



Post-COVID syndrome: People's experiences of health care and support in Gloucestershire

March 2022

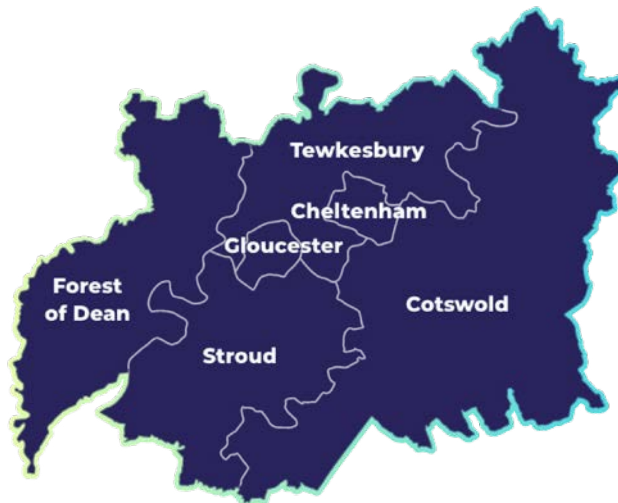
About us

Healthwatch Gloucestershire is the county's health and social care champion.

We're here to listen to your experiences of using local health and care services and to hear about the issues that really matter to you. We are entirely independent and impartial, and anything you share with us is confidential. We can also help you find reliable and trustworthy information and advice to help you to get the care and support you need.

As an independent statutory body, we have the power to make sure that NHS leaders and other decision makers listen to your feedback and use it to improve standards of care. This report is an example of how your views are shared.

Healthwatch Gloucestershire is part of a network of over 150 local Healthwatch across the country. We cover the geographical area of Gloucestershire County Council, which includes the districts and boroughs of Cheltenham, Cotswold, Forest of Dean, Gloucester, Stroud, and Tewkesbury.



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Introduction

We wanted to understand how post-COVID syndrome (long COVID) is affecting people's health and wellbeing and to find out what care and support is available in Gloucestershire.

Background

It is estimated that around 1.3 million people in the UK had post-COVID syndrome in January 2022 (source: [ONS long COVID data](#)). This post-viral condition is a new diagnosis for doctors to treat, so there are many unknowns as we learn more about how the condition affects different people.

The National Institute for Health and Care Excellence (NICE) defines post-COVID syndrome as signs and symptoms that develop during or following an infection of COVID-19 which continue for more than 12 weeks and are not explained by an alternative diagnosis. The definition explains that symptoms are wide-ranging and often overlapping clusters of symptoms which may change over time and can affect any system within the body. Common symptoms include extreme tiredness (fatigue), shortness of breath, chest pain or tightness, and problems with memory and concentration ('brain fog').

As services adapt to treat people with post-COVID syndrome, we wanted to identify what works well and what needs to be improved for patients to receive the best care and support from diagnosis to treatment.

We worked with Gloucestershire's Health and Care NHS Foundation Trust to reach people using these services, and to make sure that we asked the right questions to inform our recommendations.

What we did

We ran an online survey from 10 - 24 December 2021 (see in Appendix A: Survey questions). We also gave people the opportunity to talk to us about their experiences over the phone.

The 'GL11 Long COVID Support Group' shared our survey with their members and extended our invitation to feedback over the phone. Gloucestershire Health and Care NHS Foundation Trust shared information about the project with their staff network and their 'Post-COVID Syndrome Assessment Service'. We publicised the project through our website, newsletter, and social media channels.

Your local health and social care champion



healthwatch
Gloucestershire

Share your experience of post-COVID syndrome and help improve care and support in Gloucestershire

Complete our survey by 24 December 2021

www.smartsurvey.co.uk/s/hwg-pcs
0800 652 5193 (freephone)

Who we spoke to

Survey feedback

We collected feedback from 56 people about their experiences of post-COVID syndrome – 50 people completed our survey and six people talked to us on the phone. Read what people told us on pages 6–8.

The people who completed our survey were mostly female (68%) and White British (85%). 34% considered themselves to have a long-term health condition. Most people were aged 50 to 64 years. (See Appendix B: Demographics including location of respondents.)

Life-changing stories

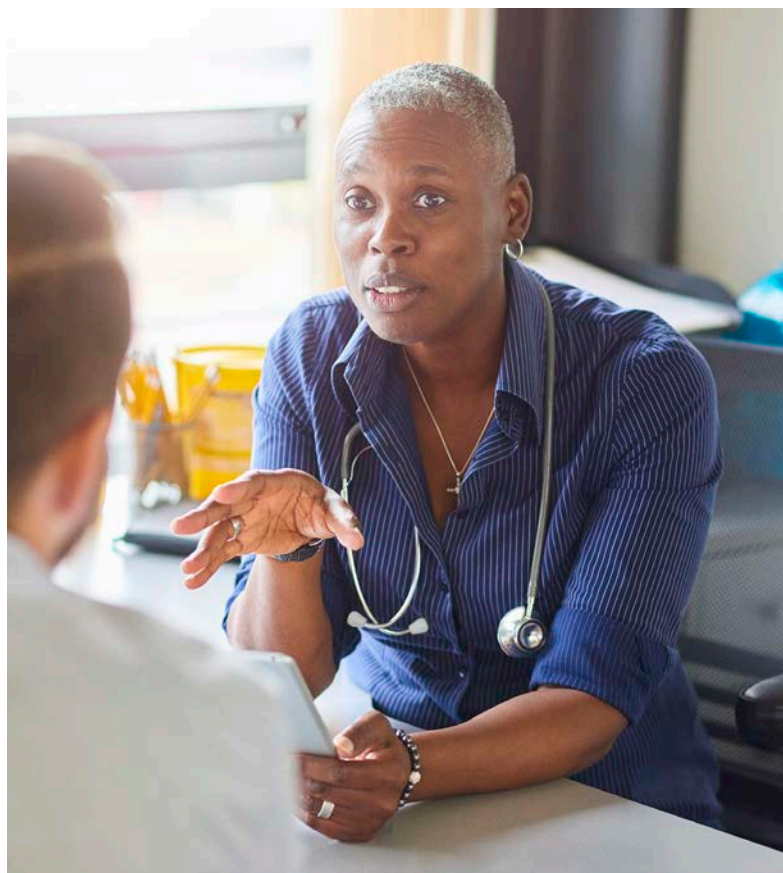
We spoke to three people in depth about their life-changing experiences of post-COVID syndrome, the challenges they have faced and the support they have received.

On page 9, you can read about Barbara, who ended up in A&E being treated for a serious heart condition after waiting 18 months to be referred for her symptoms. On page 10, Jenny's story is told by her sister Clara, who shares her views on the difficulties of getting care for her sibling who continues to struggle with severe neurological symptoms. And on page 11, Cameron shares his story about the physical and emotional challenges he experiences, and the healthcare support that makes such a difference. (All names have been changed.)

Key messages

We analysed people's feedback and identified some common themes in what they told us.

- People don't always know which services are available to help them.
- Most people were helped by their GPs and a smaller proportion were helped in hospitals.
- People are waiting a very long time to hear from the Post-COVID Syndrome Assessment Service after referral.
- Patients felt left alone to seek their own treatment options.
- Being proactive to find support could be challenging due to brain fog and fatigue.
- People were not often given the opportunity to have face-to-face conversations with clinicians.
- Long waiting times and disjointed services made mental and physical wellbeing more difficult to treat.



What people told us

We collected feedback from 56 people. Their experiences of post-COVID syndrome were broadly similar, although their attitudes differed.

Passive approach from health care practitioners

Within the survey we asked people to tell us how helpful they found the support from health and care staff, including GPs, nurses, specialists, and occupational therapists.

The majority of feedback showed that people found these services to be helpful. However, people felt as if they needed to either find their own information online or be prepared to pay for their health care. The limited access to face-to-face consultations meant that people felt isolated in trying to find support.

GPs and hospital specialists have had limited capacity to support people with post-COVID syndrome. This diagnosis is new and poses novel challenges for clinicians, who are also navigating the pressures of an ongoing pandemic and an increasing backlog of patients needing NHS care. Feedback showed that people understood that it is difficult to treat post-COVID syndrome, but they felt doctors could be more active in their support.

Of the 50 people who answered our survey:

- 41% found their primary care support to be unhelpful or really unhelpful and 50% of people found this support to be helpful.
- 29% of people found their secondary care support to be unhelpful or really unhelpful; 26% of people found this support to be helpful.
- 59% of people found it easy or very easy to understand the information shared by the Post-COVID Syndrome Assessment Service. However, people commented that they didn't have many opportunities to ask questions about the information they were given as their appointments could be short and online support could not replicate face-to-face support.
- People said they felt that post-COVID syndrome was being treated differently to other illnesses or conditions, in part due to it being a new diagnosis.

Remainder of post-COVID workshops have focused on 'being kind to yourself', 'doing less' and appear to want the patients to accept their condition. I am not passive; I want to get better and do whatever it takes to do that. In the interim it might help if someone actually checked out my heart, lungs and brain function.

COVID has robbed me of my fitness and I intend to get it back. However, the passive approach that I have encountered by health providers, combined with the total failure of the GP to follow anything through, is significantly adding to the challenge and the stress of the situation.

The whole experience has been traumatising. The GPs are arrogant and completely void of any empathy. At one point a GP implied this is just anxiety. My physical symptom list was nothing like anxiety.

Waiting times

In the survey, we asked people where they had found support for post-COVID syndrome and if they had been referred to other services. 30% of people had not been referred for support but had self-referred to services and used self-help techniques in the interim.

We also asked whether people had been signposted to the Post-COVID Syndrome Assessment Service specifically, and if so, whether they had received their first appointment. 58% of people's responses to the survey told that they had been referred to the service and were experiencing long waiting times so had not yet had their first appointment.

Comments showed that during the waiting period, the administrative processes felt tiring and frustrating; people felt that it was particularly difficult to proactively reach out for the support they need whilst experiencing debilitating symptoms.

- People who had COVID-19 at the start of the pandemic feel 'ignored' as their symptoms were not initially understood.
- 22% of people surveyed told us that digital appointments were not working for them.
- People had a range of emotions about the screening form that is used by the Post-COVID Syndrome Assessment Service to help decide how to support patients. Some people indicated a sense of relief that they were going to get support. Others commented on the amount of energy and concentration needed to fill in the forms, which made them reflect on their 'failings' or the activities that are limited by post-COVID syndrome. For some people, the screening form felt like 'Groundhog Day', as they had to repeat their experiences again and again to different health care staff throughout the referrals process as they tried to get treatment.

As time goes on and chronic fatigue continues, and other symptoms, it becomes harder to find the right help.

It wasn't in depth enough – I wanted an in person assessment for cardio/ exercise (for example, stress test or tilt table test), but no in person appointment was offered.

I've not been able to access anything for long/post-COVID as I returned to work and got on with it. 11 months later, I'm still suffering with a couple of things, but unable to get a doctor's appointment, so just living with it.

I do wish there was more support sooner. It is very hard to access help and then it only lasts a while. I have been ill for over a year now. I have tried the online Zoom support groups but can't cope with them.

At times it feels very hard to keep finding the right support. Wait times for services are too long.



Work and post-COVID syndrome

In the survey, we also asked people to tell us more fully about how post-COVID syndrome has affected their lives. Health inequalities were revealed in the comments received, particularly around the relationship between people's employment and the rest needed to help recovery.

It was clear that people with less money, who were 'struggling to make ends meet' or 'living pay cheque to pay cheque', were having to weigh up their health needs with their financial needs. Taking time off from work to rest and recover meant there was an added financial burden. This is an important health inequality to consider when looking at the wider picture of patient experiences with post-COVID syndrome.

It helps that occupational health are aware of long COVID and want to do all they can to support me returning to work.

I'm trying to work but I'm having to take a lot of time off.

Variations of length and severity are noticeable in support groups as people recover at different rates. Normal phased returns to work do not work for long COVID, in part due to these differences. For NHS staff, the HR approach does not follow suit, especially considering they most likely caught it at work.

I have had to borrow money to see alternative health practitioners out of desperation.

Wish there was financial support as it's hard to go back to work when not ready to. Can't seem to find answers.

Case study: Barbara's story

An 18 month wait for referral led to A&E treatment for a serious heart condition

"After 25 months I am well and truly over the worst. I have been lucky compared to some I know in the international support group that I belong to, who are now disabled or who have given up all hope.

"My main problem was getting a referral to Cardiology. After an 18 month wait for an appointment, they cancelled me the week before and failed to rebook the appointment as promised! In some ways I was lucky as I ended up in A&E, no thanks to 111 (complaint pending), and I'm grateful to the pharmacist who insisted I go there immediately when I asked him for help. Seven and a half hours later, diagnosed heart condition and meds prescribed - for life! My message to people is always listen to your body and, sadly nowadays, don't rely on the NHS."



Case study: Clara and Jenny's story

Lack of GP support for a nurse with severe neurological symptoms who found hospital treatment due to her professional connections

"I wanted to share about my sister, Jenny, and her experience of long COVID support in Gloucestershire. Jenny is in her early 30s, she is fit and healthy, and she is a nurse. In the early days of the pandemic, before testing was widely available, she caught COVID-19. She had no respiratory symptoms but had acute neurological symptoms and a fever. She wasn't hospitalised so she didn't get tested. Jenny is still severely ill with neurological/cognitive problems and needs to pace everything she does, including meals etc.

"Jenny's GP surgery have been atrocious as they have never examined her. I took her to A&E a couple of times to get her examined as the GP was not doing so. She accessed treatment through our professional connections in the hospital. This allowed her to be seen privately and by occupational therapy consultants and she has an appointment organised with the chronic pain clinic. We are both worried about how other patients may cope without that access and those connections.

"Jenny is now involved with long COVID clinics and support groups. The 'Your COVID Recovery' app is very useful, but it doesn't have all the information as the app has to learn as the doctors do. Each person is affected by long COVID so differently that it is a difficult subject for medical staff to tackle. Hospitals have had to focus on the most acute cases due to funding and capacity constraints, but primary care providers have not been taking the initiative to make up the difference."



Case study: Cameron's story

Multiple and long-lasting symptoms after being hospitalised with COVID

Intensive care was traumatic

"I tested positive in November 2020 and was quite poorly. I ended up in hospital for three and a half weeks, including a week in ICU. I felt like I wouldn't come out of ICU and it was game over. I met people whilst in ICU, who I got to know using hand signals. They didn't make it.

"My experience in hospital was traumatic; I was very poorly with COVID. I'm in my fifties and have underlying health conditions with my respiratory system and COVID really knocked me for six. The mental drain it takes on you is quite challenging. You aren't allowed visitors and I'm old school, I prefer face-to-face. It was difficult to come to terms with that. It was hard to come to terms with both the physical and mental challenges.

Extreme fatigue

"I came out of hospital just before Christmas 2020 but I wasn't myself. The fatigue I experienced was remarkable; I'd recovered enough to be discharged but I wasn't right. When I came out of hospital, I couldn't walk up 12 stairs without needing to stop, sit down and rest every two steps. Slowly, over time things got easier, but even having a shower was difficult and would take me two and a half times as long, because moving at all was really draining.

Numbness and pins and needles

"I have pins and needles and numbness in my right foot, which is really bizarre. At the time, it felt like I was walking on the moon as I couldn't feel my right leg. The medics checked this out and referred me to neurology in the hospital. They attached some probes to my legs to see if this was affecting both legs, or if I was getting any sensation. They determined this was a result of COVID and that this should settle down over a few months.

Brain fog

"I was suffering from brain fog, my family would be talking to me and I would have to ask what they were talking about as I couldn't remember or recollect what had been said. This too has got better and eased but it hasn't completely gone. I still have intermittent episodes where I don't have that recollection.

Breathlessness

"The one thing that I am still struggling quite a bit with is breathlessness. A couple of months after I came out of hospital, I started going for walks to build my stamina and strength. If I am walking on a bit of an incline, I get this breathlessness again. During last September, this breathlessness issue was more noticeable, so I got this checked out in the respiratory services. The tests come back negative so it comes down to long COVID.

Support groups help with mental wellbeing

"In terms of the support, I did join a group for people who had COVID badly, which had a weekly call to provide mutual support and reassurance. I went along pretty much every week. People spoke to me about their experiences and there were a few commonalities, but there were a few experiences that I hadn't heard of. This was really good for the mental wellbeing side. I think due to funding, they had to cancel this but we all gave feedback that we found this really helpful.

"Another post-COVID syndrome group started where monthly meetings would have featured speakers who would give different focuses (on physiotherapy etc.) and then people would chip in with Q&A. I've gone along to most of these too. I found these to be

quite useful and that is how I found out about your project. The support groups for mental wellbeing have been really good, they could do more of these groups, but they do need to put more money into the budgets for these. They give that sense that you are not alone. Those groups have helped; continuing and funding those would be great. I know they do not come for free.

Specialist health care helps with physical symptoms

“Going back to physical health, this has been more focused on and it is something that I have had to initiate myself. I have been to the specialists that I need to see so I can’t complain really. I was referred to the Post-COVID Syndrome Assessment Service but I haven’t yet heard from them. It would be good to have a courtesy email where they are transparent that they are trying to work through the list and that we are not forgotten.

“I also attended an event which was held with all the specialists and clinicians there, where there was a session of 2-3 hours for us to ask the different specialists about symptoms and they could give advice and guidance. They could have done more of those as I thought they were really good and it was in person; occasional events like that would be brilliant.

More support needed to help people adjust to this life changing experience

“I haven’t had to wait too long considering the circumstances. I’m in a better place. I’d like to be where I was pre-COVID but the medics say to me that there is a strong possibility that I will never get back to the old normal and I might need to adjust and accept this new normal. I think if there was more support for the ‘sufferers’ of long COVID symptoms, those who have had a life changing experience and who are finding it difficult to cope and adapt, that would be good, particularly for GPs for example.

“When I went back to work at my IT office, they asked whether I would be happy to do a talk to share my experience with my departmental colleagues. They found it very useful to hear my candid journey as they didn’t know anyone who had COVID to the same extreme as I did.

“I want to give big kudos to the NHS staff in the hospital who took care of people like me in terms of the care they gave.”



Recommendations

We believe that health and social care providers can best improve services by listening to people's experiences. We have analysed what people told us and we recommend the following actions to help improve care and support for people with post-COVID syndrome in Gloucestershire.

- Create a public awareness campaign, clearly telling people about the NHS support available for post-COVID syndrome, such as the Post-COVID Syndrome Assessment Service, the 'Your COVID Recovery' app and community support groups.
- Make sure GP practices in Gloucestershire are aware of the different services and support groups available, so that there is information ready when people first present with symptoms.
- Communicate openly and clearly with people following referral to services, about the waiting time for consultation and further wellbeing support that is available.
- Share practical and helpful tips with people, such as breathing exercises, as part of a more active approach to care.
- Invest time and resources in face-to-face support so that people feel less isolated.
- Continue to fund advice and information events as these are an effective way to provide support for patients.



Stakeholder response

Gloucestershire Health and Care NHS Foundation Trust
Mphathisi Ncube, Deputy Service Director for Urgent Care and Specialty Services

“We would like to acknowledge and apologise for those who had a less than desirable experience and delay in accessing care.

Open communication

- The questionnaire: This is often one used nationally so we will take this on board on to other wider forums. This questionnaire is important part of our assessment process and if someone feel they cannot complete it or need more support to do it then they can contact the service. We have the questionnaire in paper format and online and provide it an variety of formats.
- In terms of service appointments, it was difficult to provide accurate estimates of waiting times due to the uncertainty of recruitment. This has now improved and we will consider how we can update and inform patients about the anticipated waiting times.

Practical tips

- We have taken on feedback. The interventions, in particular the format of the intervention group, has now been reviewed and updated so it is more structured with practical tips. This includes breathlessness.

Face-to-face (F2F)

- We have had mixed feedback on this, with some patients reporting virtual is much preferred to reduce fatigue, while others would prefer F2F. Now that the restrictions are changing we are also offering F2F where necessary. Additionally we have changed the referral from requesting that GPs review patients F2F prior to referral, so that a physical assessments is performed.

“We recognise that the assessments, including completing the questionnaire, can be emotionally challenging and understand the importance of physical and mental health assessment and support.”

Thanks

Our thanks go to staff at Gloucestershire Health and Care NHS Foundation Trust for their collaboration and support in this work. Thanks also to our partners in the Gloucestershire VCS Network for promoting the project.

Thanks to everybody who took the time to tell us about their experience. We can only do what we do because you talk to us. Particular thanks go to Cameron, Clara, Jenny and Barbara for talking to us so openly and allowing us to share their stories.

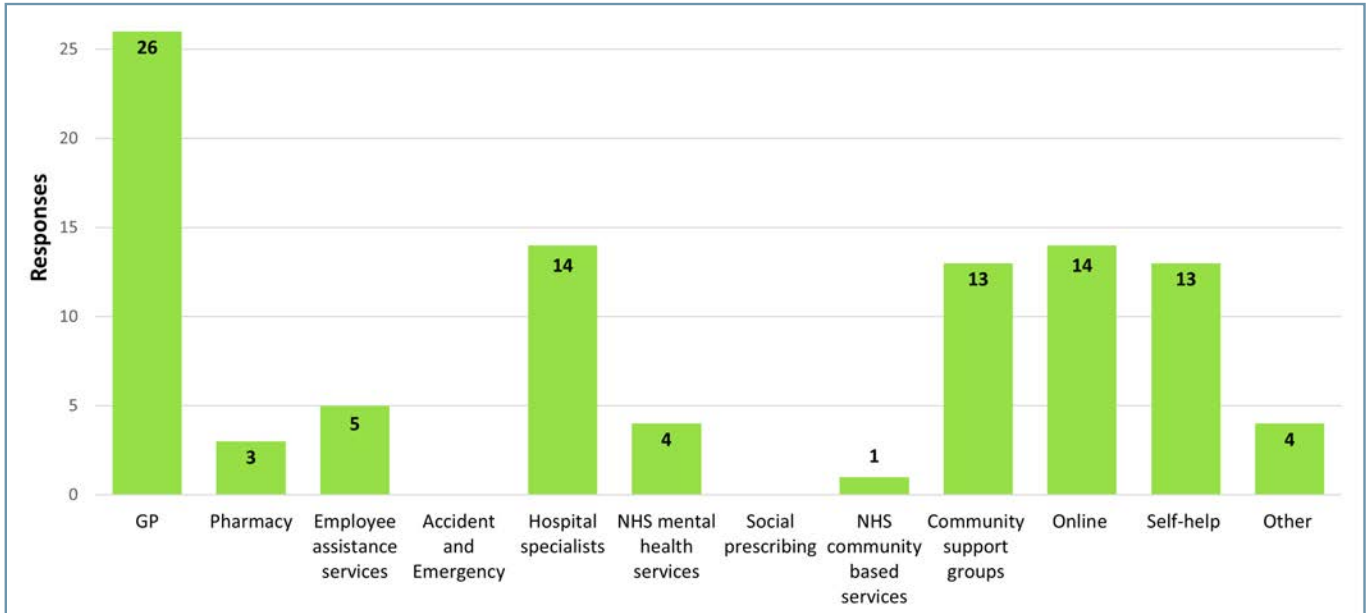


Appendices

Appendix A: Survey questions

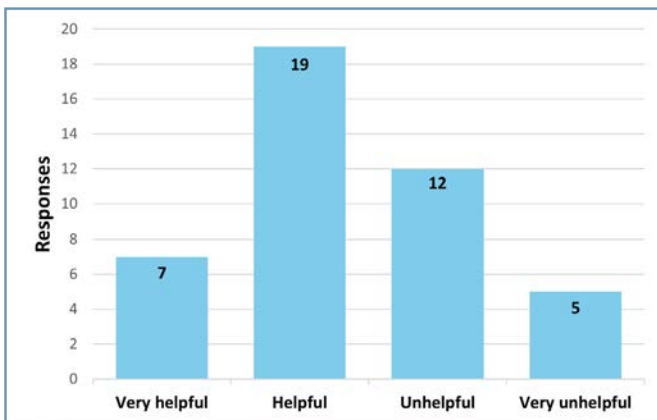
Q1. Where have you found support for post-COVID syndrome (long COVID)?

41 people responded to this question.



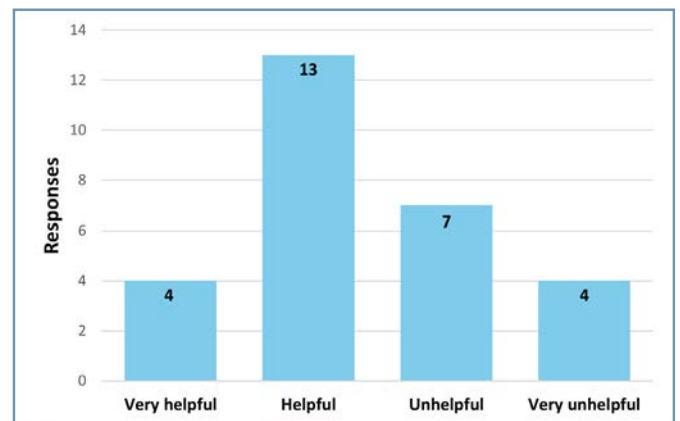
Q2. How helpful did you find the experience of using primary care, if applicable?

38 people responded to this question.



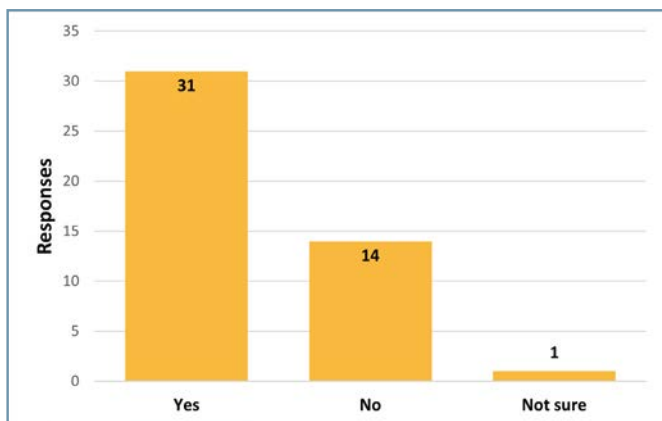
Q3. How helpful did you find the experience of using hospital or community care, if applicable?

28 people responded to this question.



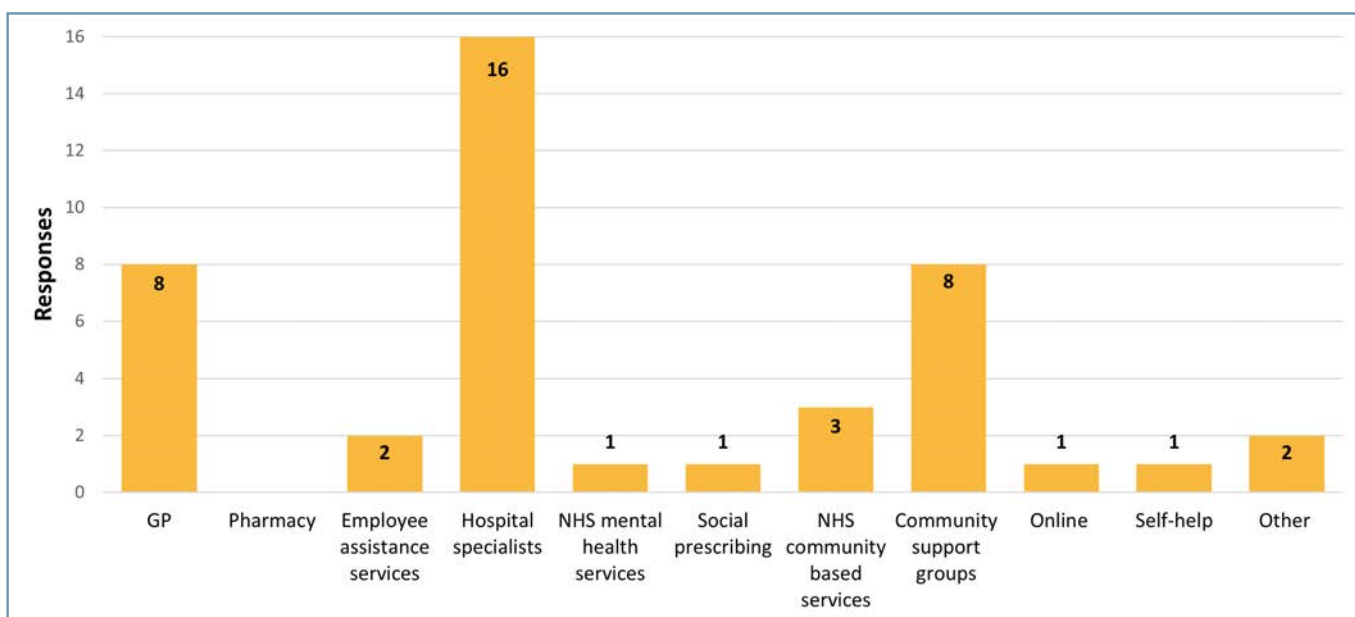
Q4. Have you been signposted or referred to support for post-COVID syndrome?

46 people responded to this question.



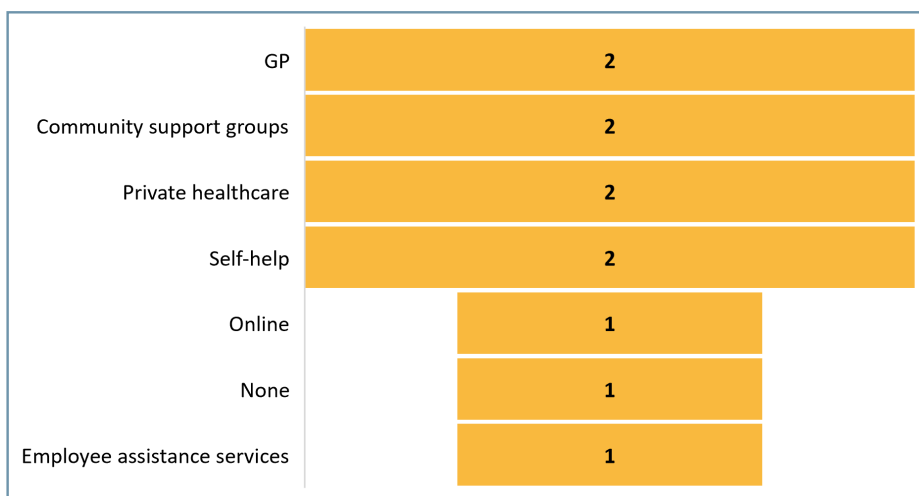
Q5. Where have you been signposted or referred to?

14 people responded to this question.



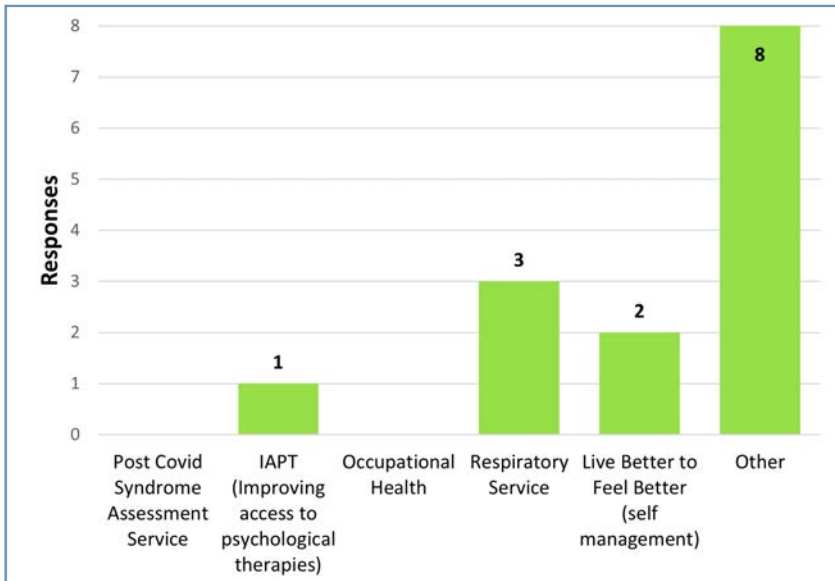
Q6. Have you self-referred or found support elsewhere?

11 people responded to this question.



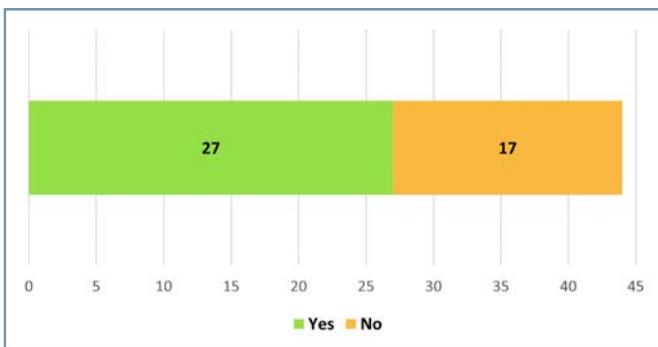
Q8. In relation to post-COVID syndrome, have you heard from any of the following Gloucestershire Health and Care NHS Foundation Trust (GHC) services?

8 people responded to this question.



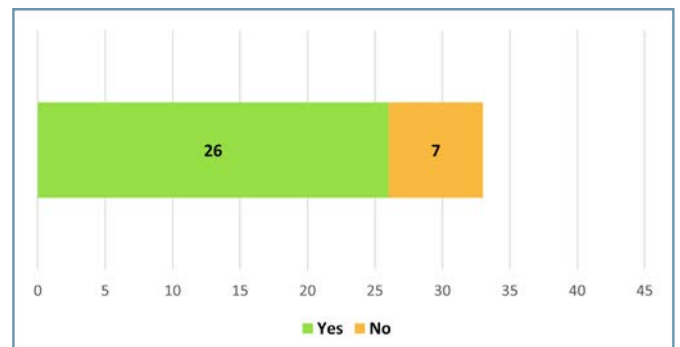
Q9. Have you heard of the Post-COVID Syndrome Assessment Service provided by GHC?

44 people responded to this question.



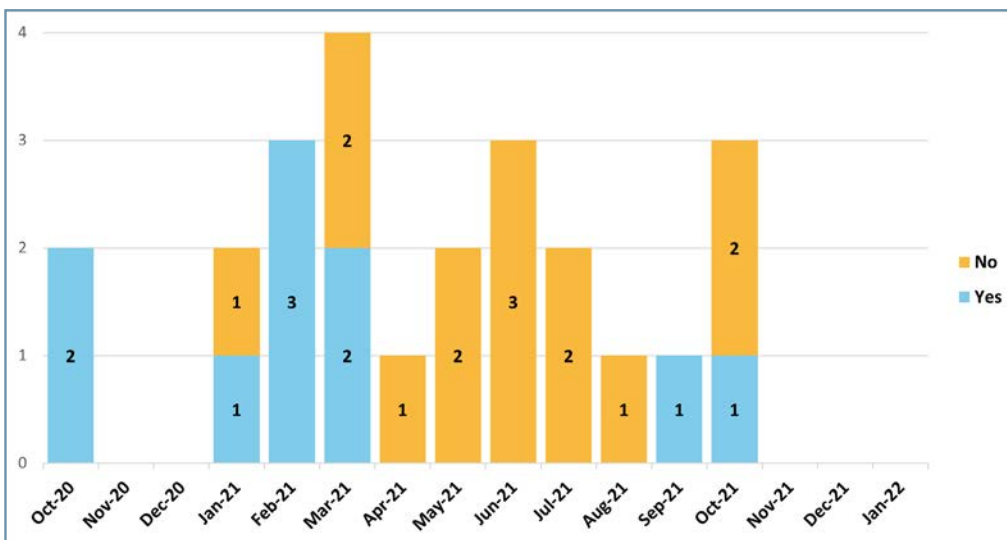
Q10. Have you been referred to this Post-COVID Syndrome Assessment Service?

33 people responded to this question.



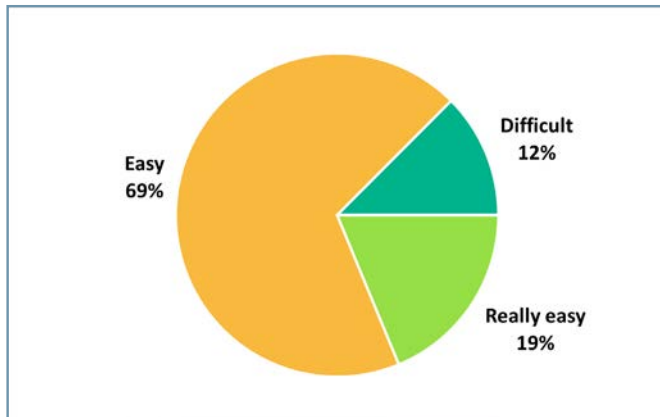
Q11 & 12. When were you referred to the Post-COVID Syndrome Assessment Service and have you had your first appointment?

10 people responded to this question.



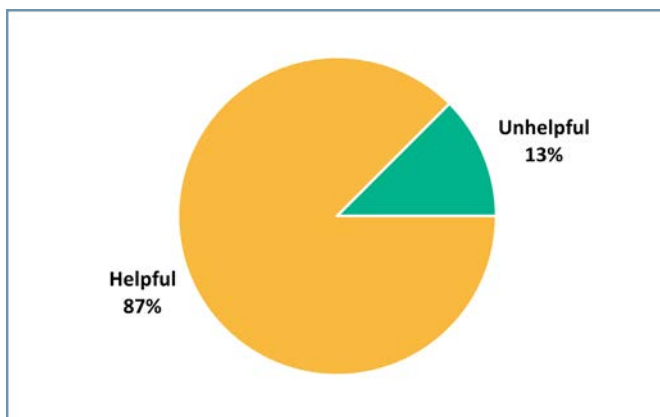
Q13. How easy to understand have you found the information and resources provided by the Post-COVID Syndrome Assessment Service?

16 people responded to this question.



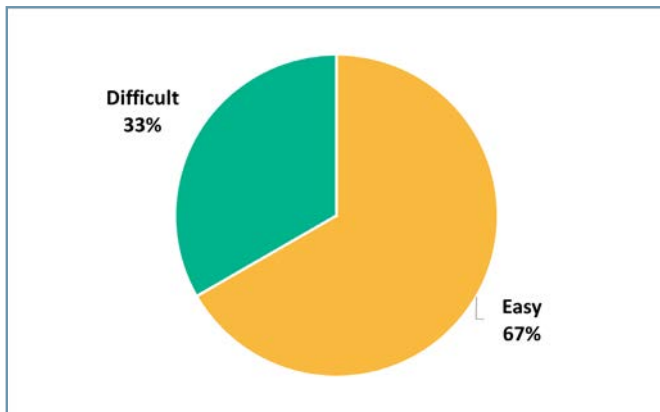
Q15. How helpful have you found the information provided by the Post-COVID Syndrome Assessment Service?

8 people responded to this question.



Q17. When you first completed the screening questionnaire how easy was it to complete?

15 people responded to this question.



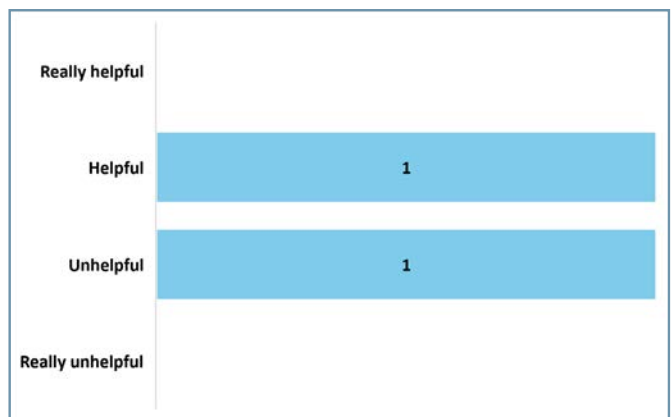
Q14. Please tell us more about this.

Indicative answers:

- "Lots of leaflets online and you can join a group, but I can't as I need to work and it's during the day."
- "No help apart from some initial scans in hospital."
- "The online links and chats don't make up for no one looking into many of the issues I suffer with."
- "Very helpful and I feel they understand me and what covid has left me with. Had a good 90-minute chat and felt reassured."

Q16. How helpful have you found the Post-COVID Syndrome Assessment Service once you have seen them?

2 people responded to this question.



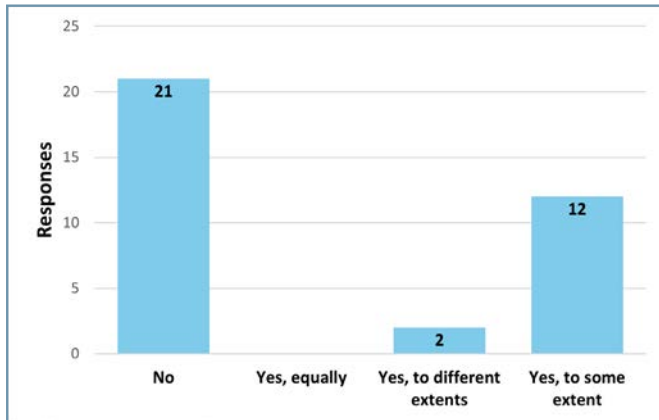
Q18. How did filling in this patient form make you feel?

Indicative answers:

- "It took a huge amount of energy and concentration to fill it in. I had two; a paper version and an online version."
- "Really upset and forced to focus on failings. It set me back psychologically and has offered nothing for months afterwards."
- "Groundhog Day."
- "Relieved that it is a step to getting better."

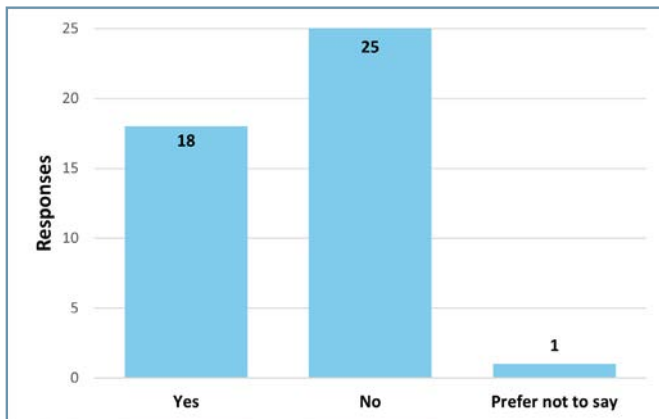
Q19. When you first completed the screening questionnaire how easy was it to complete?

35 people responded to this question.



Q21. Did you already have a long-term health condition?

44 people responded to this question.



Q23. Is there anything else you'd like to tell us about your experience?

Indicative answers:

- "The whole experience has been traumatising. The GPs are arrogant and completely void of any empathy. At one point a GP implied this is just anxiety. My physical symptom list was nothing like anxiety. Long COVID clinic lost my information and only found it when I questioned them."
- "I do wish there was more support sooner. It is very hard to access help and then it only lasts a while. I have been ill for over a year now. I have tried the online Zoom support groups but can't cope with them."
- "Wish there was financial support as I had to go back to work when not ready to. Can't seem to find answers."
- "Being ill in April 2020 without a positive test has made it harder for long COVID to be diagnosed. From May 2020 onwards I was treated for each ailment separately and referred to the service which covered my main symptom of fatigue."

Q20. Please tell us more about this.

Indicative answers:

- "My mental health needs have been met more than my physical health needs. There is more focus on my mental health than my physical health."
- "I have every symptom dealt with as separate entities."
- "I haven't had much help and not spoken to anyone face-to-face."

Q22. Please tell us if this has made a difference to your expectation and experience of the Post Covid Syndrome Service?

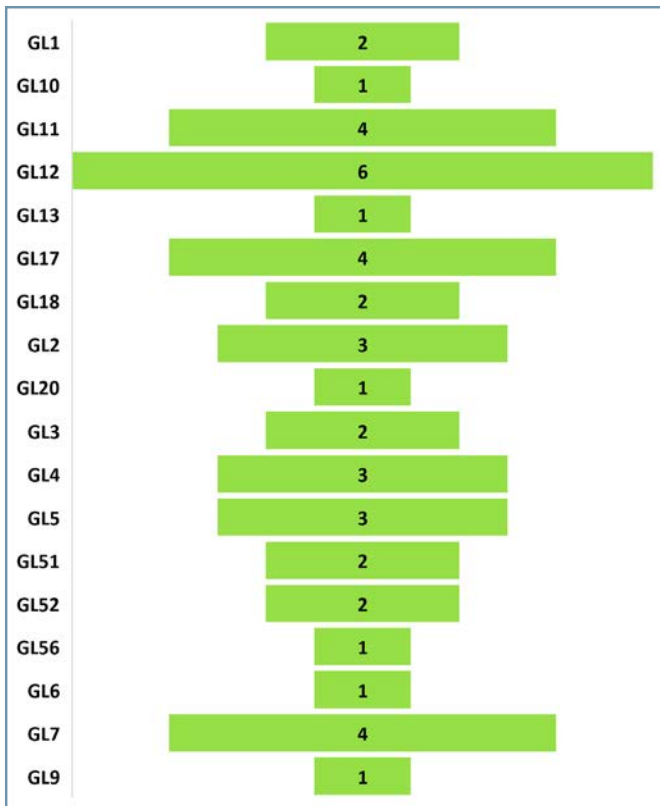
Indicative answers:

- "Hasn't made a difference to what I expect."
- "Support for other illnesses treats them as an illness and gives proper support. I know this is a new syndrome, but similar ones already exist, and I pity people with those if this is the 'support'."

Appendix B: Demographics

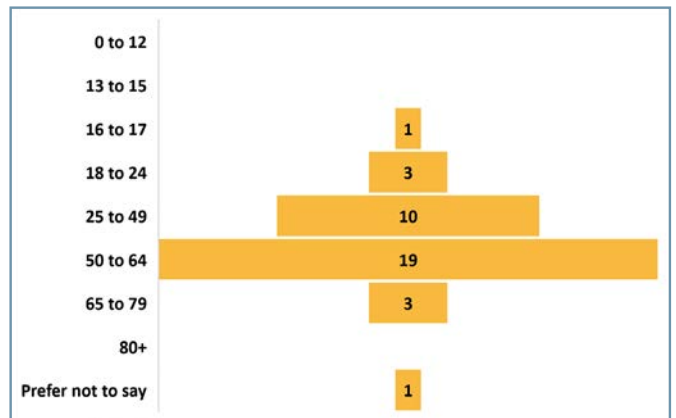
Q24. To help us understand how experiences may differ across the county, please tell us the first half of your postcode.

43 people responded to this question.



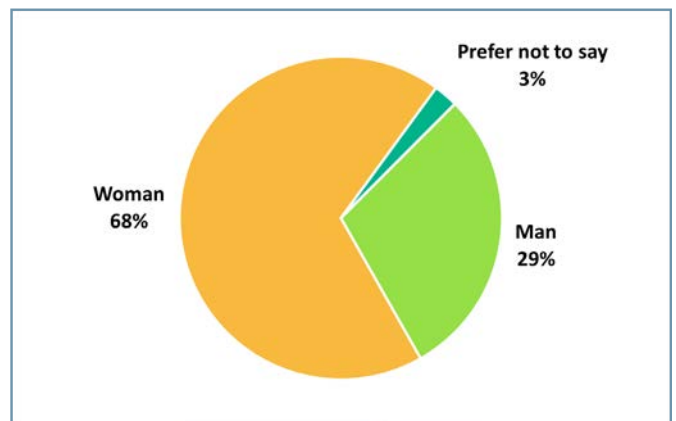
Q25. How old are you?

37 people responded to this question.



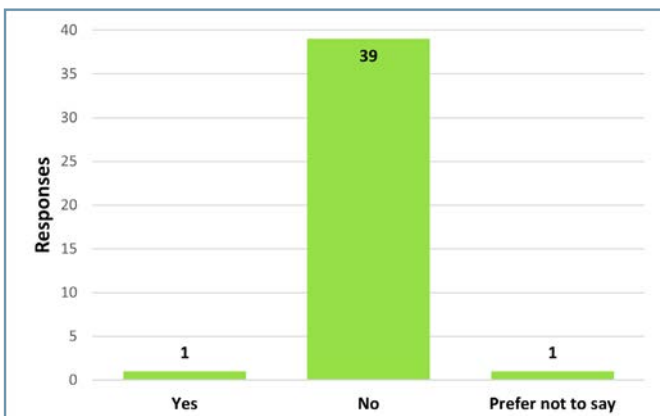
Q26. What gender do you identify with?

41 people responded to this question.



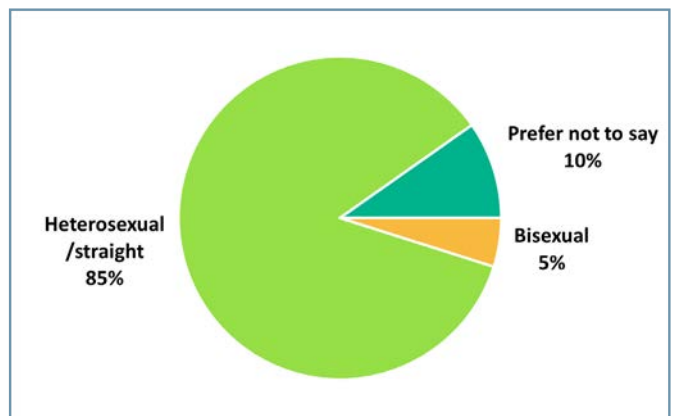
Q27. Is your gender different to the sex that was assigned to you at birth?

41 people responded to this question.



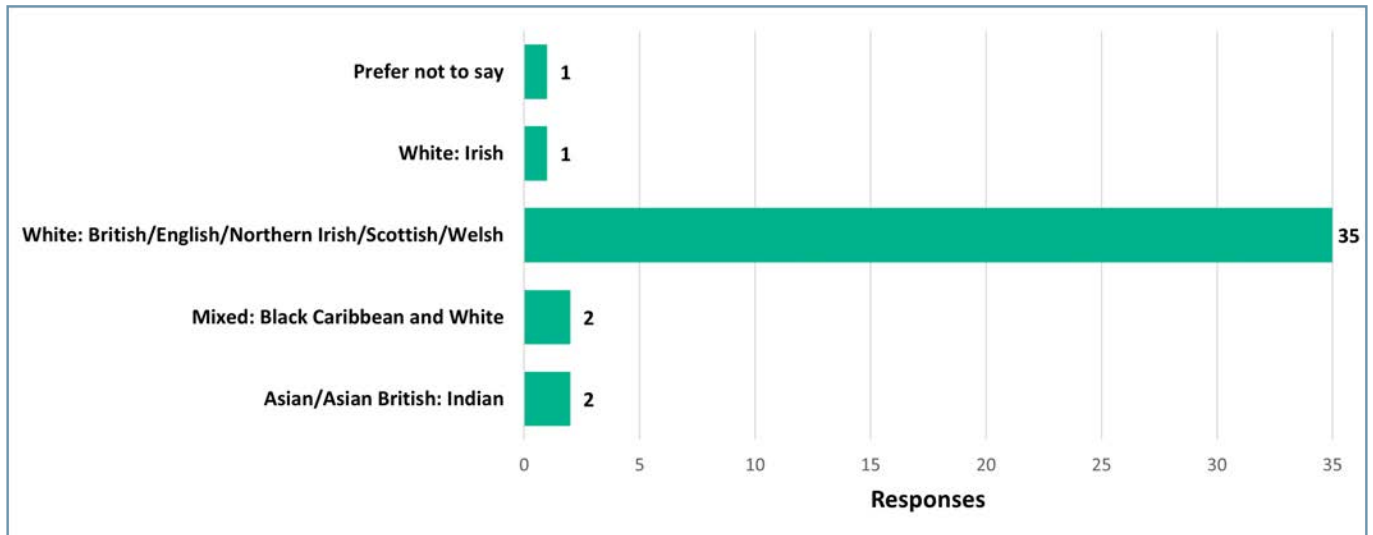
Q28. Please tell us which sexual orientation you identify with.

41 people responded to this question.



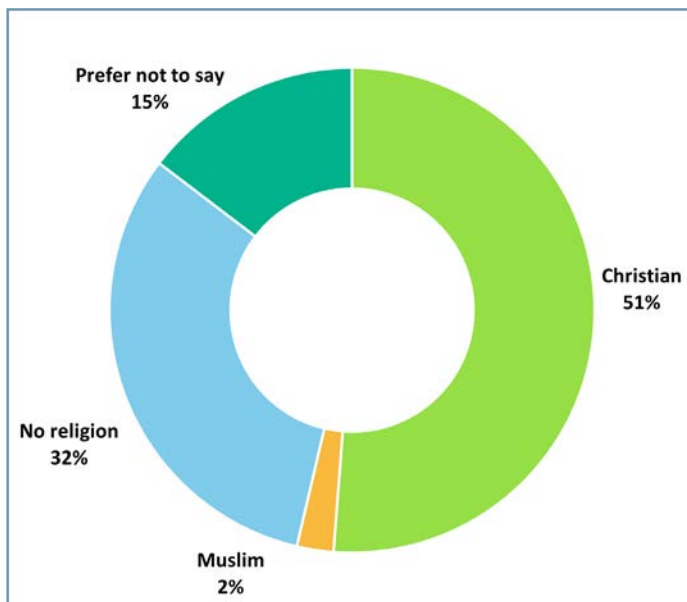
Q29. What is your ethnic group?

41 people responded to this question.



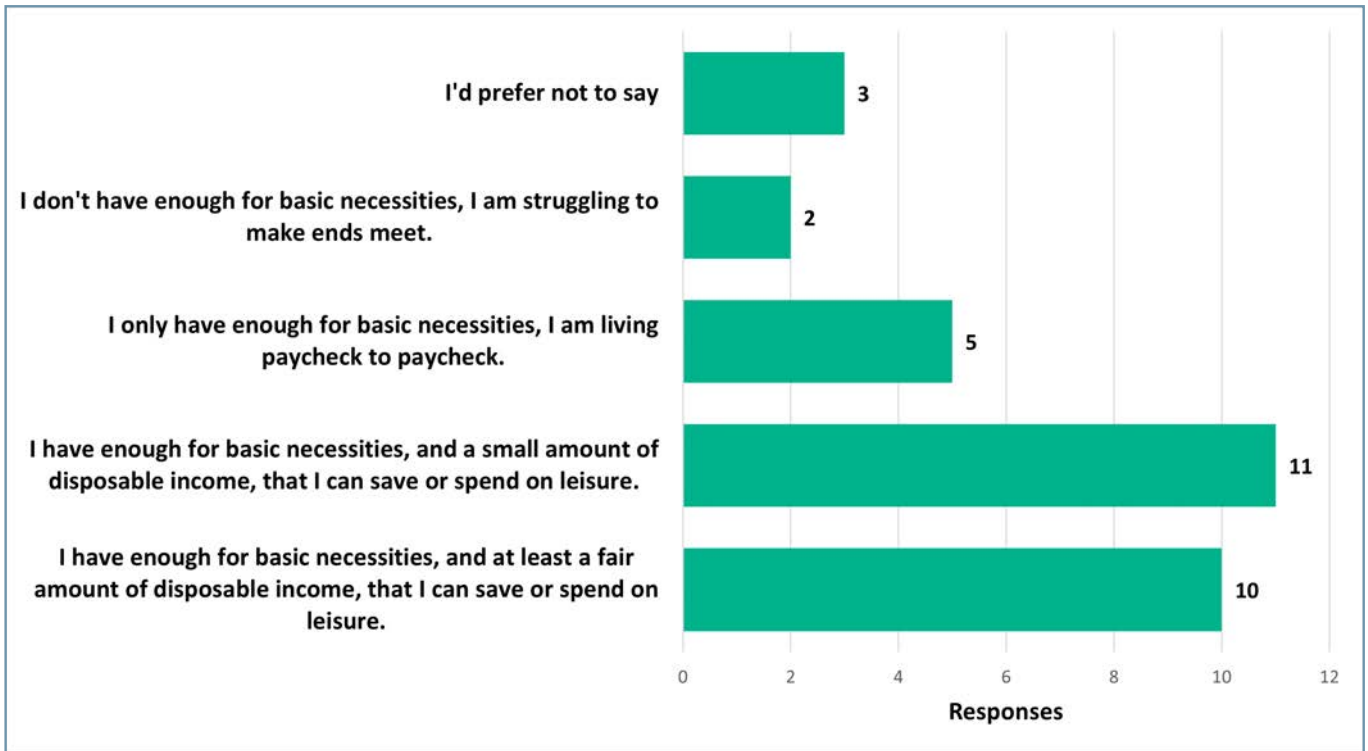
Q30. What is your religion?

41 people responded to this question.



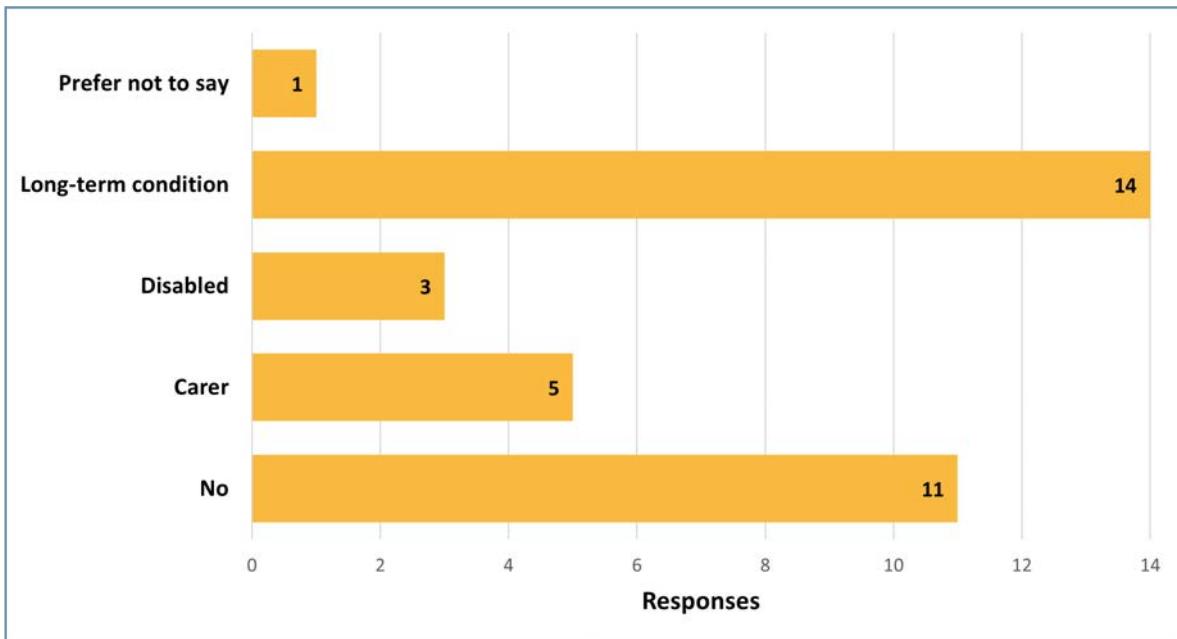
Q31. Which of the following best describes your financial status?

31 people responded to this question.



Q32. Do you consider yourself to be a carer, be disabled or have a long-term health condition?

34 people responded to this question.



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