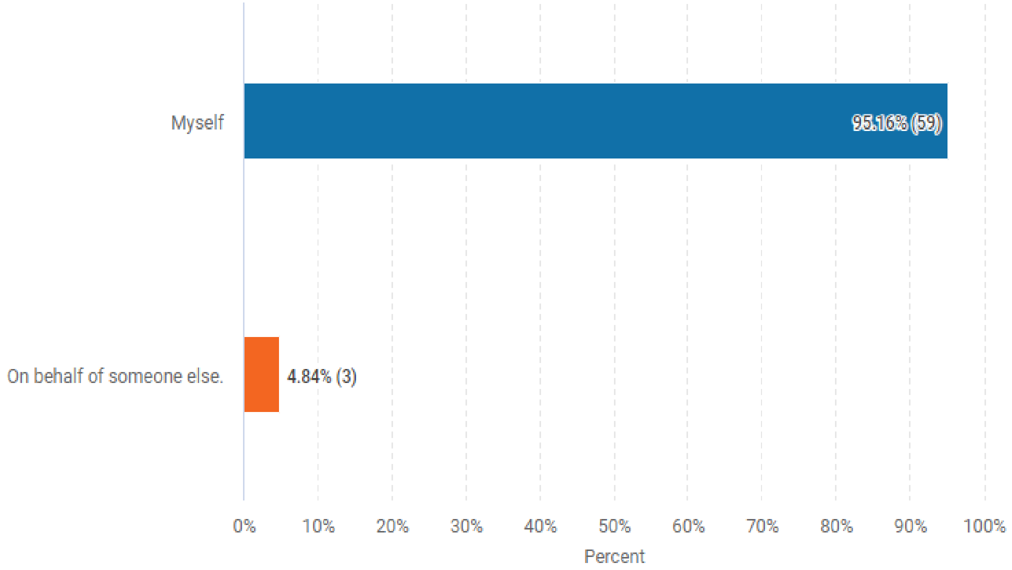
2.1 Which borough do you live in?



Total=62

The chart shows we received 62 responses, 54 from across the borough of Croydon and eight from outside Croydon.

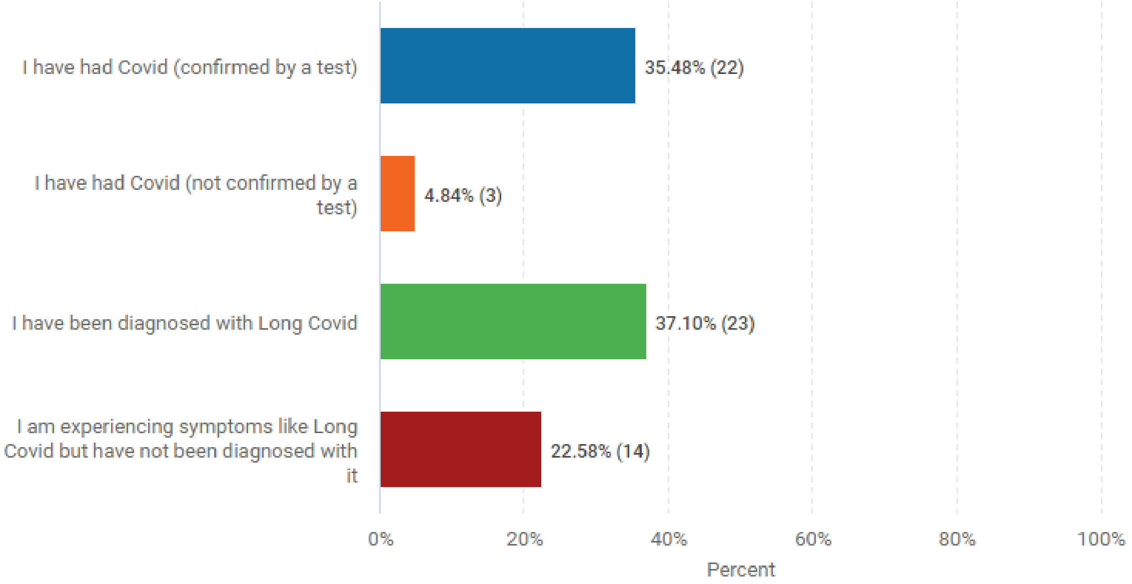
2.2 Are you completing this survey about yourself, or on behalf of someone you care for?



Total=62

Most of our respondents (59) completed the survey for themselves, three completed the survey on behalf of someone else.

2.3 Have you been diagnosed with Covid-19 or Long Covid?

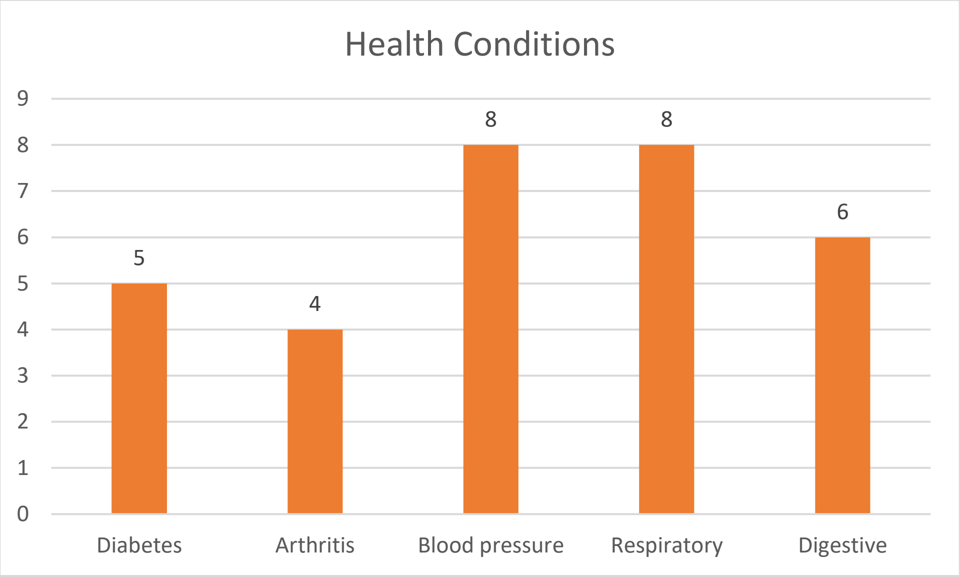


Total=62

- 22 (35.8%) had Covid, confirmed by testing.
- Three respondents reported that they had Covid which was not confirmed by a test.
- 23 (37.10%) had been diagnosed with Long Covid, and 14 (22.58%) had Long Covid symptoms but had not yet been diagnosed.
- Despite having the symptoms of Long Covid only just over 1 in 3 had a diagnosis.

2.4 Tell us about any other health conditions you have other than the Long Covid type symptoms:

There were 35 respondents who also reported other health conditions, 27 reported none. This suggests that Long Covid can affect people irrespective of their current health status.



Total=35 respondents of which 31 are shown in this graph, 4 others are included in the table below.

The graph shows eight respondents with high blood pressure or pre-existing respiratory problems, six reported digestive issues, five were diabetic and four had arthritis.

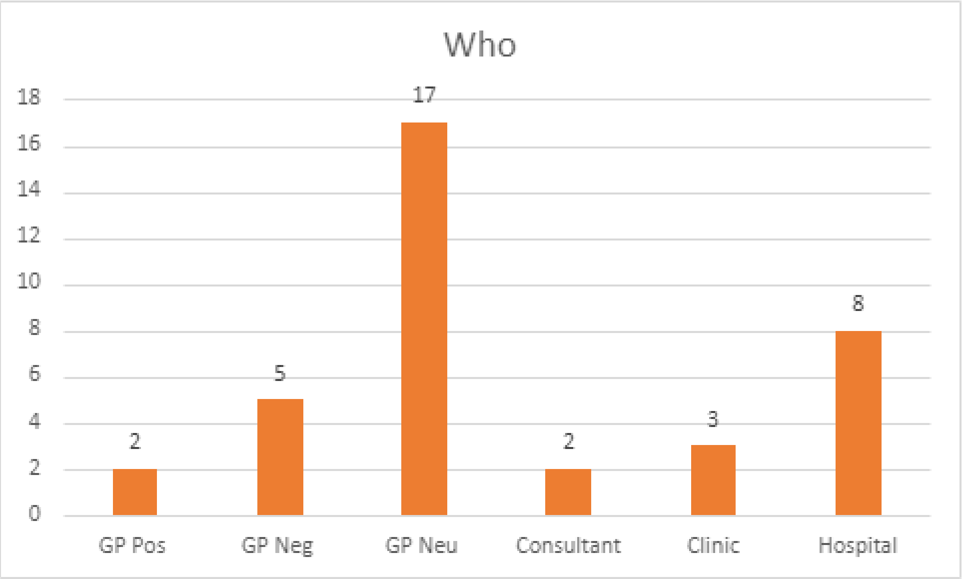
There were 36 other pre-existing health conditions reported.

Thyroid	4
Headaches, brain fog, tracheostomy	3
Stomach, joint, muscle	3
Anxiety and Depression	3

Physical disabilities	3
Menopause	2
Allergies	2
Fibromyalgia	2
Acid reflux	1
HIV	1
Obesity	1
Blood clot	1
Cancer	1
Glaucoma	1
Tiredness	1
Chronic pain	1
Hypermobility	1
Sinus tachycardia	1
Ehlers Danlos Syndrome	1
Immune system	1
Inpatient treatment	1
Polycystic ovaries	1

2.5 Please give us more details about getting or being unable to get your Long Covid type symptoms diagnosed? Please include who diagnosed you, when and where?

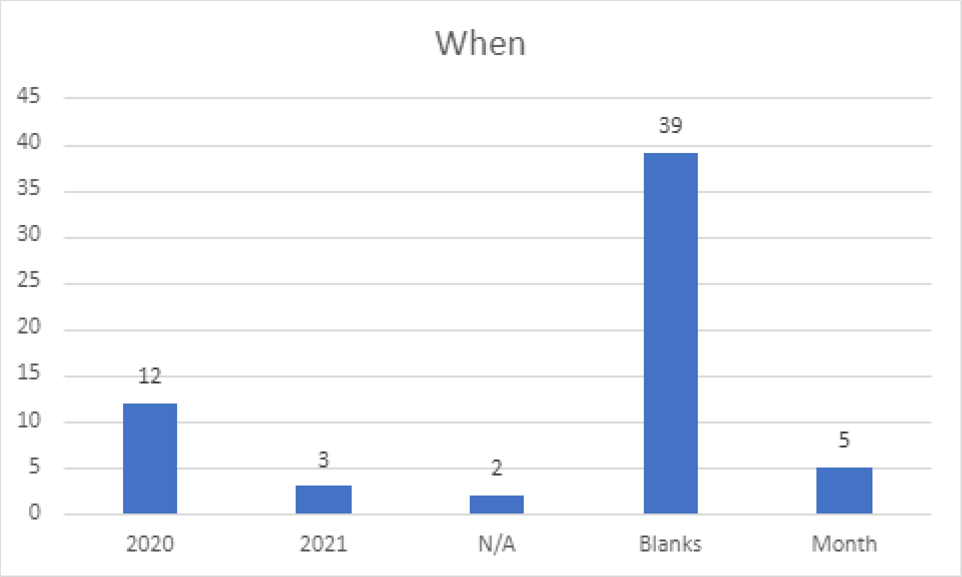
2.5a Who diagnosed you?



Total= 37

- Two respondents were diagnosed by a GP and had a positive experience.
- 17 sought diagnoses by a GP and reported a neutral experience, five had a negative experience with their GP.
- Eight were diagnosed by the hospital, three at a clinic and two by a consultant.
- GPs were clearly the place where those affected by Long Covid began, but they did not get a positive experience. Hospital, consultant, or clinic provided a better experience. It is likely GPs are not set up to be able to give a diagnosis but will refer therefore accounting for the negative or neutral experience felt by the patients here.

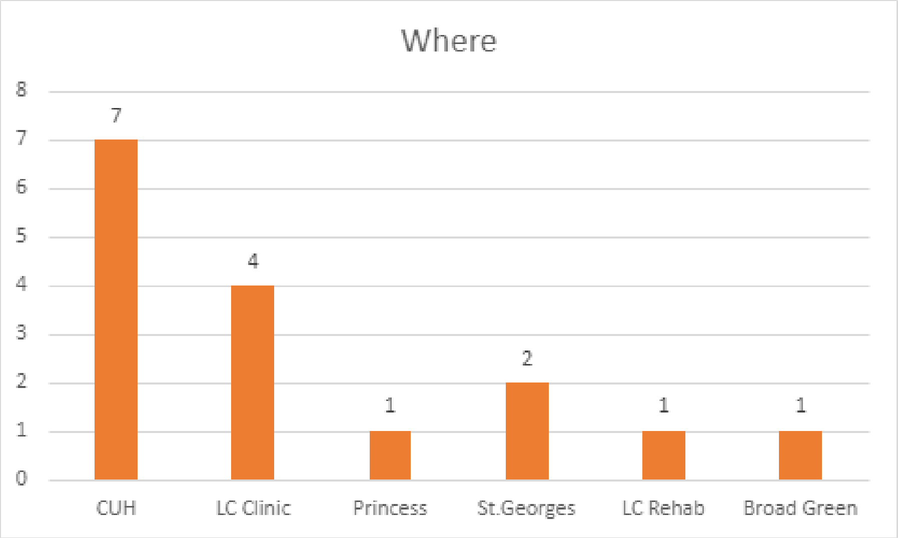
2.5b When were you diagnosed?



Total=51

39 respondents did not say when they were diagnosed, 12 were diagnosed in 2020, three in 2021, five did not state a year and two stated that the question was not applicable, they did not have a diagnosis.

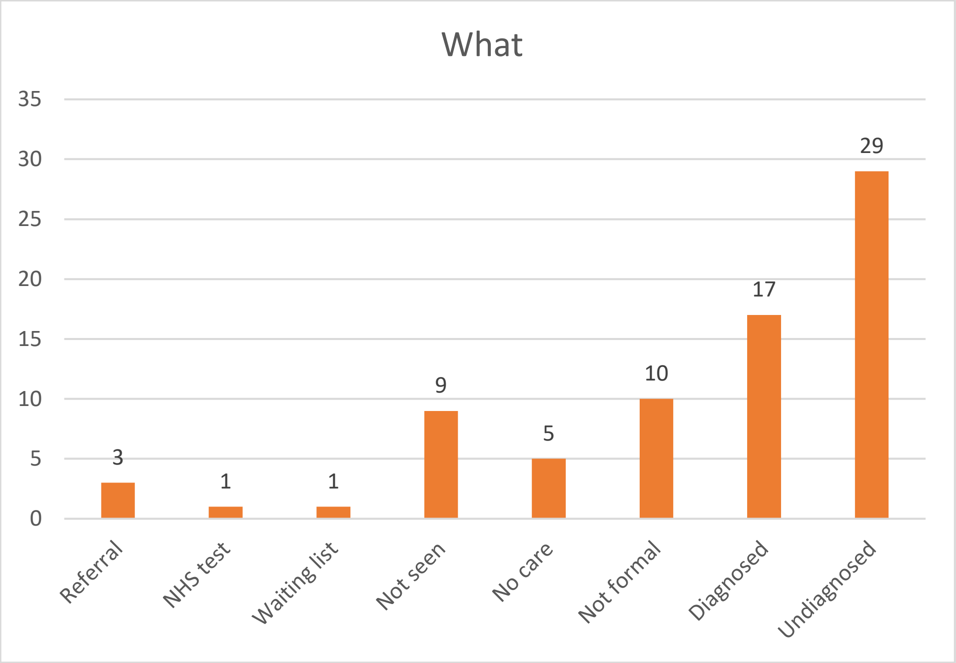
2.5c Where were you diagnosed?



Total= 16

Of those who stated where they were diagnosed: ten respondents stated that they were diagnosed at a hospital, seven at Croydon University Hospital, two at St. Georges and one at the Princess Royal. Six were diagnosed at a Long Covid Clinic or Rehab, and one respondent named the Broad Green Clinic.

2.5d What happened?



Total=75

- 29 respondents reported that they were not diagnosed, 17 reported a diagnosis, 10 reported an informal diagnosis.
- Nine respondents had not been seen yet and one mentioned a waiting list specifically.
- Five respondents reported that there was no care available.
- Three respondents had a referral, and a single respondent reported diagnosis by NHS test.

Comments from individuals on how they were unable to get their long Covid symptoms diagnosed.

Please note that comments are presented as we received them with typos and errors. They have not been edited.

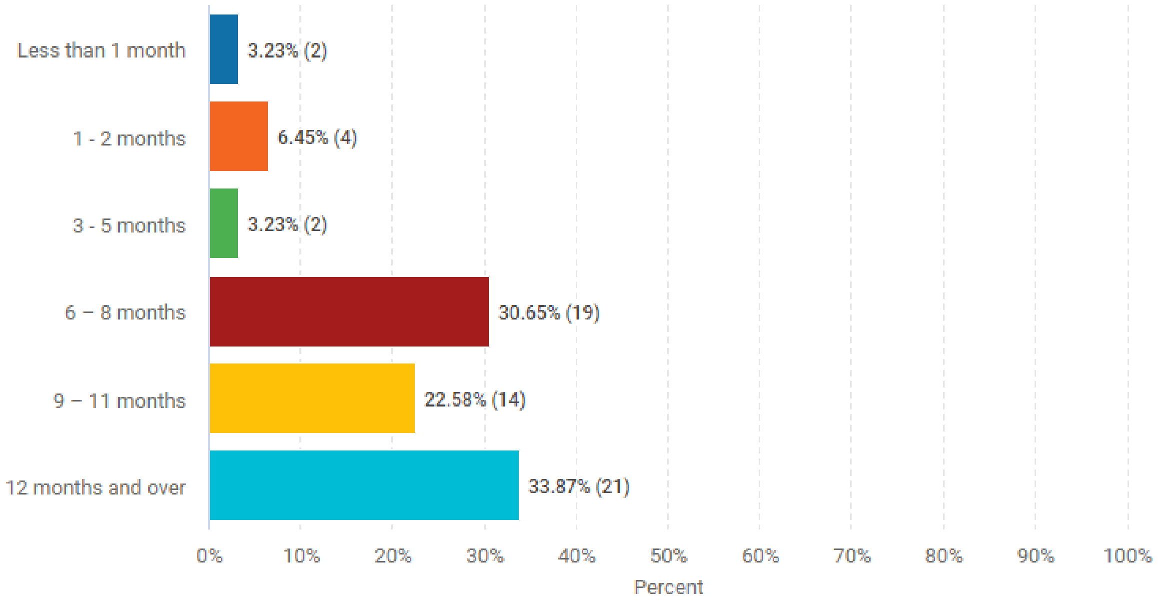
"No one has officially diagnosed that I have Long Covid. I have told my Consultant Rheumatologist that I have extreme fatigue Post Covid plus that my night sweats Post Covid have been controlled by Prednisolone which was prescribed for Arthritis. I have told my GP too".

"I have not been able to get it diagnosed because my GP seems totally uninterested"

"Have had several GP phones calls and some tests (chest X-ray, cat scan, ECG etc) GP says they don't know what to do for long Covid symptoms"

"I spoke to my GP describing my symptoms of fatigue plus muscle and joint ache and he quickly diagnosed long COVID".

2.6 For how long have you been experiencing/ did you experience Long Covid symptoms?

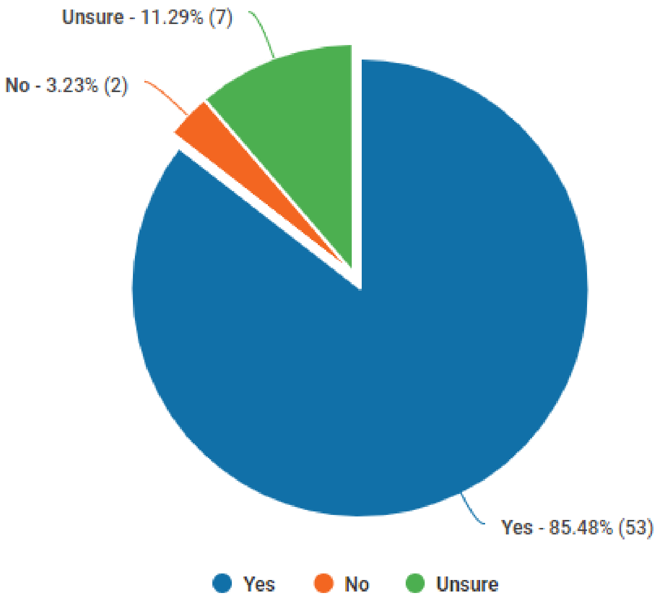


Total=62

- The graph shows 21 (33.87%) of respondents had Long Covid symptoms for 12 months or more, 19 (30.65%) had experienced symptoms for 6-8 months, 14 (22.58%) for 9-11 months, and 8 respondents experienced symptoms for 5 months or less (12.91%).

- It is interesting that most respondents have had Long Covid for more than 6 months with the largest group 12 months or more. Patients have waited to see if their symptoms have improved and for a majority, whether diagnosed or not, they have not.

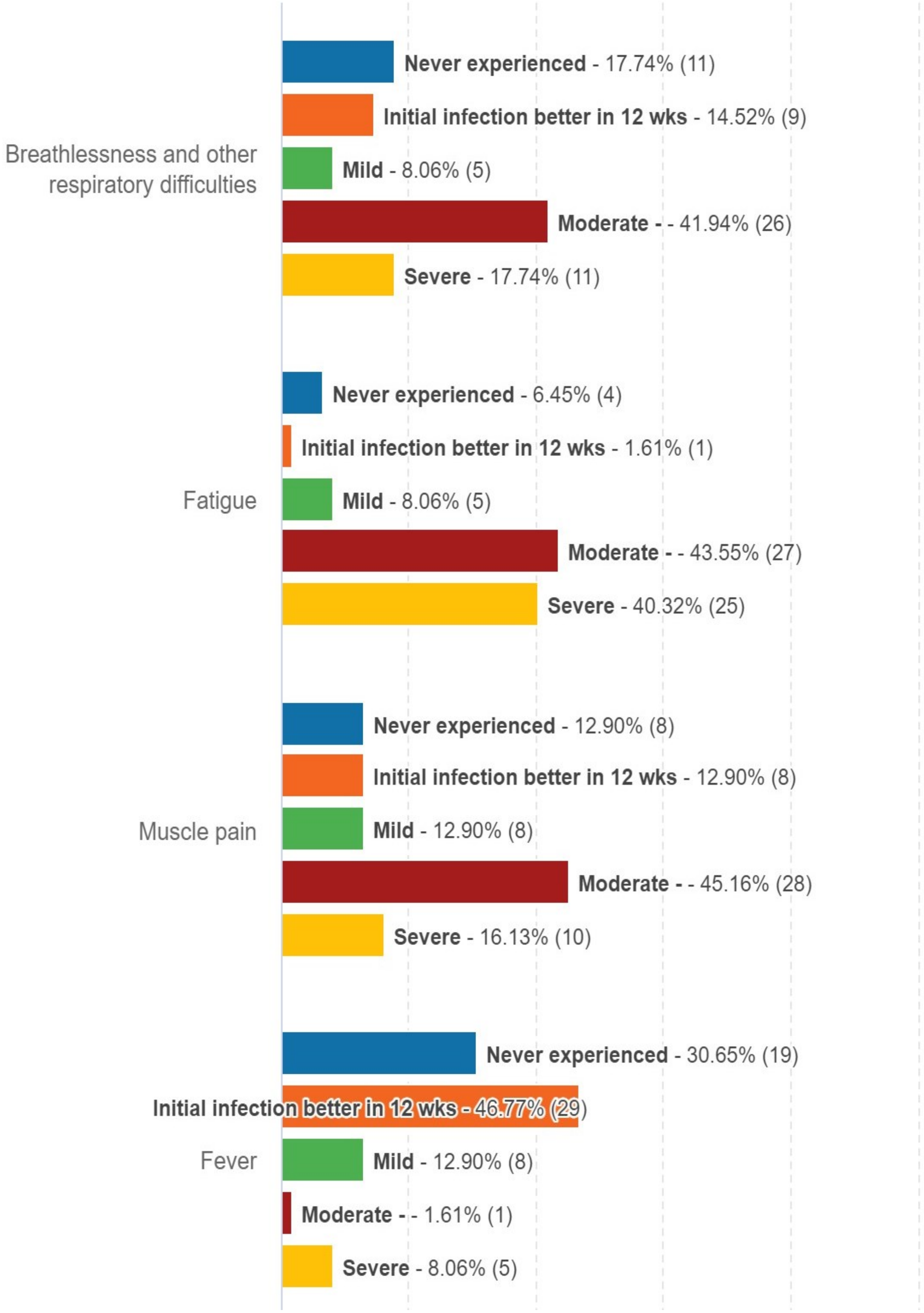
2.7 Are you still experiencing longer term symptoms?

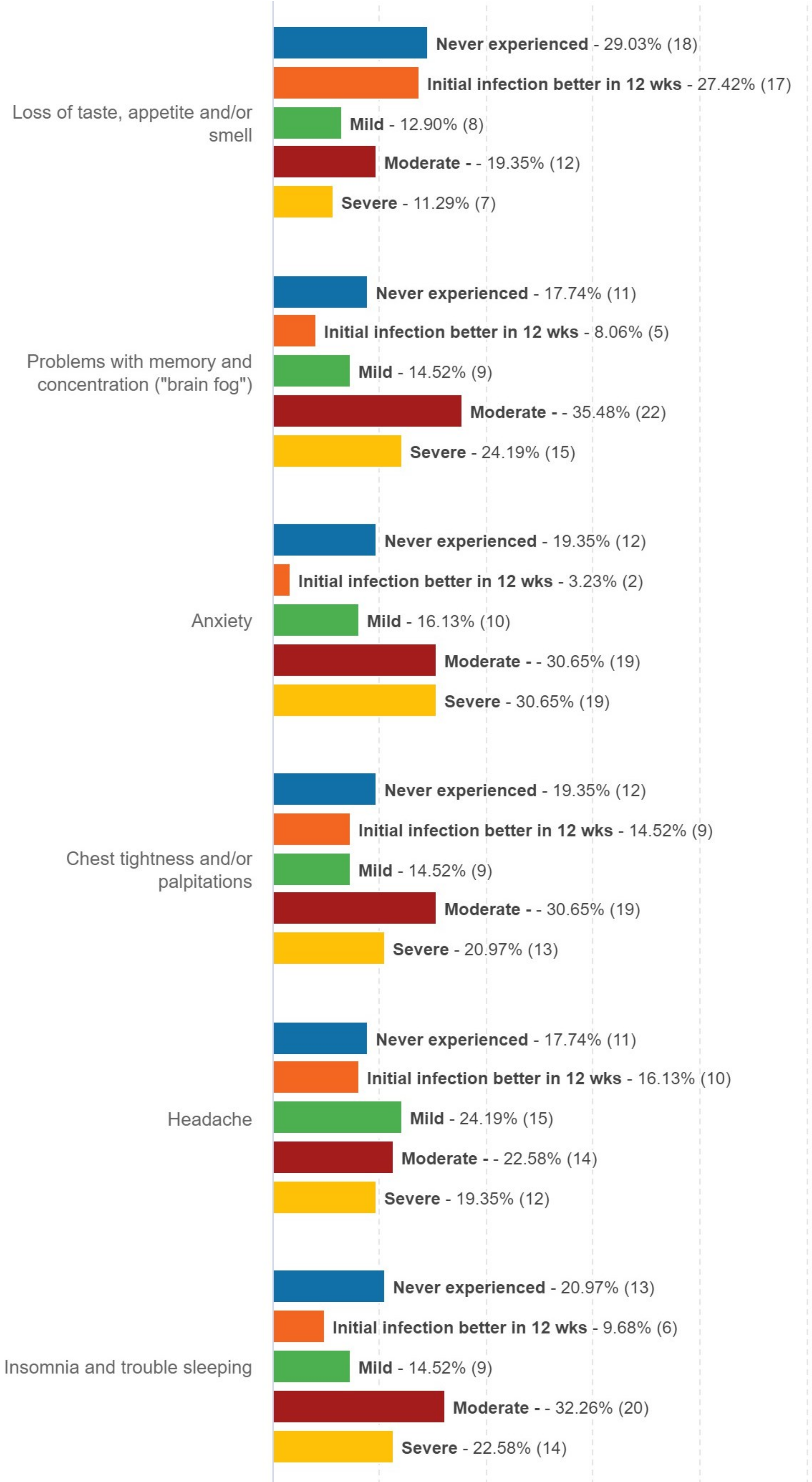


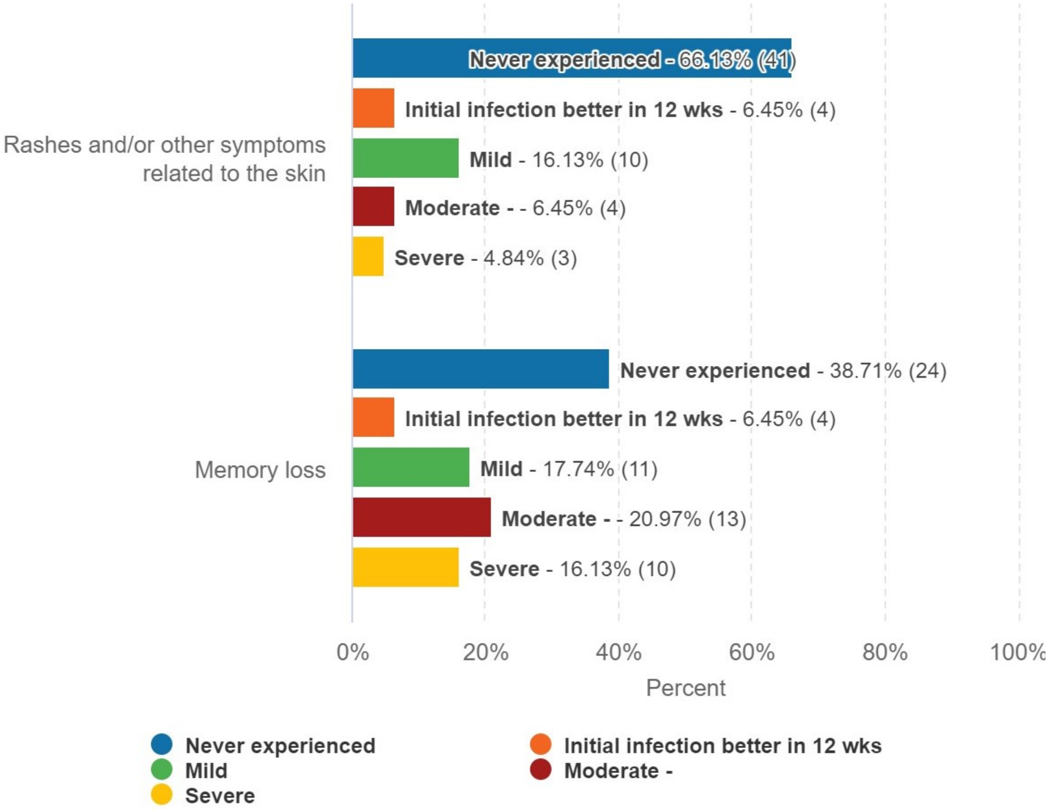
Total=62

- The chart shows that most respondents 53 (85.48%) were still experiencing Long Covid symptoms with only seven (11.29%) unsure, and two answering that they were not experiencing symptoms (3.23%).

2.8 What are the main symptoms that you experienced or are still experiencing?



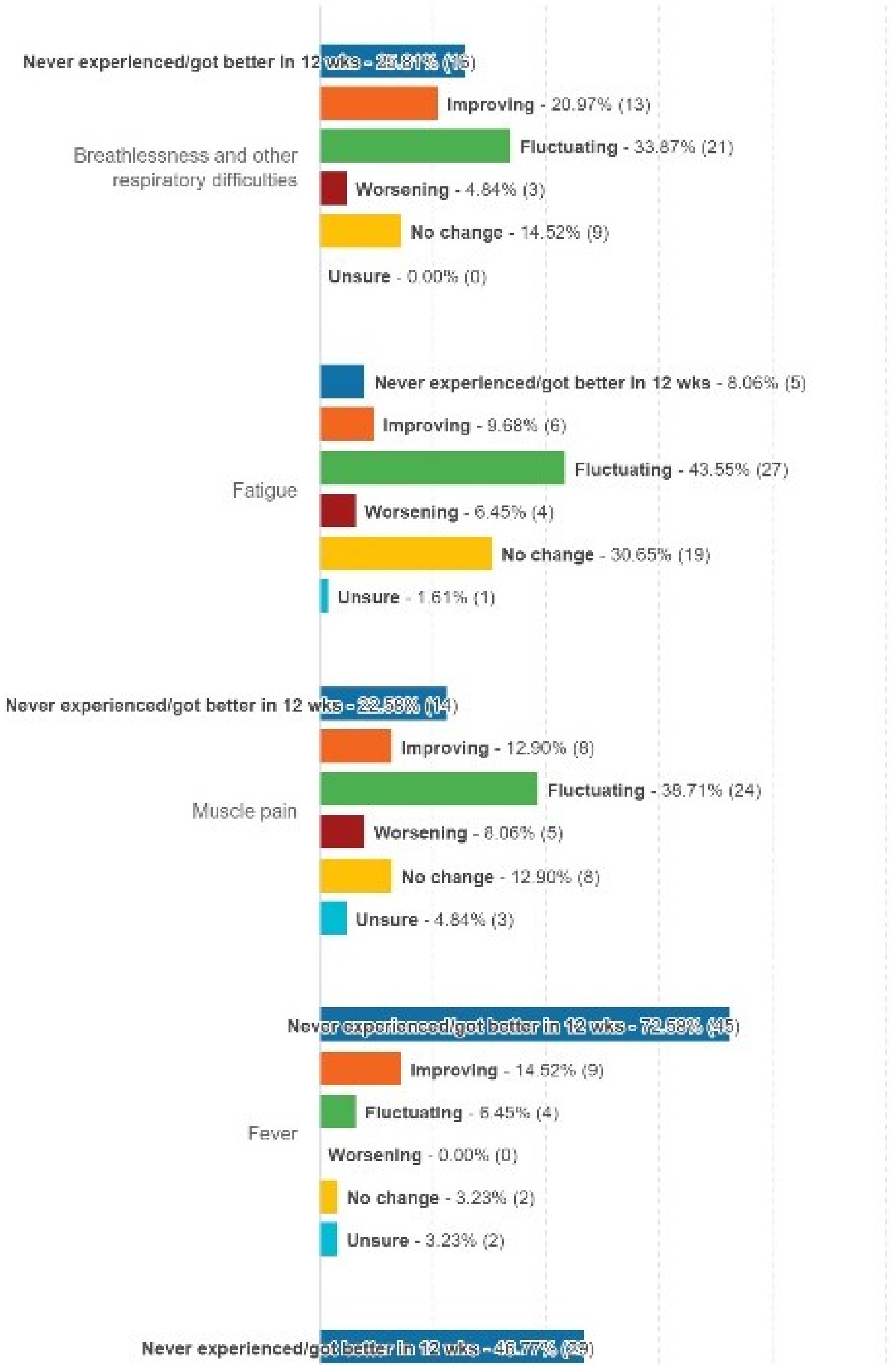

Loss of taste, appetite and/or smell
Never experienced - 29.03% (18)
Initial infection better in 12 wks - 27.42% (17)
Mild - 12.90% (8)
Moderate - - 19.35% (12)
Severe - 11.29% (7)
Problems with memory and concentration ("brain fog")
Never experienced - 17.74% (11)
Initial infection better in 12 wks - 8.06% (5)
Mild - 14.52% (9)
Moderate - - 35.48% (22)
Severe - 24.19% (15)
Anxiety
Never experienced - 19.35% (12)
Initial infection better in 12 wks - 3.23% (2)
Mild - 16.13% (10)
Moderate - - 30.65% (19)
Severe - 30.65% (19)
Chest tightness and/or palpitations
Never experienced - 19.35% (12)
Initial infection better in 12 wks - 14.52% (9)
Mild - 14.52% (9)
Moderate - - 30.65% (19)
Severe - 20.97% (13)
Headache
Never experienced - 17.74% (11)
Initial infection better in 12 wks - 16.13% (10)
Mild - 24.19% (15)
Moderate - - 22.58% (14)
Severe - 19.35% (12)
Insomnia and trouble sleeping
Never experienced - 20.97% (13)
Initial infection better in 12 wks - 9.68% (6)
Mild - 14.52% (9)
Moderate - - 32.26% (20)
Severe - 22.58% (14)

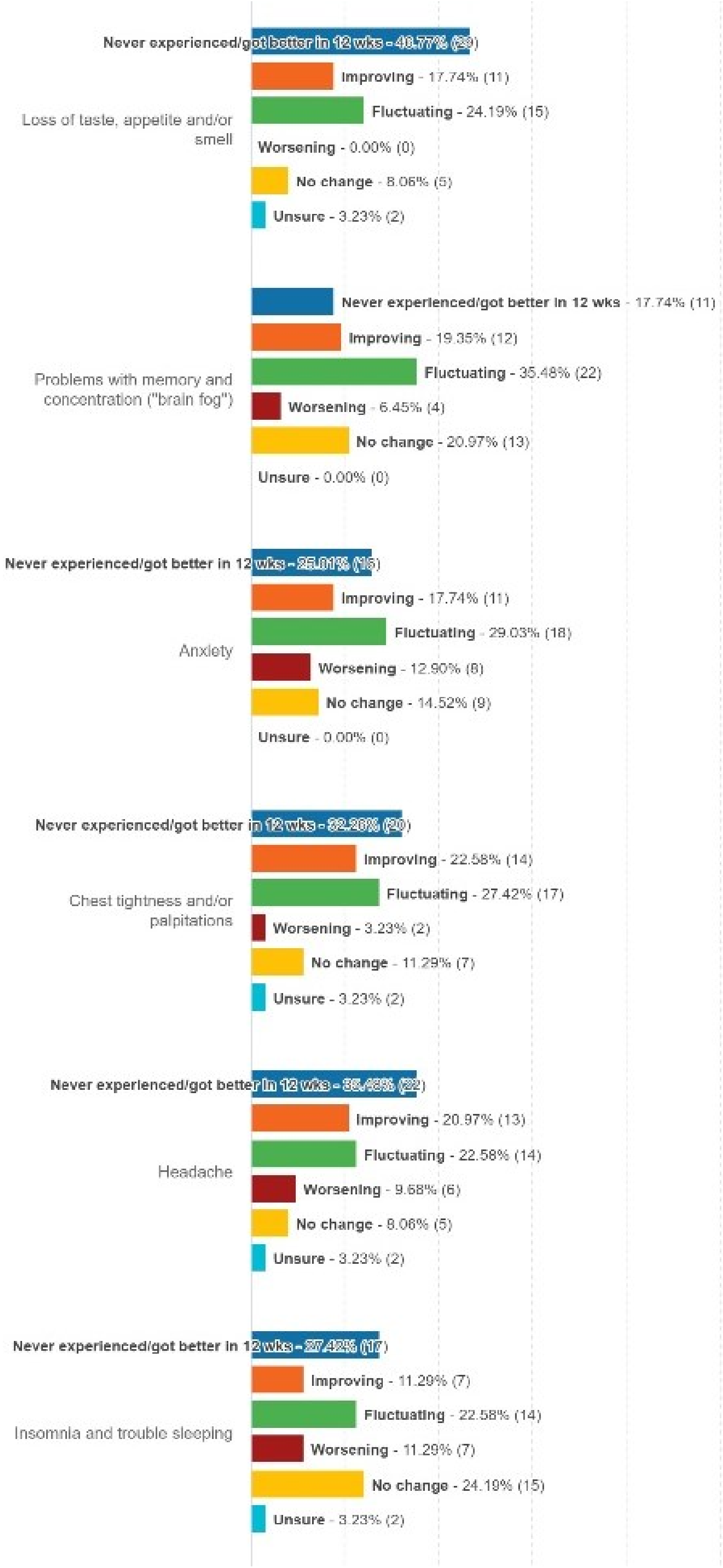


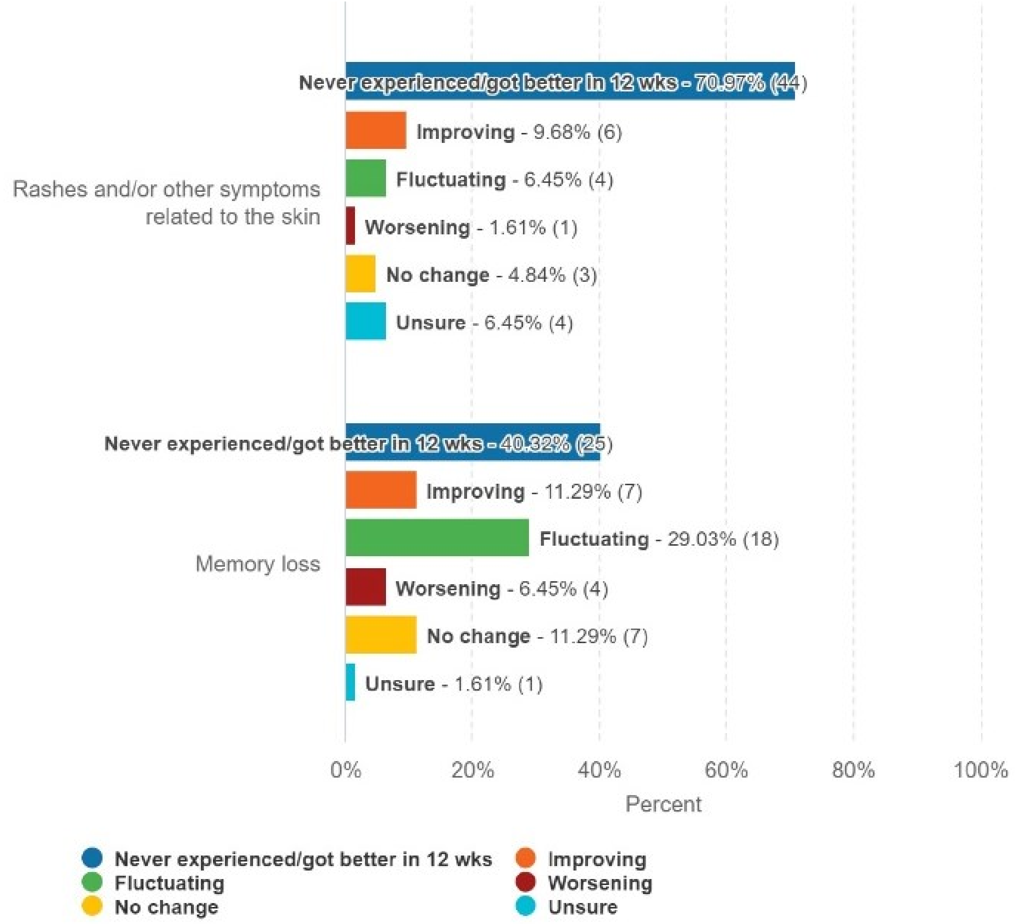
- Severe symptoms were defined as making it ‘difficult or impossible’ to do something: 25 (40.32%) experienced fatigue, 19 (30.65%) experienced anxiety, and 12 (19.35%) had severe headaches,

- Moderate symptoms, meaning respondents found it difficult or impossible to do some things, had the highest number of responses Muscle pain was the highest reported symptom with 28 (45.16%) of respondents experiencing this, second was fatigue with 27 (44.16%). 26 (41.94%) experienced breathlessness, 22 (35.48%) had problems with memory and concentration, 20 (32.26%) experienced insomnia and trouble sleeping, 19 (30.65%) reported anxiety and chest tightness/palpitations, 14 (22.58%) had headaches and 13 (20.97%) experienced moderate memory loss.

2.9 How have your symptoms changed since you started experiencing them?



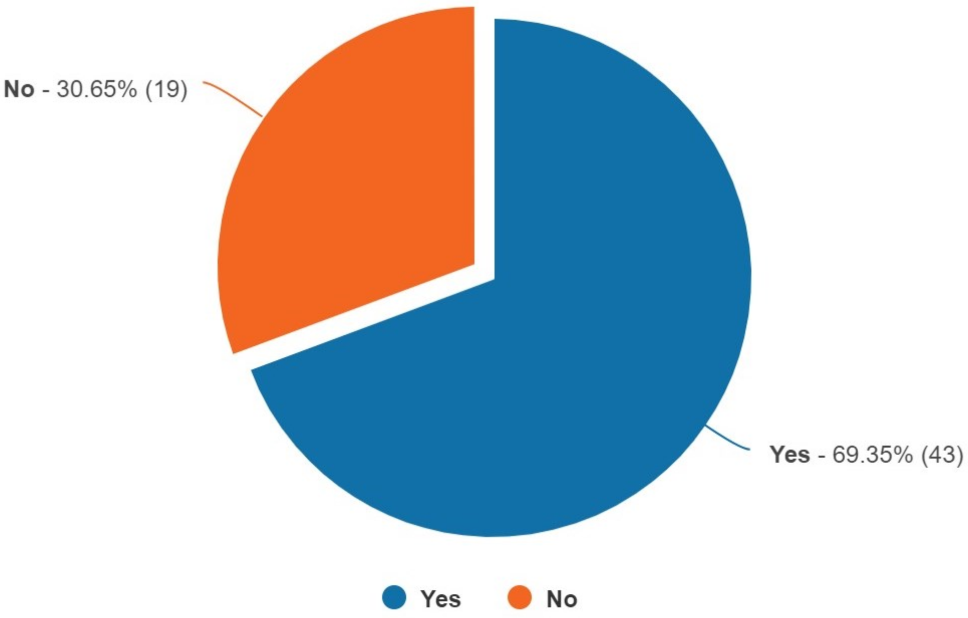

Never experienced/got better in 12 wks - 46.77% (29)
Improving - 17.74% (11)
Loss of taste, appetite and/or smell
Fluctuating - 24.19% (15)
Worsening - 0.00% (0)
No change - 8.06% (5)
Unsure - 3.23% (2)
Never experienced/got better in 12 wks - 17.74% (11)
Improving - 19.35% (12)
Problems with memory and concentration ("brain fog")
Fluctuating - 35.48% (22)
Worsening - 6.45% (4)
No change - 20.97% (13)
Unsure - 0.00% (0)
Never experienced/got better in 12 wks - 25.81% (16)
Improving - 17.74% (11)
Fluctuating - 29.03% (18)
Anxiety
Worsening - 12.90% (8)
No change - 14.52% (9)
Unsure - 0.00% (0)
Never experienced/got better in 12 wks - 32.26% (20)
Improving - 22.58% (14)
Chest tightness and/or palpitations
Fluctuating - 27.42% (17)
Worsening - 3.23% (2)
No change - 11.29% (7)
Unsure - 3.23% (2)
Never experienced/got better in 12 wks - 35.48% (22)
Improving - 20.97% (13)
Fluctuating - 22.58% (14)
Headache
Worsening - 9.68% (6)
No change - 8.06% (5)
Unsure - 3.23% (2)
Never experienced/got better in 12 wks - 27.42% (17)
Improving - 11.29% (7)
Insomnia and trouble sleeping
Fluctuating - 22.58% (14)
Worsening - 11.29% (7)
No change - 24.19% (15)
Unsure - 3.23% (2)



- **Worsening conditions:** This is where symptoms got worse as time went on. Eight (12.90%) experienced anxiety, seven (11.29%) had insomnia and trouble sleeping, six (9.68%) experienced headaches, five had muscle pain (8.06%) Four (6.45%) experienced memory loss, worsening problems with memory/brain fog and worsening fatigue.

- **Fluctuating symptoms**: This is where symptoms increased and decreased irregularly, were the highest reported with 27 (43.55%) experiencing fatigue, 24 (38.71%) receiving muscle pain, 22 (35.48%) having with problems of memory/brain fog, 18 (29.03%) with memory loss and anxiety, 17 (27.42%) experienced chest tightness/palpitations, and 14 (22.58%) had headache and fluctuating insomnia/trouble sleeping.

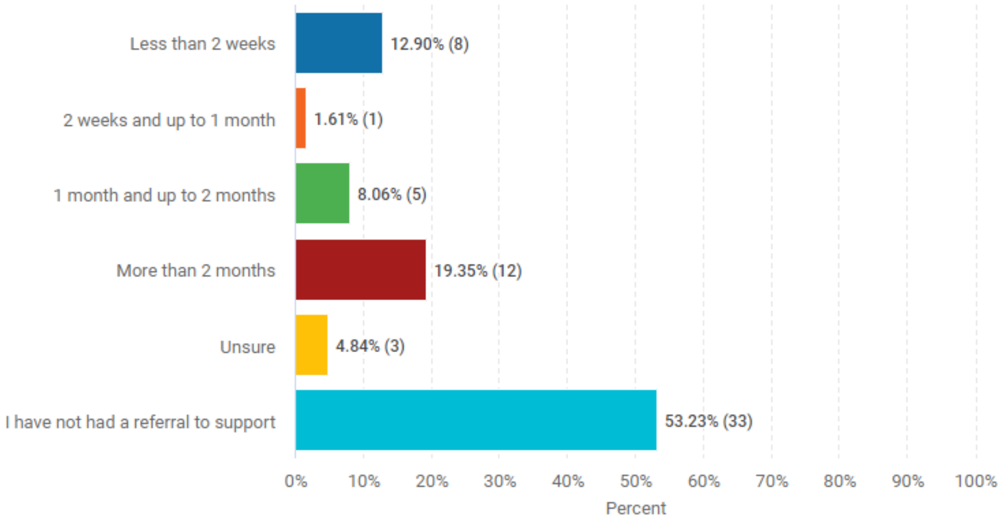
2.10 Have you been in touch with your GP or with a hospital about your symptoms and support needed?



Total=62

- The chart shows 43 respondents (69.35%) had been in touch with services, 19 (30.65%) had not.

2.11 How long have you had to wait before receiving support, after your first referral to support?

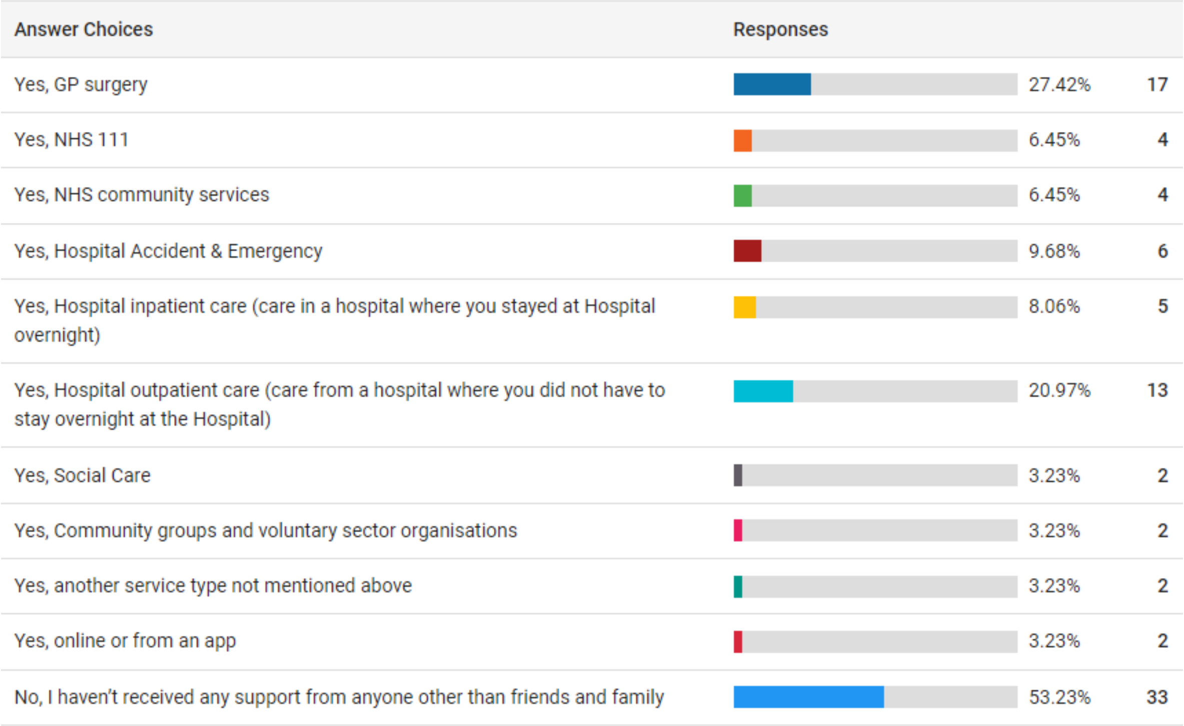


Total=62

- The graph shows that 33 (53.23%) respondents have not had a referral to support, 12 (19.35%) had to wait more than two months, 8 (12.90%) waited less than two weeks, 5 (8.06%) waited between one and two months.

- Three respondents were unsure how long they had waited (4.84%) and one waited between two weeks and a month.

2.12 Have you received any other help and how has it made a difference to your health?

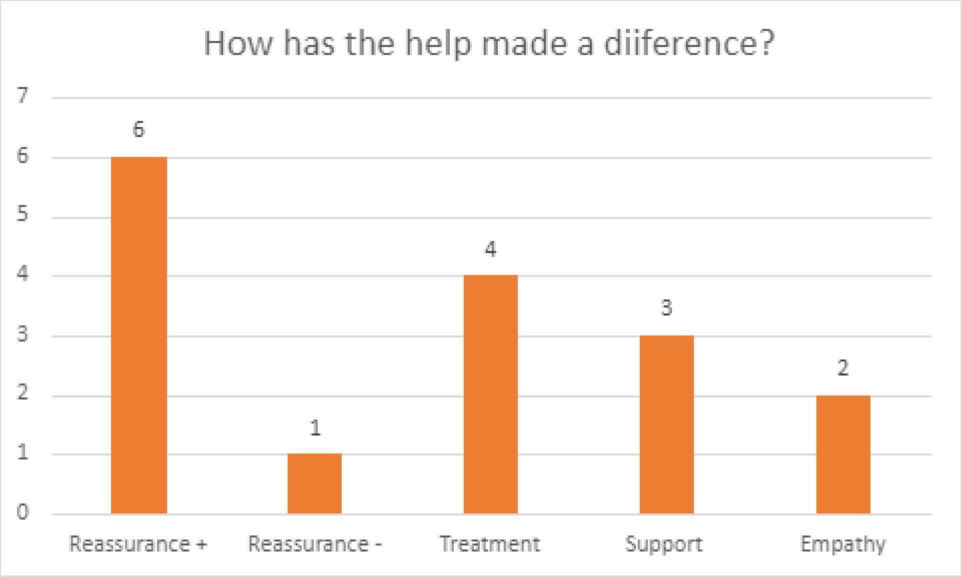


Answer Choices	Responses		
Yes, GP surgery	27.42%	17
Yes, NHS 111	6.45%	4
Yes, NHS community services	6.45%	4
Yes, Hospital Accident & Emergency	9.68%	6
Yes, Hospital inpatient care (care in a hospital where you stayed at Hospital overnight)	8.06%	5
Yes, Hospital outpatient care (care from a hospital where you did not have to stay overnight at the Hospital)	20.97%	13
Yes, Social Care	3.23%	2
Yes, Community groups and voluntary sector organisations	3.23%	2
Yes, another service type not mentioned above	3.23%	2
Yes, online or from an app	3.23%	2
No, I haven't received any support from anyone other than friends and family	53.23%	33

Total= 90 comments from 62 respondents

- The graph shows that 33 respondents (53.32%) had not received any help except from friends and family.
- The GP scored most highly from services with 17 (27.42%) reporting that they received help from their doctor.
- Outpatient care at a hospital was reported by 13 (20.97%), six respondents (9.68%) had care at A&E, and five received inpatient hospital care (8.06%).
- Four respondents (6.45%) had care at NHS community services or via NHS 111.

Has it made a difference?



Total= 16

- We asked how the help respondents received had made a difference to their health, six felt positively reassured while one felt they did not get reassurance. Four cited treatments, three said support and two said empathy.

Comments from individuals who found help from organisations and how this made a difference.

"Reassurance and advice on managing the condition."

"Strategies to support with fatigue."

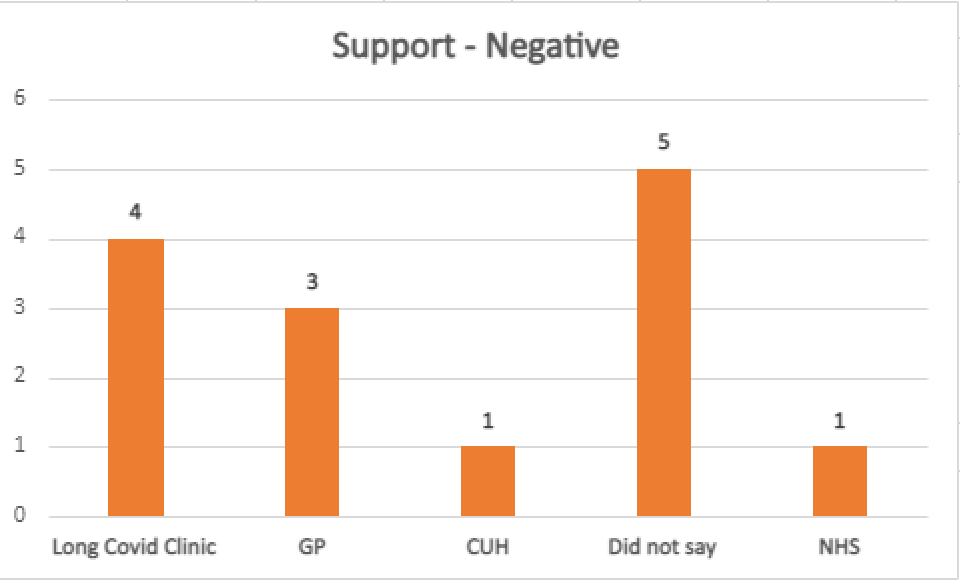
"Excellent support, advice, medical intervention, testing and medication regime as well as monitoring and real understanding, empathy, kindness and care."

"No change, nothings been found to help."

"No real support."

2.13 Do you have anything more to tell us about the support you have accessed?

We asked respondents to tell us more about the support that they accessed and coded services by sentiment as shown in the below graph.



Total=14

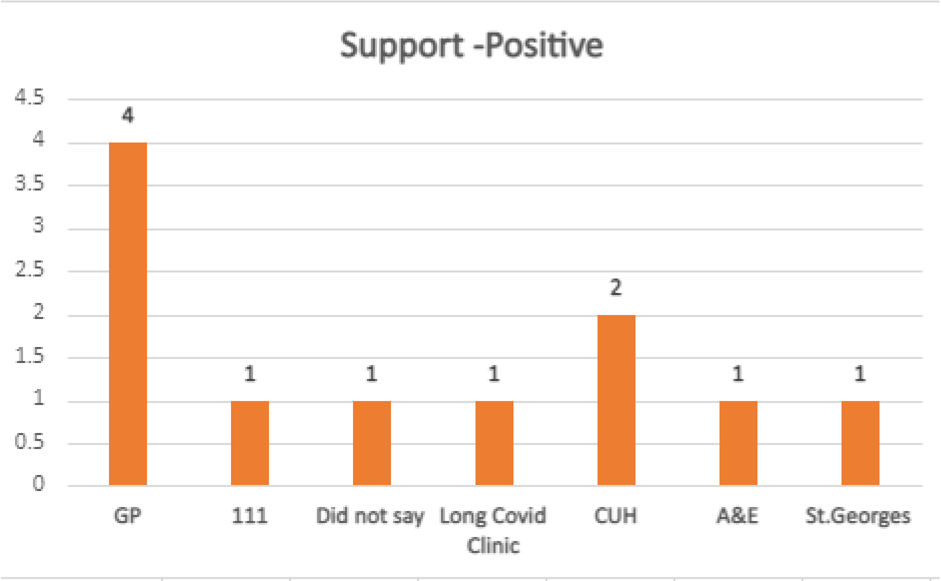
Five respondents had negative experiences of support but did not name the service, four had negative experience of the Long Covid Clinic, three had negative support from their GP, one had a negative experience of Croydon University Hospital and one stated NHS as being a negative experience.

A selection of comments from individuals who received negative support when they accessed services.

"Under long Covid clinic but seems disorganised and not much support or advice".

"My GP says that they don't know how to treat long Covid as it's so new. I feel that I'm on my own with it".

"There wasn't any if you fell through the net. Because I was an early case I feel nobody believed I could have had Covid despite having the worst dry cough for several weeks. It's only now that confirmed cases are experiencing all the same things I've had that I realise I did have Covid and long Covid".



Total=11

- Four respondents had positive support from their GP, four respondents had positive support from hospitals, two at Croydon University Hospital, one at St. Georges Hospital and one named the A&E department.
- One respondent named the Long Covid Clinic as a place where they received positive support and one named 111.
- One respondent had a positive experience but did not tell us where.

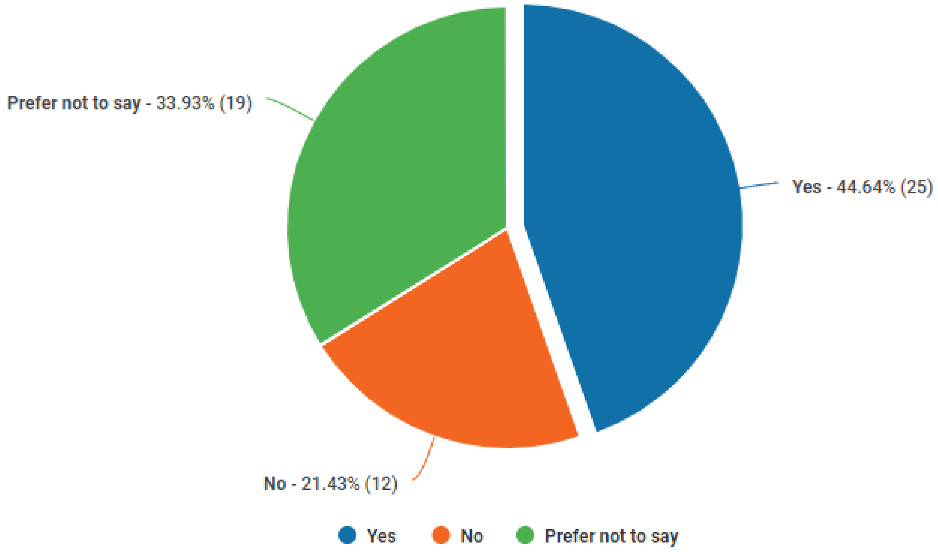
Selection of comments from individuals who received positive support when they accessed services.

"I know that I have been fortunate with the care that I have received but I cannot praise the staff who have helped me more highly".

"I think the long Covid rehab team at CUH have been amazing and I owe thanks to the. For how far my recovery has come."

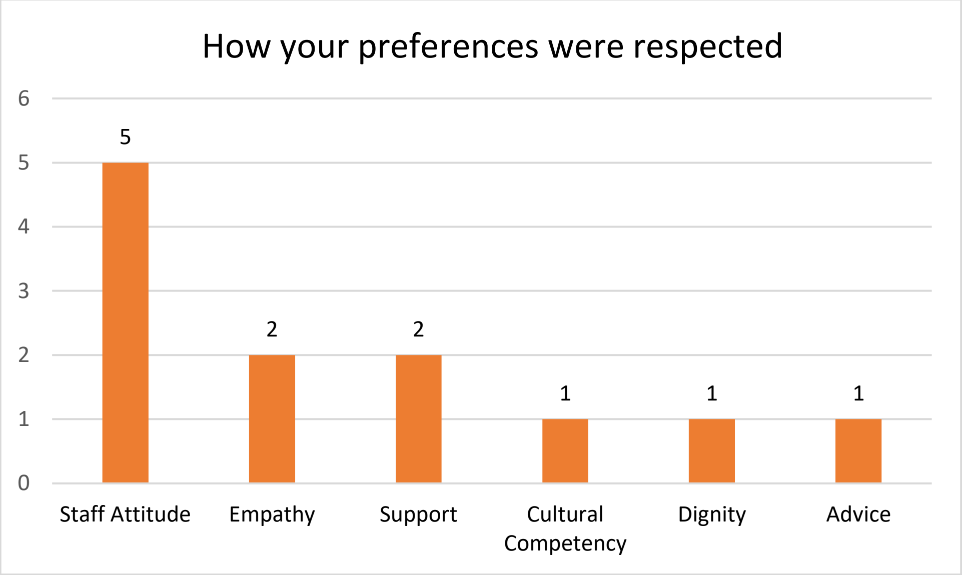
"My GP surgery was fantastic especially doctor (GP named) . She understood what I was going through."

2.14 Do you feel your personal preferences were respected (such as your lifestyle, culture, and beliefs)?



Total=56

We received 56 responses to this question, 25 (21.64%) said yes, they did feel their personal preferences were respected, 12 (21.43%) did not, and 19 (33.93%) preferred not to say. Six people skipped the question.



Total=12

- We asked respondents to tell us more about how their beliefs, lifestyle and culture were respected, five respondents cited staff attitudes, two felt empathy and two felt supported, one felt staff were culturally competent, one felt they were treated with dignity and one felt they were well advised.

- One respondent had a negative experience, staff attitude, feeling that they were not treated with dignity, and placed at risk.

Comments from individuals who shared their experiences of how their preferences were respected:

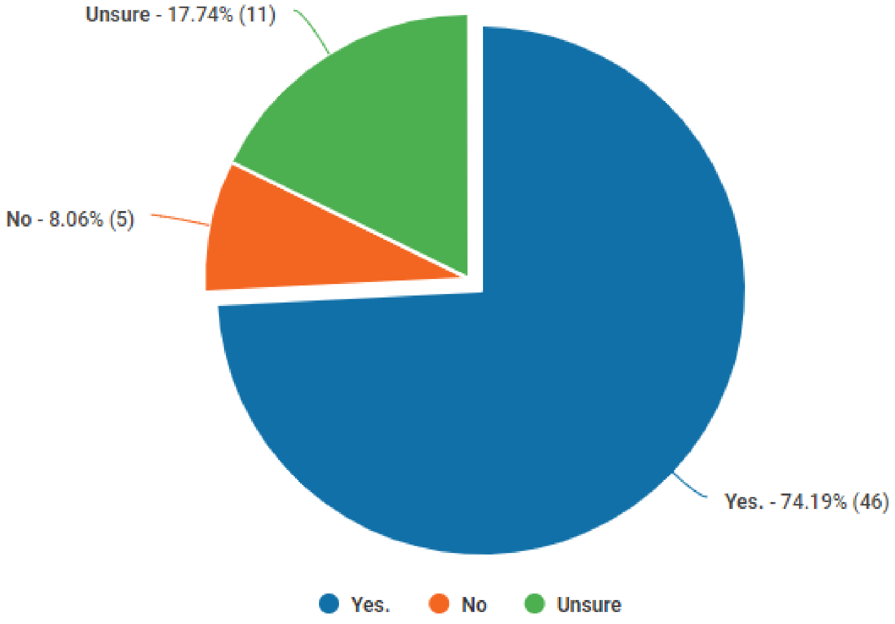
"I did not feel stigmatised because of my HIV status. I felt I received the best care possible under the circumstances and they listened to me."

"While I had Covid I refused to go to hospital, (111 wanted to send an ambulance), the doctor who spoke to me/my family understood the fears I expressed and while she strongly advised that I did go to hospital, she didn't make me feel judged of foolish. Culturally, hospital is a choice of last resort. She just made sure I understood why she was giving the advice she was and what the possible consequences and options were of my decision. I felt respected and heard and it made me feel more likely to call the service again for support. Thornton Heath HC on Gillet Road have also been amazing. Reassuring me when needed and reassuring my family/children when I was unable to speak for myself due to breathlessness and coughing. Cannot fault the response I received and am in awe that despite the pressure health care professionals were clearly under, I never felt rushed or less than."

"Respected at all times."

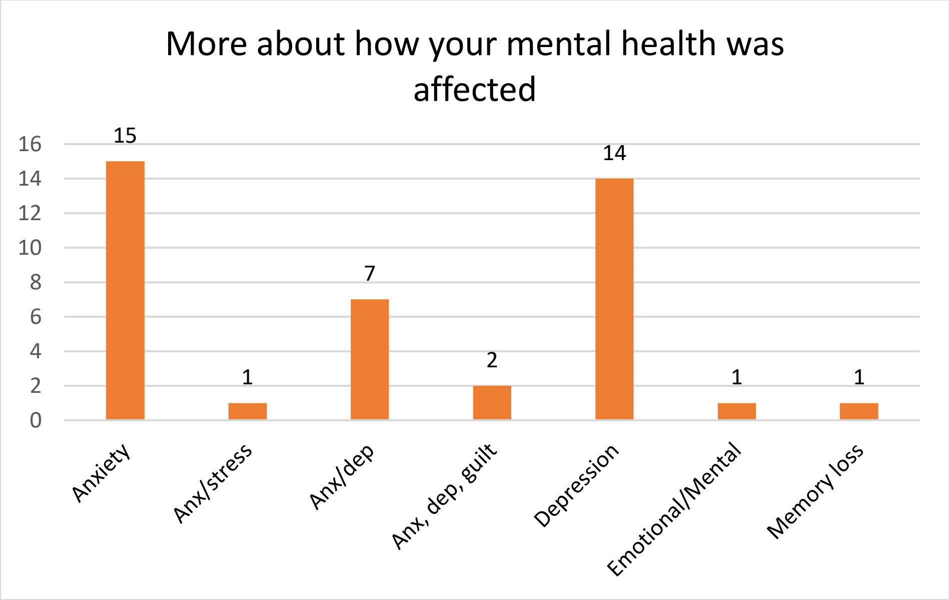
"St George's Fantastic, Croydon to be there a week telling them about head and breathing was told should done CT scan I had multiple pulmonary embolisms was told nothing I said they let me suffer like a dying animal."

2.15 Has living with Long Covid negatively impacted your emotional wellbeing or mental health? If Yes, Please tell us more about how it has affected your mental health:



Total=62

- 46 respondents (74.19%) said living with Long Covid negatively impacted their emotional wellbeing or mental health. Five (8.06%) said no, their emotional wellbeing was not affected and 11 (17.74%) were unsure.



Total=41

- We asked respondents to tell us more about how living with Long Covid has negatively impacted their emotional wellbeing or mental health.
- 15 participants reported anxiety, and 14 reported depression, seven reported both anxiety and depression.
- Two experienced anxiety, depression, and guilt, one reported anxiety and stress.
- One respondent reported memory loss and one reported emotional and mental effects.

Comments from individuals who shared their experiences of how mental health affected them:

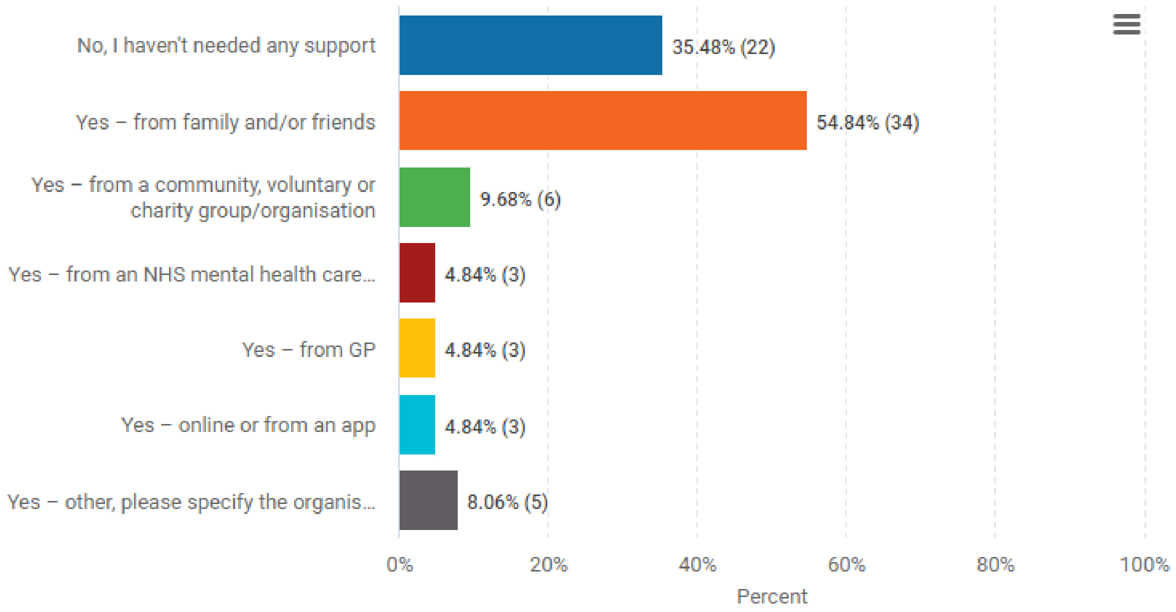
"It has ruined my life. I have been unable to work or socialise or take my usual physical activity. This has been very difficult to deal with both emotionally and mentally. But I'm still here and still fighting".

"I feel very worried all the time. I feel scared especially because of brain fog, memory loss that it might never get better."

"Anxiety. Failure to function due to sleep deprivation. Aggressive mood swings. No sense of enjoyment/is this as good as it gets. Am I going to die".

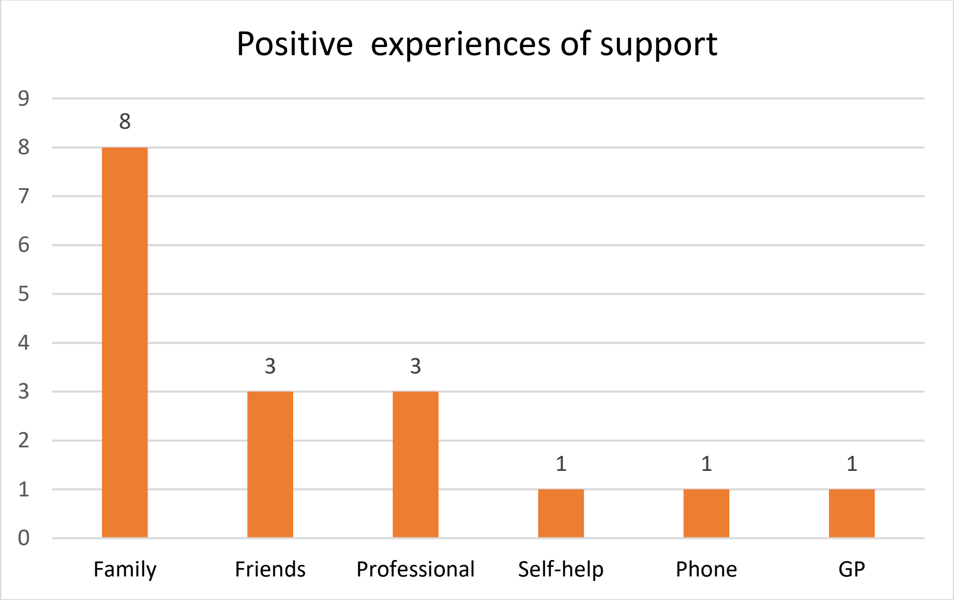
"I am trying to recover, but not been a work and financial support has not been there - so with long Covid and stresses with financial support and also it's worrying for my family."

2.16 Have you received any support for your emotional wellbeing or mental health and from where? If yes, tell us more about your experience of getting support with your emotional wellbeing or mental health



Total=70

- 34 (54.84%) of respondents received support from family or friends. 22 (35.84%) did not need any support.
- Six (9.68%) got support from a community, voluntary or charity organisation.
- Five got support from another unspecified service (8.06%)
- Three (4.84%) got support from NHS mental health care providers, GP, or online app.



Total=17

- Eight respondents cited family as being their strongest sources of support, friends and professionals were mentioned three times each, one respondent used self-help, one relied on their telephone, and another cited their GP as a positive support.

Comments from individuals who experienced positive support for their emotional wellbeing:

"Weekly zoom group session with psychologist with the long Covid rehab team."

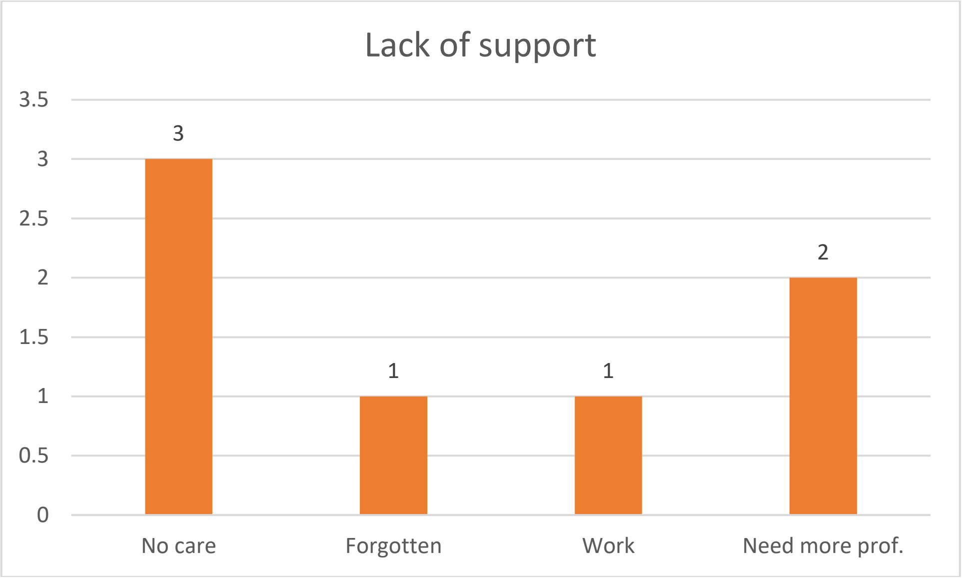
"My husband and family have been really supportive and allowed me to rest when I have needed it."

"I am lucky to have a close family and have had all the support I need."

"My family and my GP have been an amazing source of support."

"I reached out to cbt."

"YouTube has also helped."



Total= 7

- Three respondents felt that there was no care available, two had accessed some professional support but needed more than what was offered, one person felt they had been forgotten and another felt that their workplace was lacking in support.

Comments from individuals who felt there was a lack of support:

“Need more. 6 weeks not long enough.”

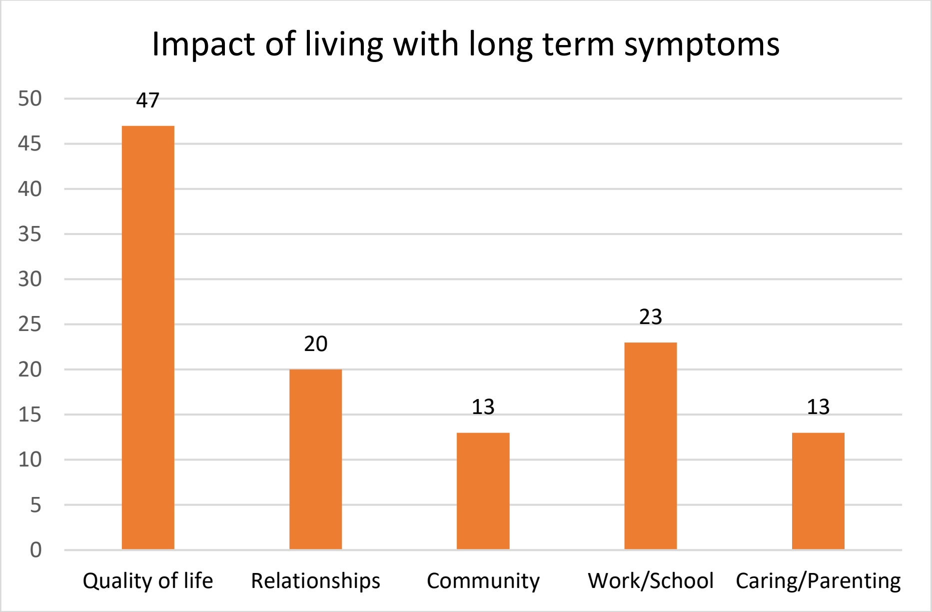
“Might attempt access further professional support and struggling to cope.”

“Non exists.”

“There is no help IAPT no help. Just get phone numbers or paid services for counselling. Also Samaritans number.”

“I had an extremely negative experience with a work doctor and another employee in my last employment, who both expected me to be fully recovered in two weeks, but that was in the minority, everyone else was very supportive.”

2.17 Has living with long term symptoms had an impact on the rest of your life or those around you?



Total=106 responses from 55 respondents

- 47 (75%) respondents felt that their quality of life was impacted, 23 (37%) respondents reported that their work/school life was affected, 20 (32%) respondents felt that their relationships were affected, 13 (20%) cited community roles and 13 (20%) said caring or parenting roles were impacted by living with long term symptoms.

- Most respondents who were negatively affected in one area were affected in other areas.

- Two respondents felt that their relationships were positively impacted which is not shown on the graph.

Comments from individuals who have been living with long term symptoms and as a result had an impact on their quality of life and those around them

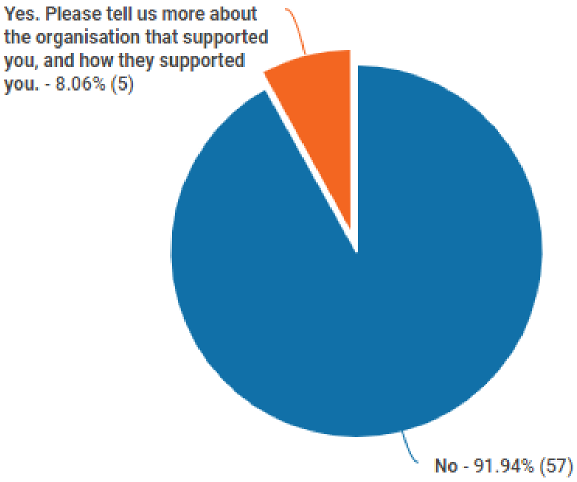
"I have no quality of life. The only people I see are my parents. I am unable to work. I live alone so no-one depends on me. I have not been able to support my parents during these difficult times."

"Yes I can no longer take my little one too school my 16yr old does it, she also helps round the house in fact she does most things as I can't even change the bed."

"I think COVID has affected everyone's life, my stress comes from being constantly in pain with my muscles /joints and my problem with my eye."

"Not been back to work since getting COVID. Debilitating. People not affected don't understand or get fed up with you keeping on about it. Unable to deal with important issues. No family life going through divorce now. No physical contact with people Isolated apart from medical appointments and shopping Little social life."

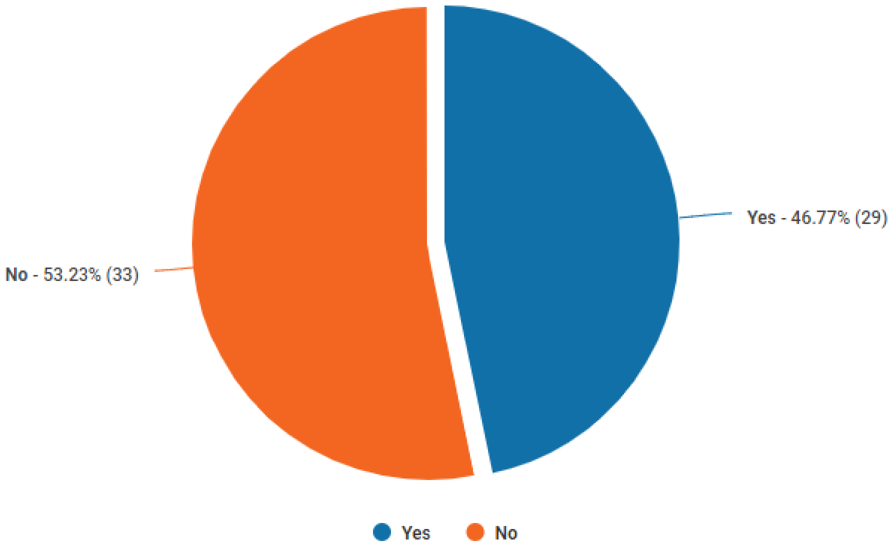
2.18 Have you received support to manage daily living or ongoing care needs?



Total=62

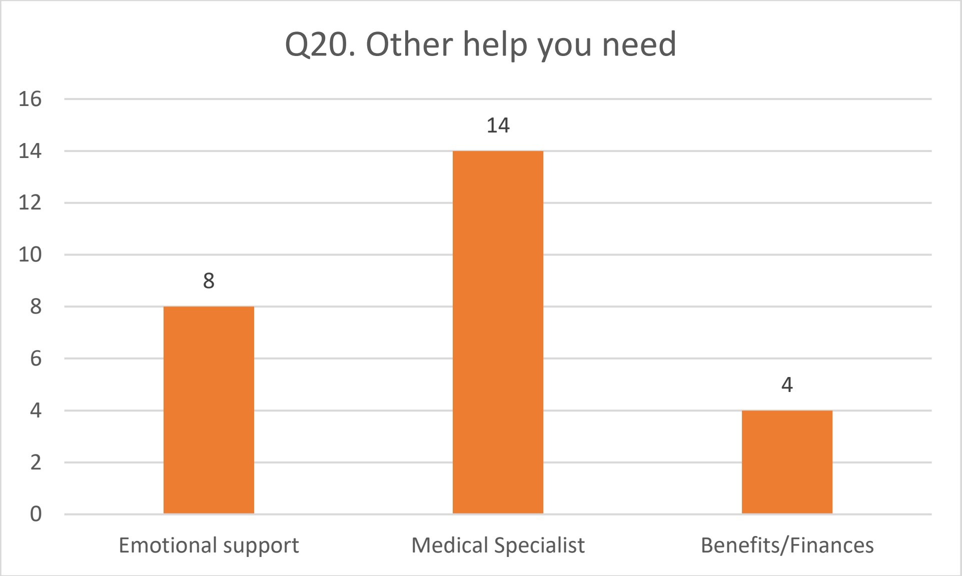
- Five respondents (8.6%) received support from services to manage their daily living, 57 (91.94%) said no, they did not.

2.19 Do you have someone (a friend, relative, neighbour, or other type of carer) who helps you with your daily living (not as part of their paid profession)?



- Total=62
- 29 respondents (46.77%) said yes that they did have a carer, and 33 (53.23%) said no. This suggests over half of those responding did not previously need care support.

2.20 Is there any other support or information for your Long Covid like symptoms that you're not currently getting that you think would help you?



Total=26

- 14 respondents felt they needed more specialist medical help.
- Eight respondents needed emotional support and four said they needed financial advice around benefits.

"I don't know there is anything that would help other than financial support as I have been living off my savings throughout."

"I would like to be part of a support group as sometimes it feels that I am all alone."

"I think the effects are long lasting and help from the council to access benefits such as mobility and disabled badges would be beneficial to most people with long Covid symptoms."

"I need help with the miuscle pain."

"PTSD ?"

"I would like advice on exercise (breathing & physical) and whether I should even be classed as disabled due to the length & severity of my symptoms."

2.21 Is there anything else you would like to share with us or that we should have asked you?

“I'm grateful for the opportunity to complete this survey. I hope it is useful in the fight against long Covid.”

“I really think there needs to be more clarity about how long symptoms have to continue for there to be a generally accepted point where you are seen by a medic for a diagnosis. GPs do not seem very knowledgeable.”

“NHS were amazing.”

“I don’t think it will make any difference in what I say.”
“What was lacking in the support or service available' should have been asked for lessons learned.”

“I hope that one day we may be free of this awful body destroying infection. And that the people who have not had Covid stay very safe whilst this is very much amongst us still.”

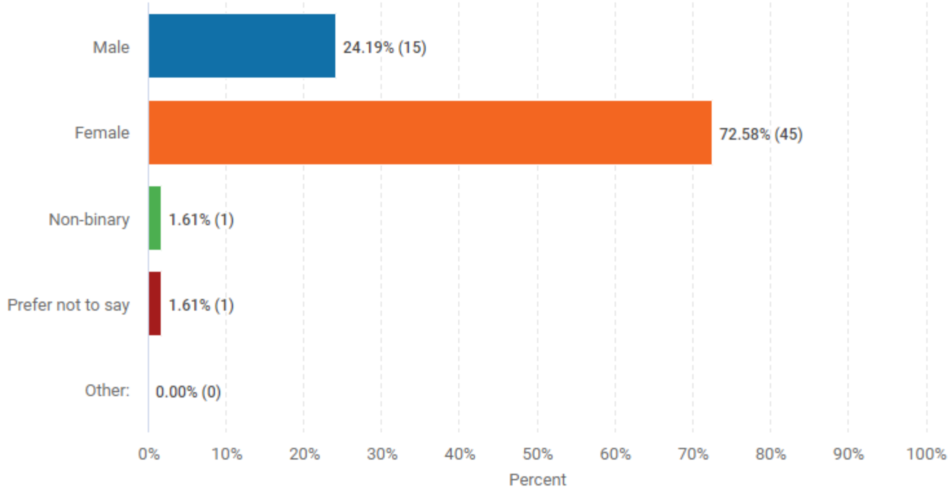
“Long Covid has wreaked havoc on my life and my husband who has suffered too for nearly 18 months now. We are fortunately beginning to come out of it now but we are changed and weaker for the experiences we have had.”

“This has been the worst year and a half in respect of health that we have had in our 33 marriage and without the support of our GP I am not sure how we would have managed.”

“Do you know where to get suitable, free help support and advice.
No pay what benefits can you get.”

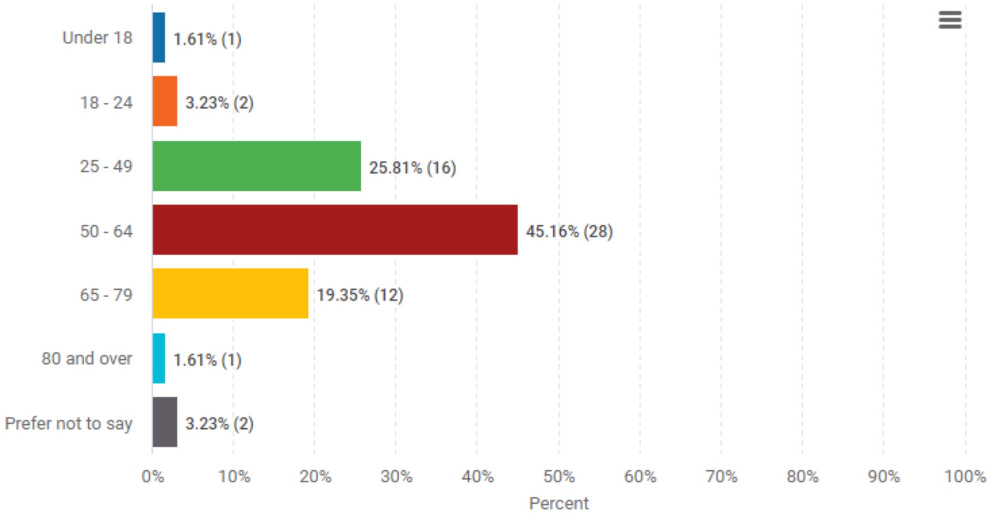
3 Key Demographics

Gender



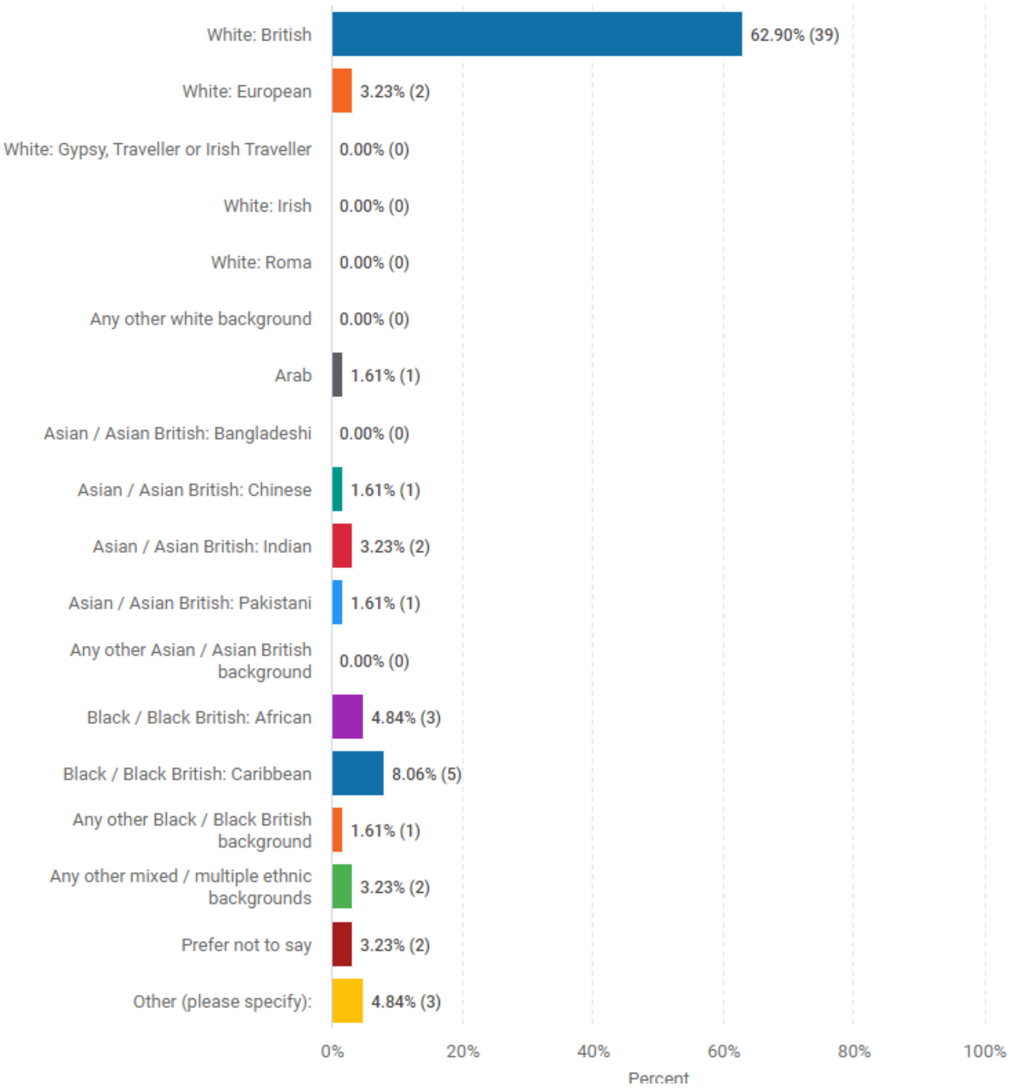
45 (72%) of our respondents were female, and 15 (24%) were male and 1 nonbinary.

Age



28 (45%) of our respondents were aged 50-64, 16 (26%) were aged 25-49, 12 (19%)were aged 65-79 at the time of completing the survey, two (3.23%) were aged 18-24, one was aged over 80, one was under 18 and two preferred not to say.

Ethnicity



Our respondents were mostly White British (39), other respondents were Black Caribbean (5) Black African (3) White European (2) Asian Indian (2) Any mixed background (2) Arab (1) Asian Pakistani (1) Asian Chinese (1) and Any other Black background (1). Two preferred not to say and three specified 'other'. Compared with Croydon's demographics this over represents White British and underrepresents other ethnicities – although this is not unusual for this type of online survey.[3]

---

[3] **Croydon Observatory (2022)** Population *Overview* - see https://www.croydonobservatory.org/population/#/view-report/87014b69cc914a438349d2e0affff35f/___iaFirstFeature

4 Responses to our research

Matthew Kershaw, Trust Chief Executive and Place Based Leader for Health, said:

“Croydon was one of London’s hardest hit boroughs, with 100,000 people testing positive for COVID-19 since the start of the pandemic – broadly a quarter of the local population. Our aim is to get as many people back to full health as possible, but from what is now known about the virus, many may face a long road to recovery.

“With Croydon GPs alongside our expert hospital teams and neighbouring trusts, we are providing continuing treatment and support for post-COVID patients, including those who had prolonged stays in intensive care. We’re also reaching out to offer more care at home for patients that didn’t need treatment in hospital for the virus, but who are now struggling to manage COVID’s after effects, including chest pain, chronic fatigue and brain fog.

“This Healthwatch report is a helpful reminder for the prolonged impact COVID-19 can have. This is something we are acutely aware and one that we working on to wrap our care and support around people in our community.”

Rachel Flowers, Croydon’s Director of Public Health, said:

“Today’s report from Healthwatch Croydon provides useful insight into how we can provide the best care and support for those whose lives continue to be impacted by Covid. We want to commend the dedication of our local NHS staff, social care colleagues and many others who worked long and hard during the pandemic to protect people in Croydon from the virus and to stem the rise of infections.”

5 Quality assurance

Developing Research Questions

1. **Overall does the research ask the right questions?** Yes, Healthwatch Croydon reviewed other work to ask questions that would be relevant to planning and delivery of this service
2. **Has consideration been given to how the findings will be used?** This will be shared with local and national stakeholders such as commissioners and public health to influence future planning and service delivery
3. **Is the research design appropriate for the question being asked?** Yes, under the circumstances an online survey was consider the appropriate method
4. **Has any potential bias been addressed?** With online surveys, there is always the likelihood that some people from certain ages, genders and ethnic groups are more likely to complete this survey than others. Healthwatch Croydon promoted this as widely as possible and these limitations are presented in the report.
5. **Have ethical considerations been assessed and addressed appropriately?** There were no significant ethical considerations with this survey.
6. **Has risk been assessed where relevant and does it include?**
    a. **Risk to well-being** No significant risk
    b. **Reputational risk** Only in that we do not produce accurate results or do not deliver work in time to make a difference.
    c. **Legal risk:** No significant risk
7. **Have appropriate resources been accessed and used to conduct the research?** Yes, staff and volunteer time was used effectively. Some online advertising was used to increase numbers.

8. •**Where relevant have all contractual and funding arrangements been adhered to?** This was core work agreed by the Local Leadership Board, so no contract or funding was defined for this work.

Data Management

9. **Is the collection, analysis and management of data clearly articulated within the research design?** Yes,
10. **Has data retention and security been addressed appropriately?** Yes, all responses are on Smart Survey and data only download to staff computers
11. **Have the DPA/GDPR and FOIA been considered, and requirements met?** Yes.

Thinking about Research Subjects

12. **Have all relevant legal requirements been adhered to ensure that the well-being of participants has been accounted for? i.e., the Mental Capacity Act** Not relevant for this project
13. **Has appropriate care and consideration been given to the dignity, rights, and safety of participants?** All responses are received with anonymity.
14. **Were participants clearly informed of how their information would be used and assurances made regarding confidentiality/anonymity?** Yes, this was presented within the survey.

Collaborative Working

15. **Where work is being undertaken in collaboration with other organisations have protocols and policies been clearly understood and agreed, including the development of a clear contractual agreement prior to commencement?** We worked closely with the five other Healthwatch of South West London to understand more about the context of Long Covid ensure that the questions we asked were relevant to helping

further develop services. There was a set number of questions which we agreed to adopting but allowing for individual Healthwatch variability to reflect local needs. We adopted the full survey as we felt that we did not want to diverge too much from other surveys that began before we started ours.

16. **Have any potential issues or risks that could arise been mitigated?**

17.

Risk	Level	Management
Not enough respondents.	Medium	Continue promotion and time of the survey.
Information we receive not useful.	Low	Review the survey to ensure we get the information we need
Complexity and length of survey	Medium	If completed numbers are low keep running the survey until enough are reached.

18. **Has Healthwatch independence been maintained?** Yes, Healthwatch's independence has been always maintained and it was Healthwatch Croydon's decision on what questions were selected and how the project progressed.

Quality Assurance

19. **Has a quality assurance process been incorporated into the design?** Yes.

20. **Has quality assurance occurred prior to publication?** Yes.

21. **Has peer review been undertaken?** Not relevant for this work.

Conflicts of Interest

22. **Have any conflicts of interest been accounted for?** There are no conflicts of interest.

Intellectual Property and Publication

23. **Does the research consider intellectual property rights, authorship, and acknowledgements as per organisational requirements?** This is owned by Healthwatch Croydon who are managed by Help and Care
24. **Is the research accessible to the public?** Yes, this will be published on the Healthwatch Croydon website on 29.06.2022.
25. **Are the research findings clearly articulated and accurate?** To our best knowledge they are.

Evaluation and Impact

26. **Have recommendations been made for improving the service?** Yes.
27. **Has the service provider acted based upon the recommendations?** This insight along with similar data from other South West London Healthwatch is being used to plan future services
28. **Is there a plan in place to evaluate the changes made by the service provider?** We will challenge service providers locally and at place to ensure suitable services are provided.

6 References

Croydon Observatory (2022) Population *Overview* – see https://www.croydonobservatory.org/population/#/view-report/87014b69cc914a438349d2e0affff35f/___iaFirstFeature

Douaud G et al (2022) *SARS-CoV-2 is associated with changes in brain structure on UK Biobanks*. 21 February 2022 https://www.nature.com/articles/s41586-022-04569-5_reference.pdf

NHS (2021) *Your Covid recovery:* https://www.yourCovidrecovery.nhs.uk/what-is-Covid-19/long-Covid/

(Accessed 7 June 2022)

Call 0300 012 0235

Email info@healthwatchcroydon.co.uk

www.healthwatchcroydon.co.uk

Be social with us on Facebook, Twitter, Instagram, Pinterest, LinkedIn, and Google.

24 George Street Croydon CR0 1PB