

The **LongCovidSOS GP survey** was posted in the Body Politic/Slack support group and in the Long Covid Support Group on Facebook. 271 responded with 270 remaining after data cleaning. Please see the Appendix for data, charts and graphs.

The survey was directed at UK participants only. 86% of respondents were from England, 9.2% from Scotland, 4.1% Wales and 0.7% Northern Ireland. The group was heavily skewed towards females at 83.8%; this is not necessarily a reflection of the gender demographics for Long Covid, but likely to be due to the heavy female bias found in online support groups. The largest age group selected was 35-49 at 44.3%, however the combined total for those over 50 came to 45.4%. 10.3% were in the 20-34 age group. No respondents were under the age of 20.

On average, as of 09/09/2020, the length of illness reported was 165 days which translates to approx. 5.3 months or 23 weeks. 68% of respondents were first taken ill in March 2020. 98.5% are still suffering symptoms. Almost 92% did not receive a positive PCR swab test result, which we interpret as being due to the lack of community testing when the vast majority became sick. Antibody testing achieved only 11.1% positive results which is likely related to limited availability and prevalence of false negatives. The majority, 86.7%, were not admitted to hospital.

Almost a quarter of respondents did not contact their GP during the acute phase of their Covid-19 infection, during the height of the pandemic people with symptoms were directed to 111. However 97.4% have consulted their GPs since. Of those that did not, the most cited reason was lack of sympathy demonstrated by their GP during the acute phase (40%). 78% of all consultations in the post-acute phase were carried out by telephone, with only 16% being face to face. The average number of telephone consultations was 4. Most respondents were not offered video or online appointments (85%) and only 50% were able to see a GP in person. More than half of respondents consulted with 3 or more GPs during this period, with 4 claiming to have seen 10 or more different practitioners.

In terms of the GP response to long covid symptoms, we asked respondents to choose from six approaches which were based on feedback previously posted in support groups. We also provided an option for them to choose 'other', which accounted for almost 20% of responses. The percentages below are based on the **80% who selected one of the six options**:

**1. My GP was aware of the possibility of Long Covid and was sympathetic but did not have any practical advice**

This was the most frequently cited response at 33.3%: willing to accept that long-term symptoms were a feature of Covid-19 but unaware of any steps that could be taken to alleviate them. More females (34.8%) than males (22.9%) encountered this attitude. It was more prevalent in Wales (37.5%) and particularly high in those patients presenting with neurological-type symptoms (45.5%)

**2. My GP was sympathetic, and we discussed treatment options**

22.9% reported a sympathetic and pro-active response from their GP. The percentage was slightly higher if the patient had consulted the GP during the acute phase (24.1%) and

considerably higher if they had been hospitalised (30.8%) or admitted to ICU (33.3%). The data suggests that fewer males encountered this approach (17.1%) than females (24.3%)

**3. My GP told me that I probably had post-viral fatigue, that I needed to rest and/or suggested I look online for information about PVF / chronic fatigue**

22.0% respondents were told they had post viral fatigue, and as would be expected 37% presenting with mainly fatigue symptoms reported this diagnosis, as well as a higher proportion of those who had been admitted to hospital (26.9%). Interestingly, even some of those presenting with mainly neurological problems (1 respondent) and those with SOB/Cardio symptoms (8.2%) are included in this group.

**4. My GP suggested that my symptoms suggest I may be suffering from anxiety due to having had Covid/experiencing lockdown/some other reason**

10.7% This type of approach has been the subject of much frustration in support groups. 18.2% of those with neurological symptoms were given this diagnosis, possibly due to some symptoms being similar to those presenting in anxious patients. However a comparable percentage of sufferers with SOB/Cardio issues also were told they had anxiety. Hospitalised patients however were far less likely to be deemed only anxious (3.8%).

**5. My GP did not accept that I had a Covid-19 infection**

This rather unhelpful approach was reported by 8.7%, none of whom had received a positive swab test. Oddly, two patients who had been admitted to hospital are included in this group. The proportion of males (20.7%) was markedly higher than females (6.6%)

**6. My GP told me Covid-19 only lasts two weeks and so it must be some other virus or illness that is causing my symptoms**

This reaction may have been more prevalent earlier in the pandemic when long term covid symptoms were less known, only 3.2% respondents were included in the group although they surprisingly include one person who had been admitted to ICU.

**More than two thirds of GPs (69.7%) did not follow up the initial post-covid contact by phone or other means.**

**Some comments from those that chose 'Other', demonstrating the wide range of reactions even among GPs from the same practice:**

- *Did not really show much interest*
- *I had almost all of the above. I had one GP tell me I should seek counselling, another that post Covid doesn't exist, a couple that were sympathetic but not offering anything else, finally I spoke to one end of July that believes in post Covid and referred me*
- *I had different responses from different GP's. The majority dismissed my symptoms as mere anxiety. Eventually a Locum GP & then one of the practice GP's diagnosed long Covid. I was then referred to a respiratory Consultant.*
- *All of the other gp's gave me the impression that they were annoyed that I was ringing with yet another symptom.*
- *I had very mixed responses from all GPs at my practise -as knowledge also grew - but at times it was dismissive and harmful*

- *My GP was aware of long covid & has tried to be helpful - referred for CT scan & echo, but now doesn't know where to go next, to help me.*
- *One GP suggested anxiety and said that symptoms varying in intensity (i.e. peaks and troughs) meant it couldn't be viral, and told me off for requesting a chest x-ray after symptoms persisted for two months. A second GP believed me and sought a cardiology referral*
- *Sympathetic initially, not now. Offered amitriptyline. Refused other requests for help.*

94% of respondents were sent for at least one type of **test** by their GP – the most frequent of these being Blood Tests (reported by over 80%) and X-rays (53%). CT scans were only offered to 10% patients and echocardiograms to 7%. 5% managed to get an MRI on GP referral. Stool tests were difficult to obtain despite the frequent report of GI symptoms with only 4 respondents reporting success in being referred for this.

In terms of **being referred to specialists**, we asked respondents to choose from 6 different options:

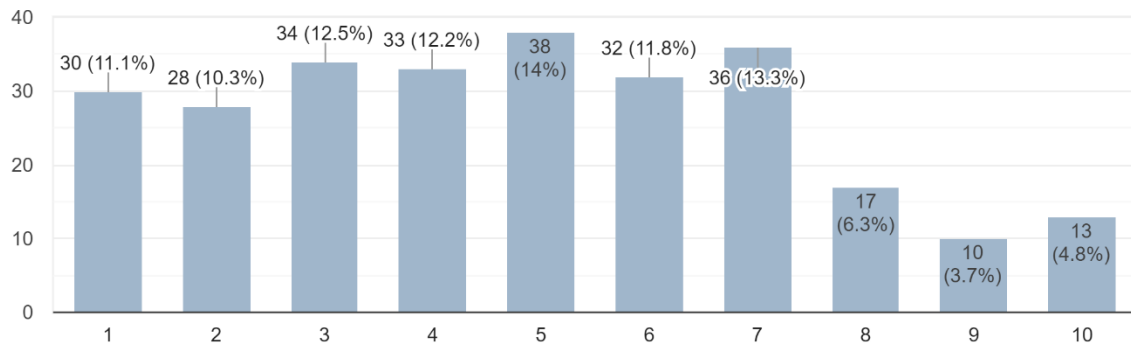
1. **We did not discuss referring me on to any specialist services**  
This was reported by the largest group, 37%. An even higher proportion of hospitalised patients (40.6%) were in this cohort, with those in Wales (54.5%) particularly unlikely to be referred on.
2. **My GP recommended a specialist referral – NHS**  
24.4% were fortunate enough to be referred within the NHS, just under a quarter of respondents. Those with a positive swab test were slightly more successful (27.3%) as were those in Scotland (32%). Patients presenting with GI issues were more likely to be referred (57.1%) as were those with SOB/Cardiac symptoms (32.2%)
3. **My GP did not refer me although I requested a referral**  
16.6% were unfortunately unable to get a specialist referral and even 12.5% of those who had been hospitalised were denied this opportunity.
4. **My GP referred me privately**  
11.8% were referred privately, however of these almost a third did not have health insurance. As a result, these patients had to pay to see a private consultant because of problems securing an NHS referral.
5. **My GP referred me to the local Covid Hub**  
6.7%. Only respondents in England selected this option, with a higher proportion presenting with fever (16.7%)
6. **My GP referred me to a dedicated post-covid rehab clinic**  
Only 3.7% have been able to access dedicated post-covid rehabilitation. Patients who had been hospitalised had almost twice the chance of being sent to these clinics (6.3%).

Of those 36.2% who did secure a referral, the most frequent was to a Respiratory specialist (41%) followed by Cardiology (37%) and Neurology (20%). Only one referral to a Vascular surgeon was reported despite extensive research highlighting the vascular nature of Covid-19 disease.

We asked respondents to rate their GP in terms of care provided on a scale between 1 and 10. The average score was 4.9.

Overall, how happy have you been with the care provided by your GP during the post-covid period? Please mark below on the line between 1-10 where 1=very dissatisfied, 10=very satisfied

271 responses



We also asked respondents to provide some qualitative data on their experience. Here are some examples highlighting the contrasting approaches taken by GPs during the pandemic:

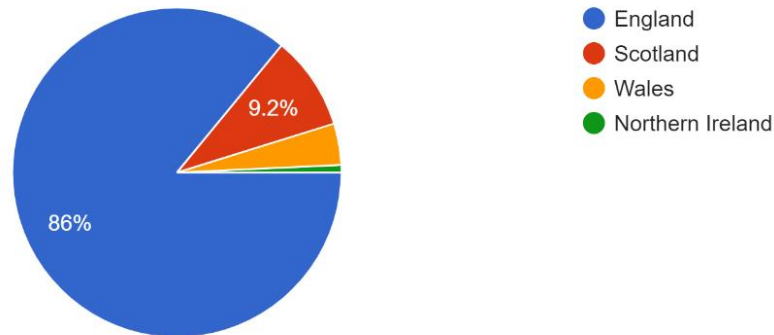
- *A couple of the GPs have been lovely and others have been rude uncaring and dismissive*
- *Absolutely horrendous, they refused to admit it was covid, then didn't know how to treat it, then refused to treat it, then blamed in on anxiety (it definitely wasn't), then accepted there were physical symptoms, still didn't know how to treat it. Were so reluctant to make referrals. Referrals took 6 months to come through. I'm still waiting. The whole process has been a total nightmare.*
- *All HCPs have been supportive in their manner. Clinical diagnosis of covid. Nearly 5 months unwell, but I get the impression this is not long enough to be significant (medically). I've had blood tests but have not been told what has been ruled out (only that blood tests are fine). I have done my own research. I will book a GP appointment at 6 months if still unwell (currently fatigue, PEM, brain fog, tinnitus, headaches, low/high heart rate).*
- *Although at times my GP was sympathetic I felt like I was wasting her time and she wanted me off the phone. Whenever I suggested I would like a referral / tests in general she always had a reason not to do them. I felt like a nuisance and that they thought I was making up all of my symptoms. Some GP's were better than others but in general I was told 'it's post viral fatigue, give it time'. After 3 months I stopped calling (I'm 6 months in). I have been told point blank there's no help.*
- *At first I felt quite well supported by the GP. She requested tests, examined me, and generally called me at 2 week intervals. I was upset with a locum who had clearly not read my notes. GP3 tried to end the phone consultation before I had the chance to talk about worrying symptoms and told me I was being impatient. GP4 was reluctant to refer me to a rheumatologist after 2 months of joint pain and stiffness and said I would be a low priority. I have been extremely anxious about this.*
- *At first it was suggested I had anxiety. When I was positive for antibodies their attitude changed considerably and I felt like i was taken seriously. One of the gps admitted however that they only really have the resources to deal with each symptom rather than treat the illness as a whole.*

- *At times I felt like I had to beg for help or guidance, the phone consultations tended to be rushed to be completed in 10 minutes. Not entirely their fault, but a general lack of information on Covid*
- *Been pointless, feel unbelievably, no help, not actually helped any except given me a sick note for work.*
- *Closed door, telephone only, I have chest issues and no one has ever listened to my chest, always advised to go to A&E, very poor service (and I work for the local CCG - which the practice know)!*
- *disheartening to be told i did not have covid, and frustrating to have my self-diagnosis debunked with no alternate diagnosis offered*
- *Dismissed by two GPs - increased the sense of isolation and fear. The third GP has been much better in including me in the conversation but could have done more to follow up the symptoms that weren't cardiac.*
- *Dr was brilliant she understood the covid virus. Since she went on maternity leave the doctors practice don't know what to do with me. No local covid centre to be referred to and they have no antibody tests either*
- *Excellent listener, willing to admit she (and other doctors) don't know enough about covid yet, did blood tests as precaution to rule out any other medical cause of long-term symptoms. Never hurried me when discussing case, supportive in the timing of my return to work (7 wks after cough started). Told me that the practice was having weekly covid meetings and that many patients were in same position. Never once suggested it was anxiety*
- *Felt GPs have been told virtually nothing about long covid and are only aware of the problems we are suffering if they've tried to inform themselves or experienced covid themselves.*
- *For a long time my main GP didn't believe me about covid as my tests were negative. A recent visit another GP wouldn't even acknowledge long covid and said that it was irrelevant what caused my fatigue and chest pain! I still do not have a covid diagnosis*
- *From first contact with receptionist to GP and all following Interactions all have been fantastic. They treat me with respect and state that I have had a very bad time with COVID-19*
- *Frustrating. There is no support other than go to A and E. No possibility of referral to specialists despite persistent symptoms. No rehabilitation advice.*
- *gp advised I had post viral fatigue and I needed to rest and pace. Gp didn't know about long covid symptoms and didn't seem interested. No follow up. I have no confidence in my gp helping me so I don't contact them.*
- *GP continually had no idea what I was describing as my numerous symptoms. Kept asking me if I was anxious. When paper for primary care was published by BMJ I felt as if I was taken more seriously and referrals have now been made. I have been waiting nearly 3 months for 24 hour heart monitor.*
- *GP has been unable to provide any help through NHS and I have had to resort to organising this myself and being seen privately*
- *GP incredibly supportive has said will take time as body been through a trauma. Supporting me with reduced hours note to employer and resting*
- *GP listens to my issues & tries to research info to help, but when tests come back with no indication of anything wrong, she doesn't know what to do next. If I explain that I've read articles from other countries about people in my position & treatment protocols for long haul - she just says that she can't prescribe the various medications, as no protocol for it in UK. I've been ill for over 6 months & still have dreadful chest pain, as paracetamol not effective any longer.*
- *GP sympathetic but has no idea how to treat beyond anxiety medication*
- *GP would sit in silence not knowing what to say to me. It was as if he wasn't allowed to discuss covid with me and was just letting me vent. It wasn't until NHS111 sent him an urgent report after I contacted them due to difficulty breathing (June) that he started to pay attention and sent me for a chest x-ray.*

## APPENDIX

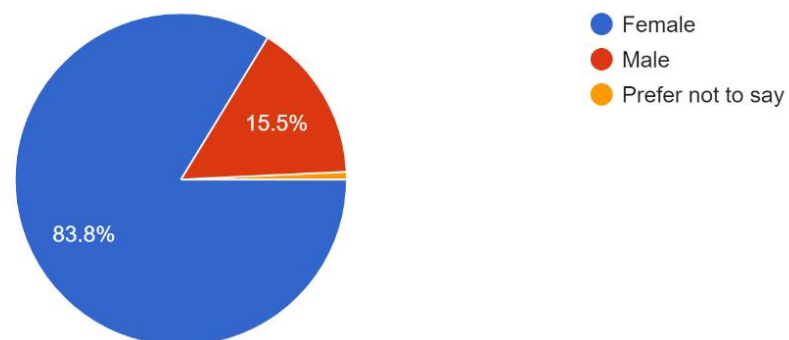
Which country do you live in?

271 responses



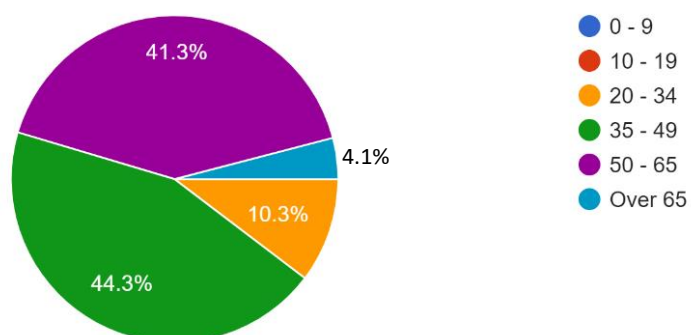
What is your gender?

271 responses



Please select your age group (or the age of the person you are filling this in for) :

271 responses



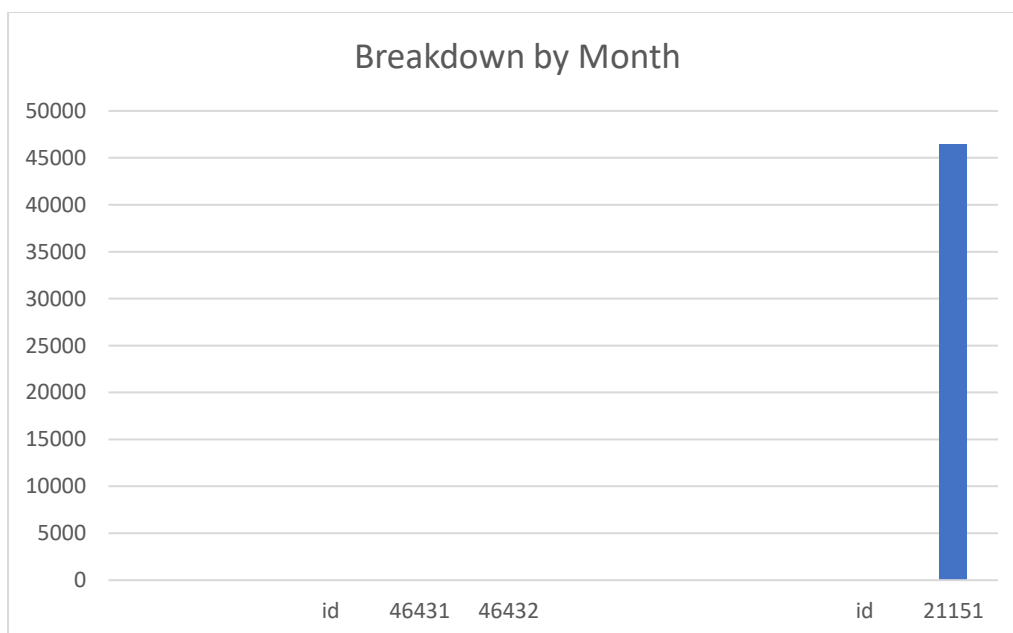
When did you first experience symptoms of Covid-19?

**Averages: Days 165, weeks 23, months 5**

**Breakdown by Month**

Months	No	%
1	2	1%
2	5	2%
3	5	2%
4	12	4%
5	58	21%
6	175	65%
7	10	4%
8	1	0%
9	2	1%
	<b>270</b>	
Average	<b>5.53</b>	

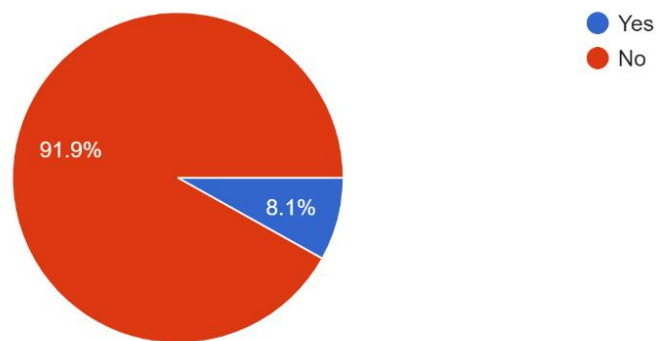
Month	n	%
Jan	1	0%
Feb	13	5%
Mar	183	68%
Apr	48	18%
May	12	4%
Jun	4	1%
Jul	5	2%
Aug	1	0%
Dec	3	1%
	<b>270</b>	





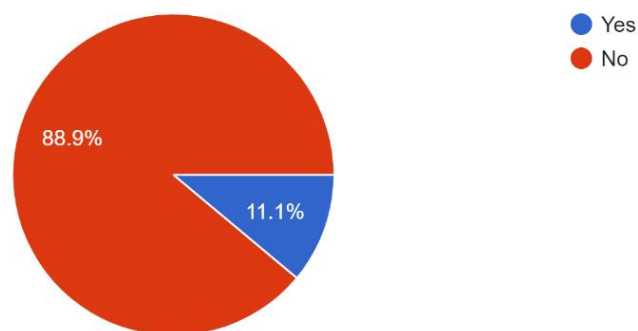
## 3. Did you have a positive PCR/Swab test?

271 responses



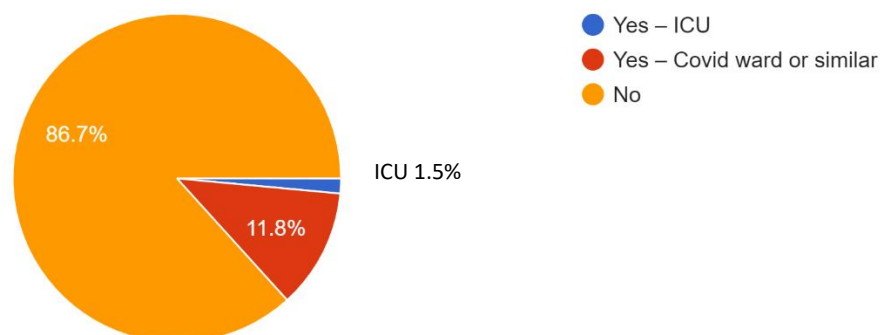
## Have you had a positive antibody test?

271 responses



## Were you admitted to hospital?

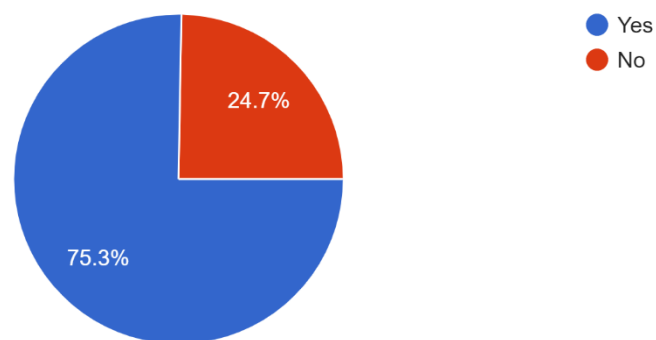
271 responses





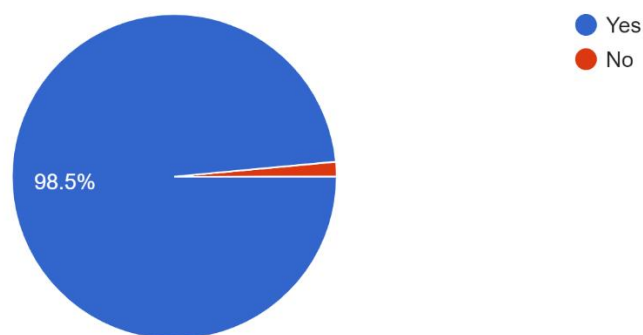
During the acute phase of your illness, did you contact your GP surgery?

271 responses



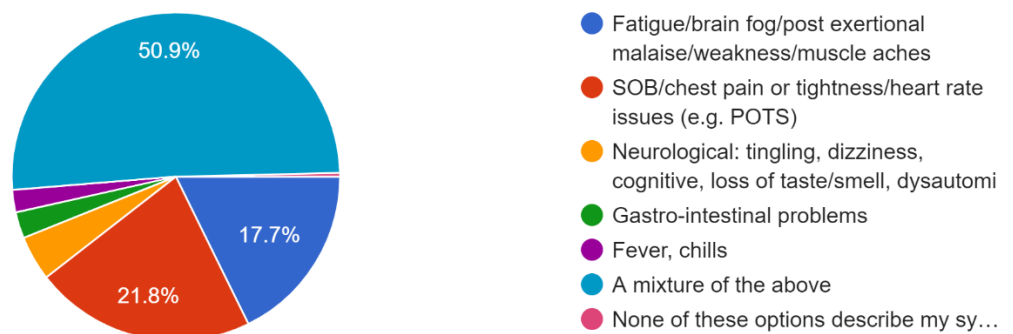
Are you still suffering symptoms?

271 responses



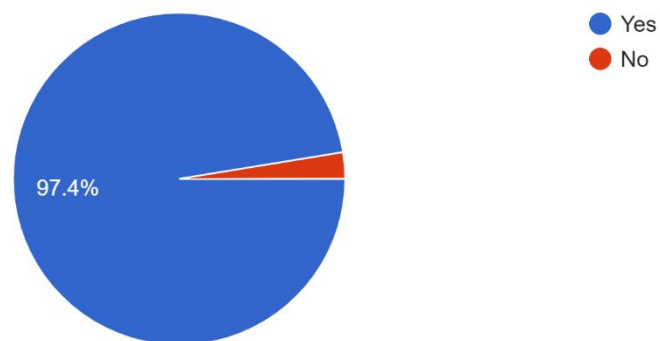
Please choose from this list the main or most serious or most troubling type of symptom you have or had during the post-acute ('long covid') phase of your illness:

271 responses



During the post-acute/long covid phase, did you contact your GP surgery?

271 responses



If you answered 'No' to the last question, please indicate why you didn't get in touch with your GP

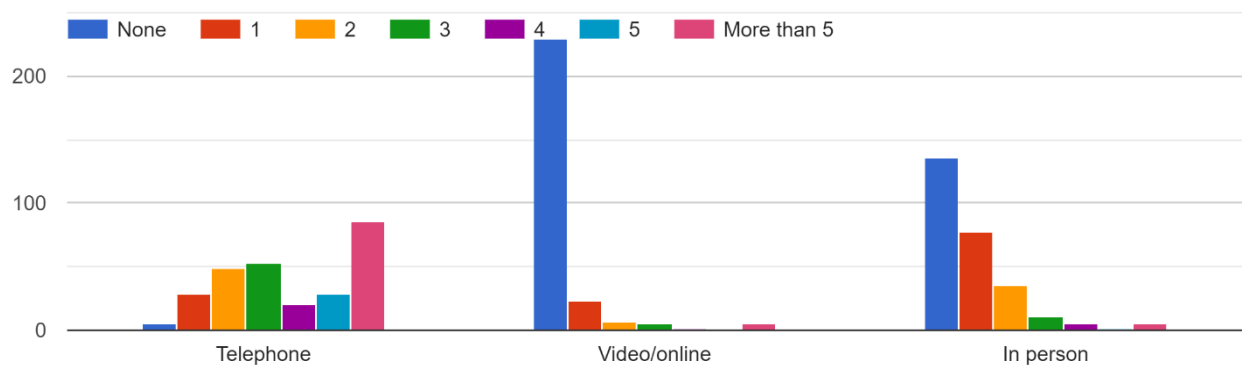
10 responses

n=10



Approximately how many consultations have you had with your GP during the post-acute period?

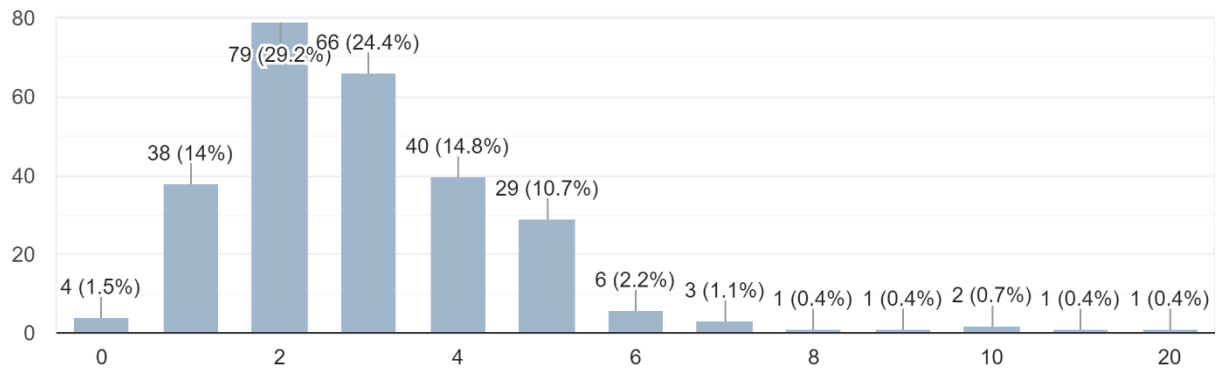
Please specify according to type of contact



Consultation	n	%
Tel	1105	78%
Video	84	6%
Person	234	16%
	<b>1423</b>	

How many different GPs from your practice have you been in contact with?

271 responses

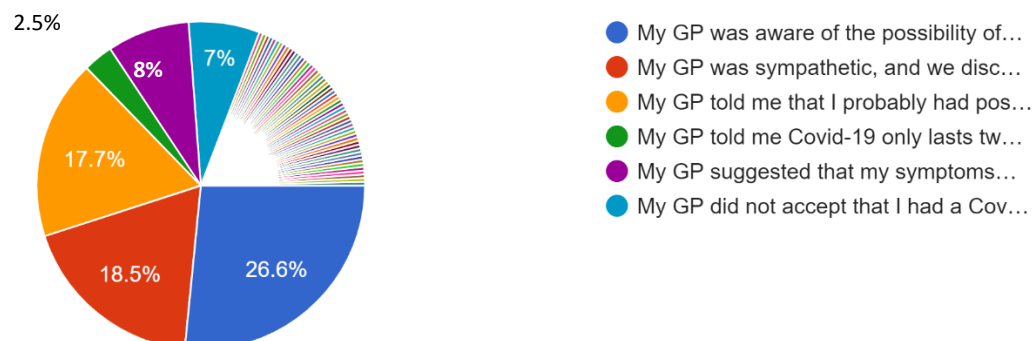


No of Different GPs	n	%
0	4	1%
1	38	14%
2	79	29%
3	65	24%
4	40	15%
5	29	11%
6	6	2%
7	3	1%
8	2	1%
10	2	1%
15	1	0%
20	1	0%

**270**

Please choose the closest from this list regarding your GP's approach to your post-covid symptoms:

271 responses



My GP was aware of the possibility of Long Covid and was sympathetic but did not have any practical advice	26.6%
My GP was sympathetic, and we discussed treatment options	18.5%
My GP told me that I probably had post-viral fatigue, that I needed to rest and/or suggested I look online for information about PVF / chronic fatigue	17.7%
My GP suggested that my symptoms suggest I may be suffering from anxiety due to having had Covid/experiencing lockdown/some other reason	8.0%
My GP did not accept that I had a Covid-19 infection	7.0%
My GP told me Covid-19 only lasts two weeks and so it must be some other virus or illness that is causing my symptoms	2.5%
Other	19.7%

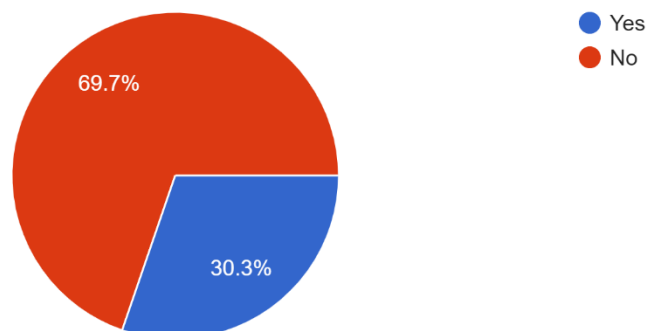
#### Other comments:

- Different GPs held very different perspectives – from caring and helpful to gaslighting
- 1st appeared neutral and unhelpful, 2nd sympathetic but focused on antidepressants in case i got depressed rather than symptoms i had, third empathy and acknowledgement and helpful and understanding given the level of GP lack of guidance.
- The first GP I spoke to via 111 in April told me I couldn't have been sick with Covid for more than 14 days and so I must have had two separate illnesses. One GP suggested my neurological symptoms were down to stress/ anxiety.
- Did not really show much interest
- I had almost all of the above. I had one GP tell me I should seek counselling, another that post Covid doesn't exist, a couple that were sympathetic but not offering anything else, finally I spoke to one end of July that believes in post Covid and referred me
- I had different responses from different GP's. The majority dismissed my symptoms as mere anxiety. Eventually a Locum GP & then one of the practice GP's diagnosed long Covid. I was then referred to a respiratory Consultant.
- All of the other gp's gave me the impression that they were annoyed that I was ringing with yet another symptom.

- *I had very mixed responses from all GPs at my practise -as knowledge also grew - but at times it was dismissive and harmful*
- *My GP accepts I have Long Covid but insists I do not need further tests or treatment as they can't help.*
- *My GP has been incredibly supportive and has kept up to date with all the information as been make very slow progress forward not referring for any tests apart from blood tests*
- *My GP was aware of long covid & has tried to be helpful - referred for CT scan & echo, but now doesn't know where to go next, to help me.*
- *My GP was reluctant to commit to a Covid diagnosis but willing to diagnose post-viral fatigue (not specific to Covid) and was unable to offer any advice other than repeated blood tests and rest.*
- *My GP(s) agreed I had had Covid. Was suffering long term symptoms. Referred me to Covid recovery as soon as available in my area. My GP also checked how I was coping mentally (and in way implied anxiety was causing symptoms rather were my symptoms making*
- *Not spoken to them as do not feel they will listen or take interest*
- *One GP suggested anxiety and said that symptoms varying in intensity (i.e. peaks and troughs) meant it couldn't be viral, and told me off for requesting a chest x-ray after symptoms persisted for two months. A second GP believed me and sought a cardiology referral*
- *Sympathetic initially, not now. Offered amitriptyline. Refused other requests for help.*

Did your GP follow up your initial post-covid contact by phone/text/email?

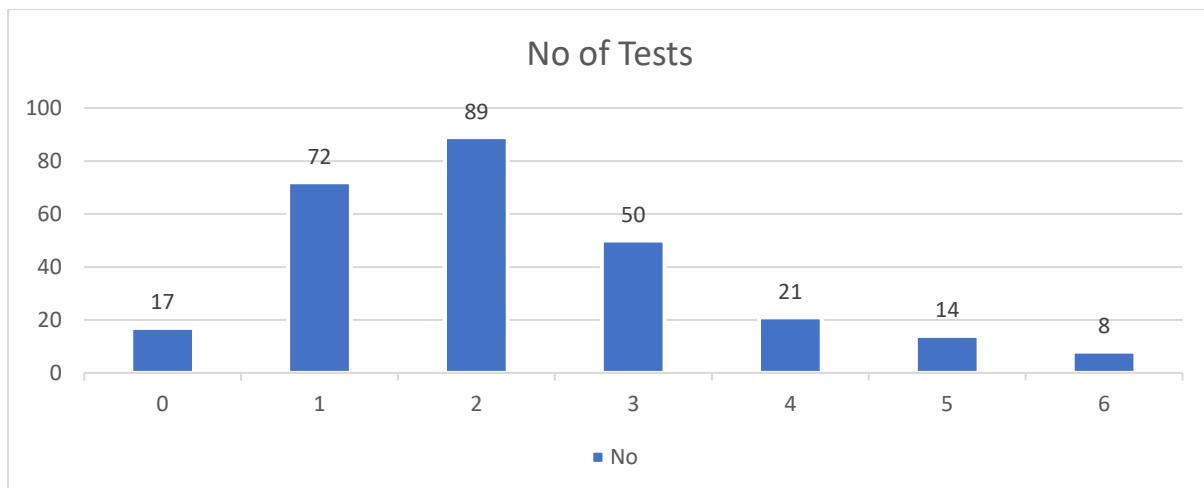
271 responses



Did your GP send you for any tests? Please indicate all/any that apply

94% - tests

6% - no tests

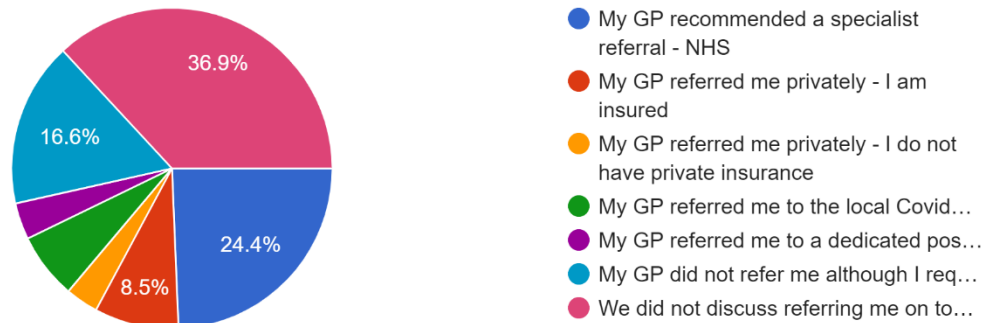


- Have been told lung tests are unavailable because of covid
- Pelvic ultrasound!!!! (This patient had neither previous nor current gynaecological issues)
- Referred me for CT scan but the hospitals refused
- 24 hour ecg reluctantly

Test	No
Blood test	220
X-ray	142
ECG	78
Antibody test	36
CT Scan	27
Echocardiogram	19
MRI	14
Lung function	12
Stool	4
Sent to A&E	4
Abdominal ultrasound	3
Sputum	3
Thyroid	2
Colonoscopy	2
Holter	1
Gastroscopy	1
Endoscopy	1
Urine	1

Did you have any discussions regarding referral to specialists and/or other therapists? Please select the closest outcome to your most recent consultation

271 responses



GP Referral	n	%
We did not discuss referring me on to any specialist services	100	37.0%
My GP recommended a specialist referral - NHS	66	24.4%
My GP did not refer me although I requested a referral	44	16.3%
My GP referred me privately - I am insured	23	8.5%
My GP referred me to the local Covid Hub	18	6.7%
My GP referred me to a dedicated post-covid rehab clinic	10	3.7%
My GP referred me privately - I do not have private insurance	9	3.3%

**If you have been referred, please select which specialists/therapists you have been referred to**

Specialist	No
Respiratory specialist	57
Cardiologist	51
Neurologist	28
Physiotherapist	9
Infectious	7
Rheumatologist	7
Gastroenterologist	4
Fatigue	3
Counsellor/psychotherapist	3
Psychiatrist	2
Speech therapist	2
Ophthalmologist	2
Vascular surgeon	1
Immunologist	1



Endocrinologist	1
Covid hub doctor	1
Nutritionist	1

180

Referrals

Not referred 132 48.90%

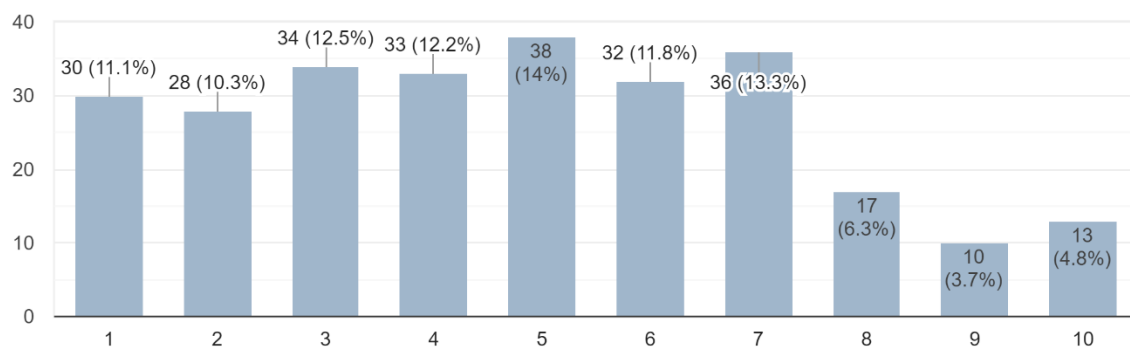
Referred 138 51.10%

**270**

- *Referral Not accepted - not Covid +*
- *Please note I got my referral to neurologist via A&E & not via my GP*
- *I will only be referred on depending on the outcome of MRI which I'm still waiting for an appt for*
- *I was referred to a rapid chest pain clinic but nothing else.*

Overall, how happy have you been with the care provided by your GP during the post-covid period? Please mark below on the line between 1-10 where 1=very dissatisfied, 10=very satisfied

271 responses

**Average score: 4.9**