

GP Engagement with Patients with Long Covid: Report based on Survey carried out by Long Covid SOS February – March 2024

In September 2020 Long Covid SOS carried out a survey to assess the experiences of patients with Long Covid when consulting their GP. The report is available [here](#). At that point in time many who completed the survey had been experiencing symptoms for 6 months after a Covid-19 infection. 3½ years on, there remain very limited treatment options for Long Covid and patients are still struggling to get the care they need. Although there are clinics for Long Covid in England, there is much variation between services and provision is very patchy in the devolved nations. At the end of March 2024 the Long Covid team at NHS England is to be disbanded and responsibility for running and monitoring Long Covid services will fall to the Integrated Care Boards (ICBs). GPs remain the first point of contact for patients, and their approach influences the care that a patient will go on to receive. Long Covid SOS is working on resources for GPs, and at this time of change and uncertainty in Long Covid care an updated survey seemed necessary, with a view to comparing results to establish how things have changed in the intervening 3½ years.

Methodology

At the end of February 2024 Long Covid SOS posted the survey on social media platforms including X/twitter and Instagram. The survey was also shared in the Covid-19 Research Involvement Group on Facebook and other online support groups. Responses were invited from people living in the UK.

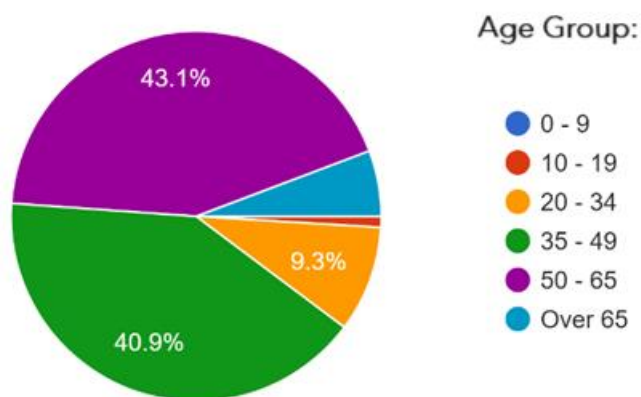
Results

313 responses were received, slightly more than in 2020. 74.8% were from England, 19.2% were from Scotland, 4.8% from Wales and 1.3% from Northern Ireland. The disproportionately high number of responses from Scotland may reflect dissatisfaction due to the relative lack of Long Covid services in that country.

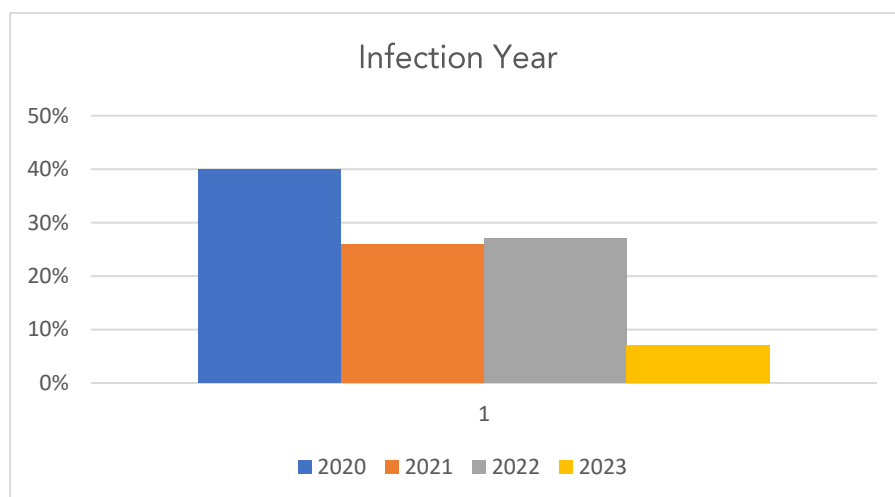


86.6% of respondents were female, slightly higher than in our 2020 survey and considerably higher than the estimated proportion of females with Long Covid which is [around 58%](#), likely due to a female bias in support groups and on social media.

43% were aged 50-65, and 41% 35-49.



40% were first infected by Covid-19 in 2020, 26% in 2021, 27% in 2022 and only 7% in 2023.

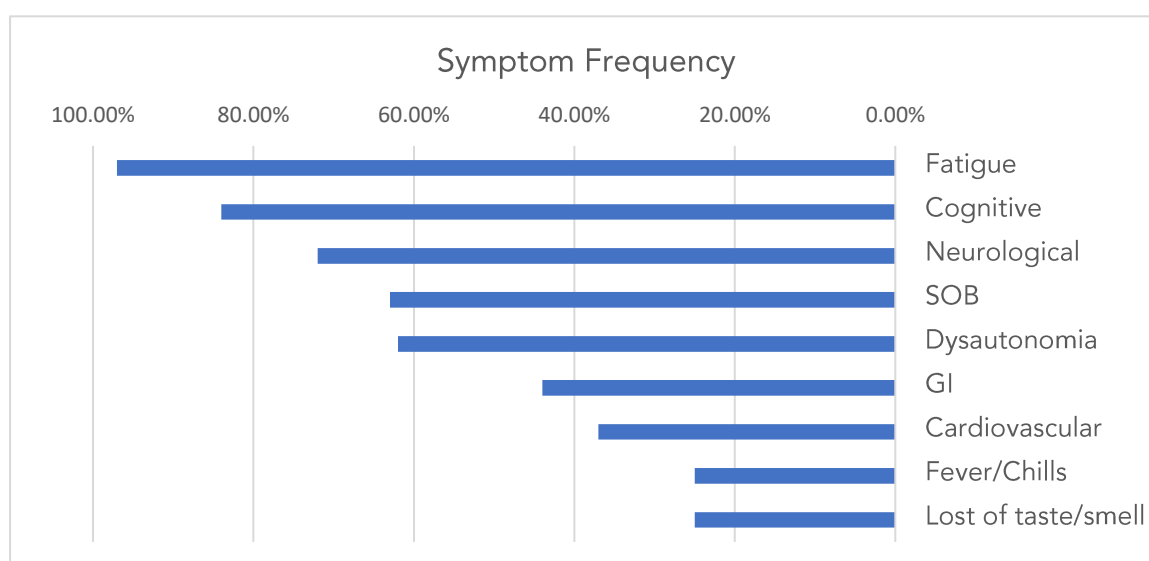


The average length of illness as of 18/03/24 was 1010 days, or 2 years and 9 months. Only 3 participants had recovered.

90% were not hospitalised during their acute Covid infection. Only 52% consulted their GP during their acute infection, however more than 97% did contact their GP about their Long Covid symptoms, with 84% having seen a GP in the past year. Of these, **the average time since their last GP appointment was approx. 3 months.**

9% had never had a face-to-face appointment with their GP about Long Covid, 19% had had more than 5, and 16% more than 10 face to face appointments. 92% had telephone consultations, with 22% reporting more than 10. Only 12% were offered video or online consultations. Unsurprisingly, in our 2020 survey only 50% were able to see a GP in person. On average, respondents saw just under 4 different GPs.

The most frequently reported **symptoms** were Fatigue/post exertional malaise/weakness (97%), cognitive issues (84%), neurological problems (72%), shortness of breath and breathing issues (63%), PoTS/dysautonomia (62%), gastrointestinal issues (44%), cardiovascular problems (37%), fever/chills (25%), loss of taste/smell (25%).



GP Approach to patients with Long Covid Symptoms

We provided 5 choices, with a free text option for 'other':

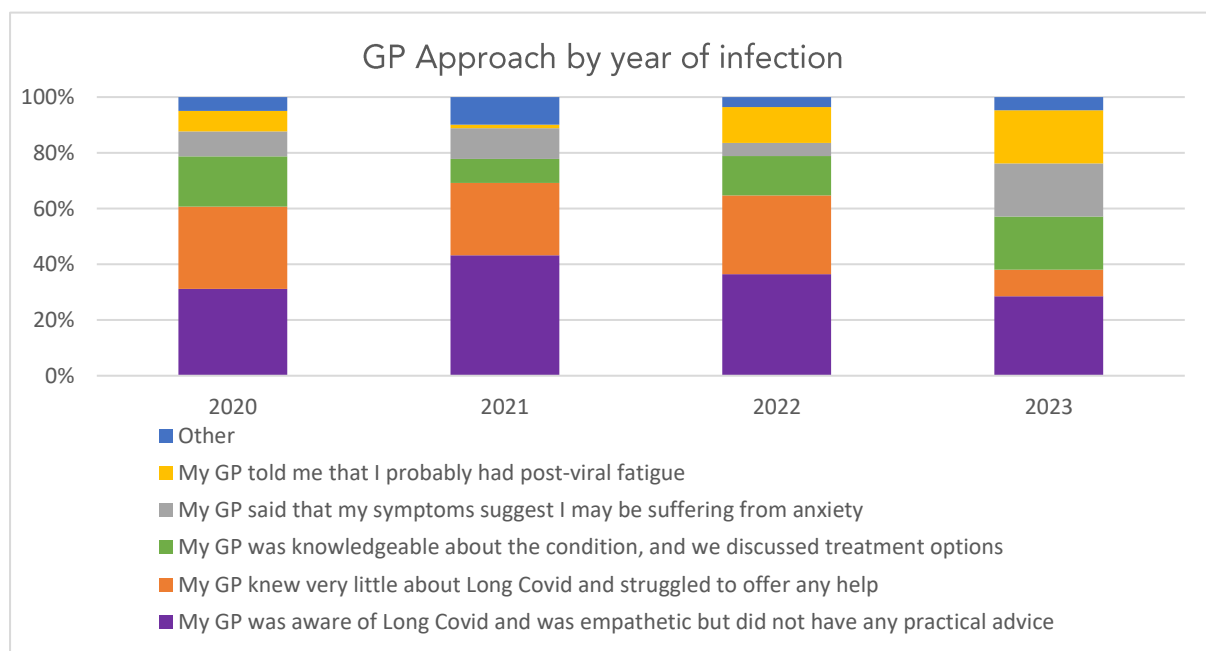
1	My GP was aware of Long Covid and was empathetic but did not have any practical advice	35.5%
2	My GP knew very little about Long Covid and struggled to offer any help	26.8%
3	My GP was knowledgeable about the condition, and we discussed treatment options	14.4%
4	My GP said that my symptoms suggest I may be suffering from anxiety due to having had Covid/the impact of the pandemic/some other reason	9.0%
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 chronic fatigue	8.0%
6	Other (some of the 'other' responses have been allocated to the options above depending on the comments)	6.4%

More than a third selected option 1 and taking 1 and 2 together, greater than 62% of respondents indicated that their GP **was not able to help them**, rising to 71% when the diagnosis of anxiety is included. This is very concerning given that Long Covid has been impacting people since the start of the pandemic and according to the most recent [ONS data](#) there are 1.9 million people reporting symptoms in the UK. NHS England set up Long Covid services towards the end of 2020 and the RCGP has published guidance and held training webinars for doctors. NICE [Guidelines](#) on Long Covid were published in late 2020 but have not been updated since November 2021.

We did some further analysis to see if some of these scores are coloured by experiences early in the pandemic when not much was known about the condition. Below are data based on the year of infection:

	All	2020	2021	2022	2023
n	313	126	81	85	21
My GP was aware of Long Covid and was empathetic but did not have any practical advice	35.5%	31.1%	43.2%	36.5%	28.6%
My GP knew very little about Long Covid and struggled to offer any help	26.8%	29.5%	25.9%	28.2%	9.5%
My GP was knowledgeable about the condition, and we discussed treatment options	14.4%	18.0%	8.6%	14.1%	19.0%
My GP said that my symptoms suggest I may be suffering from anxiety due to having had Covid/the impact of the pandemic/some other reason	8.9%	9.0%	11.1%	4.7%	19.0%
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 chronic fatigue	8.0%	7.4%	1.2%	12.9%	19.0%
Other	6.4%	4.9%	9.9%	3.5%	4.8%

The relatively small number of respondents who were infected in 2023 is likely to put the figures for that year into question (in particular given the high score for an anxiety diagnosis), however there is no clear pattern that GP knowledge of Long Covid and their subsequent approach has improved over the years.

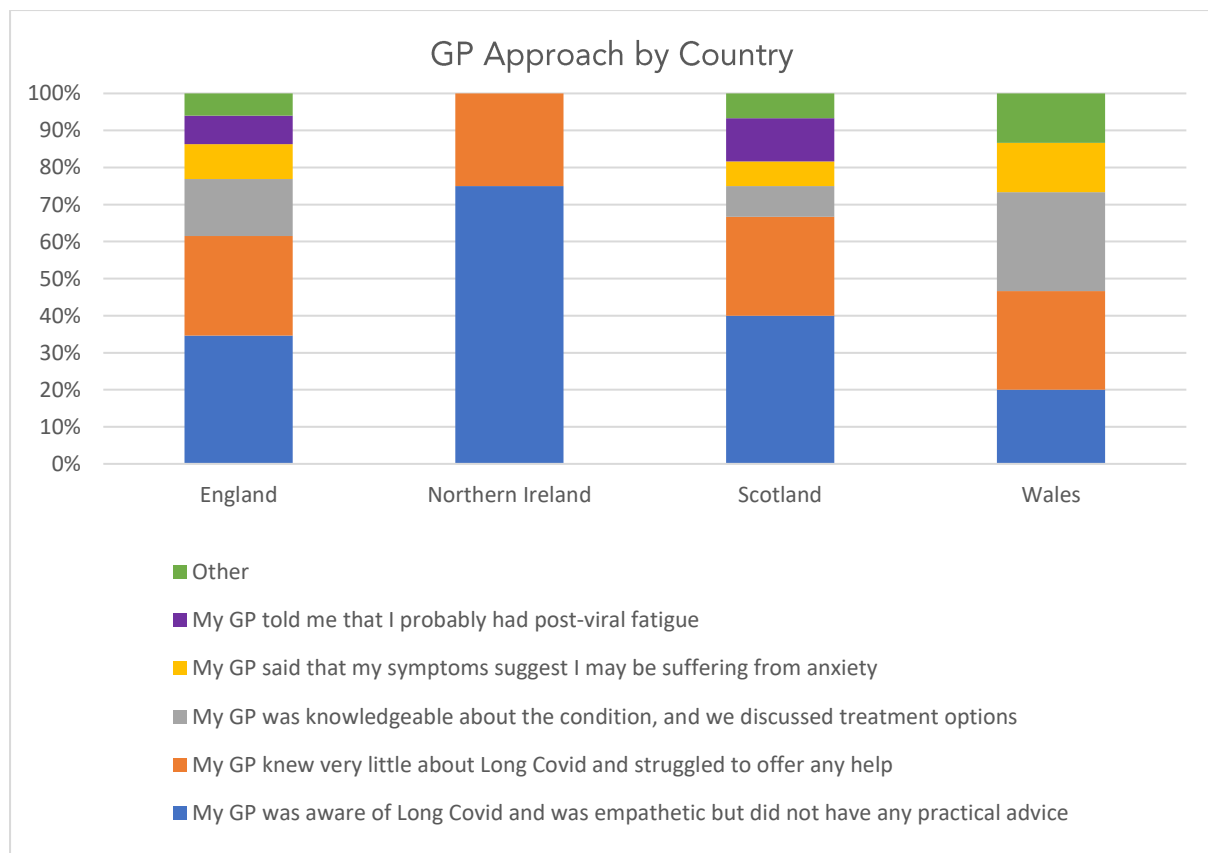


In our 2020 survey, the questions were slightly different due to the circumstances, but these comparisons can be made:

1. My GP was aware of Long Covid and was empathetic but did not have any practical advice: 33.3% selected this option in 2020, compared to 35.5% in 2024
2. My GP told me that I probably had post-viral fatigue: 22%, compared with 8.0%, a reduction of 64%
3. My GP was sympathetic and we discussed treatment options: 22.9% compared with 14.4% in 2024 – a reduction of 37%
4. My GP suggested that my symptoms suggest I may be suffering from anxiety: 10.7% compared with 8.9%

The 37% reduction in those willing to discuss treatment options could be due to the existence of Long Covid clinics (mostly in England), however it is certainly not encouraging.

Looking at these data by country we can see that Scotland (60 respondents) and Northern Ireland (4) score low for knowledgeable GPs, although things seem to be better for people in Wales (15)



Analysis of the data by **gender** did not reveal anything significant.

Some observations from participants who selected 'other':

"First 5 GPs weren't knowledgeable at all and offered little help - some sympathised and others told me I just needed to accept my symptoms. One yelled at me saying 'what do you want me to do exactly?!' And refused to order tests I'd requested"

"In the early days I taught the GP and surgery about Long Covid and still do teach on occasion"

"Some have been knowledgeable but helpless, some earnest but had knowledge that was inaccurate or out of date. Most have been horrified when they realised just how few resources there are available" (in Scotland)

"My doctor put Long Covid in air quotes and refuses to call it Long Covid saying 'chronic fatigue syndrome or whatever you want to call it'. Shrugged a lot."

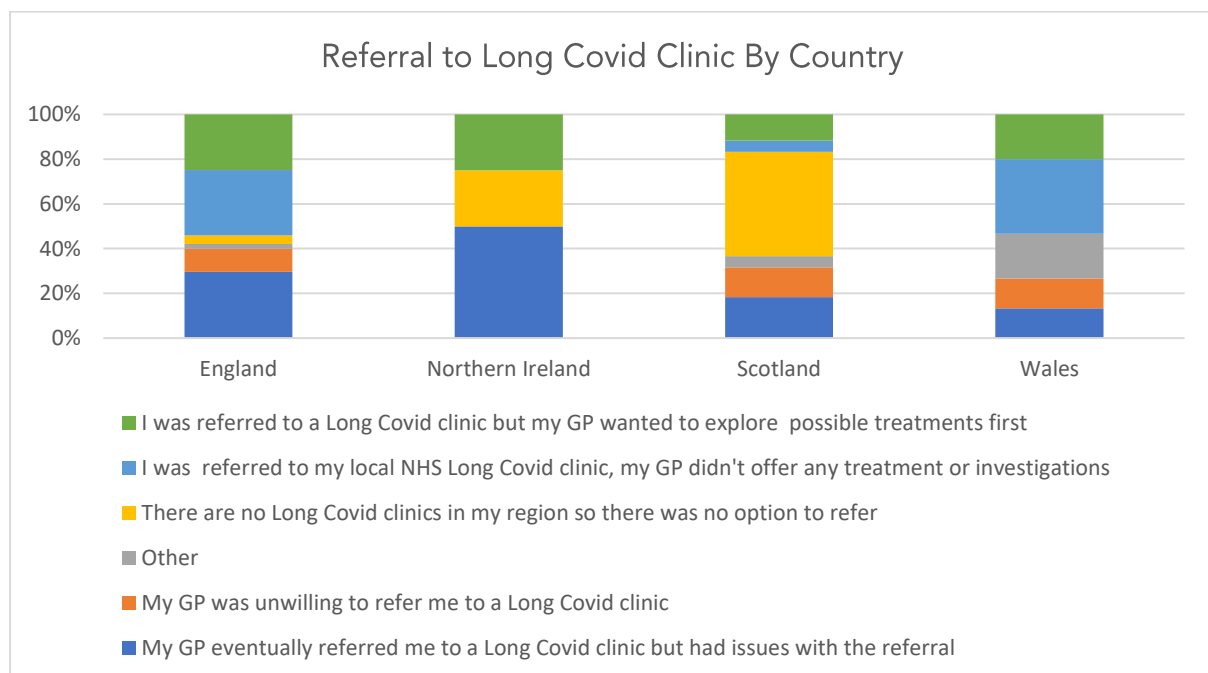
"My GP knows nothing about ME or Long Covid and has diagnosed me with nothing other than vague suggestions of anxiety, Covid is not responsible."

"They said there had never been and was no treatment for someone like me"

Referral to Long Covid Clinics

There are no dedicated Long Covid clinics in the devolved health regions but some secondary care clinics offer treatment.

In England, where around 100 NHS England clinics exist, 54% were able to secure a referral. However, 30% claimed that their GP had problems with the referral and 10% of GPs were unwilling to refer. In Scotland, almost half the respondents did not have a clinic of any kind to be referred to.



"A referral was only made after I formally complained. Then 4 referrals were rejected as they were incomplete. I am now under the LC clinic."

"I had a lot of tests first, it took a lot of time to get referred as they kept losing paperwork. It took over 4 months and would have been longer without my partner advocating"

"It was me who asked for it and only the register GP helped me. The other GPs were sending me to a cardiologist and giving me Diazepam for anxiety."

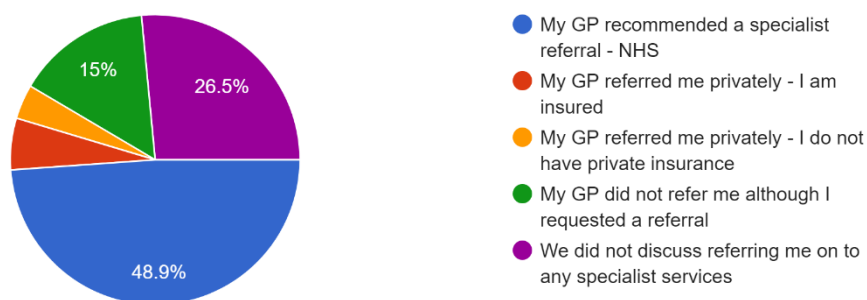
"One GP at my practice was very unhelpful and I felt strung along for months without medication or referrals, only listened to me when I brought along my male partner, then a different GP eventually referred me to a Long Covid clinic."

Specialist Referral

Just under half of the sample were referred to NHS specialists, twice as many as in 2020. The proportion who were refused a referral was very similar to the last survey, at 15%. Slightly fewer were referred to private specialists this time, but 40% of these were people who did not have private insurance. The most frequently reported referrals were to cardiology (50%), respiratory (42%), neurology (35%), rheumatology (22%), ENT (22%), physio (22%) and psychotherapy (19%)

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

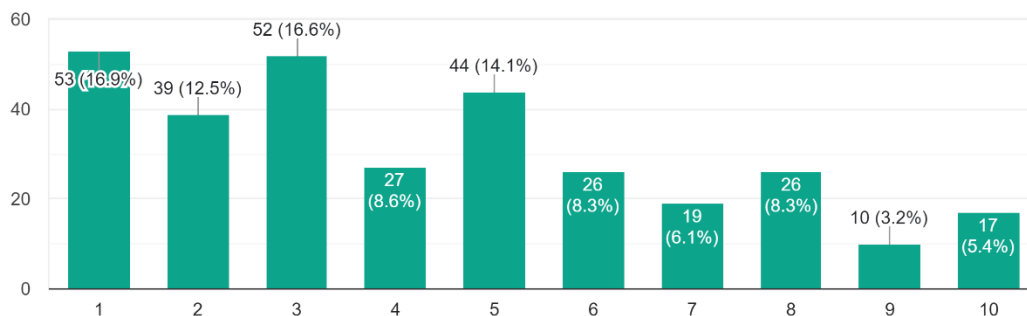
313 responses



Overall Rating

We asked respondents to rate their GP in terms of care provided on a scale between 1 and 10. The average score was 4.4. In 2020 the average score was 4.9.

Overall, how happy have you been with the care provided by your GP during the time you have had Long Covid? Please mark below on the line between 1-10 where 1=very dissatisfied, 10=very satisfied
313 responses



55% rated their GP 4 or less out of 10, with only 31% scoring their GP 6 or more. This suggests a relatively high level of dissatisfaction.

Whereas in 2020 most of those surveyed would have been experiencing symptoms for around 6 months at the most, as of Feb/March 2024 many will have been through years with Long Covid and their frustration with the lack of available care will be more acute. It is possible that people have higher expectations of their GPs now that Long Covid has been known about and researched for almost 4 years. Unfortunately the knowledge and ability of GPs to help patients has, for various reasons, not been able to keep up with scientific progress to date.

Participants were invited to leave comments – a selection spanning the range of approaches:

“My GP practice is better than most but they have little understanding of Long Covid and won’t do anything unless a consultant asks them to. They have been proactive & sympathetic in check ups regarding mental health but never ask about Long Covid. One GP said ‘a lot of people aren’t sure Long Covid is actually a thing’.”

“I’ve found each GP to be sympathetic and supportive; I’ve been given some info (e.g. NHS websites) to access; blood tests/ECGs/chest x-rays/echocardiograms etc were booked in promptly as part of the necessary referral process to the long covid clinic; specific advice has come from the specialists rather than the GPs though. Importantly, I’ve never felt disbelieved.”

"My GP is just as frustrated as I am about the lack of treatment and specialists available in my area. I have suggested medications to try but he has been unwilling to prescribe. I have been seeing him every month just to check in how I am but he does not offer any treatment. There is no help locally." (Scotland)

"Initially help was poor but as long covid became better known the GP was more helpful though now it's basically a case of get on with it. I have repeatedly asked for help with bloating, acid reflux etc but this has not been looked into."

"Although empathetic, they seem poorly equipped to offer any practical help. The only medication I have been given is beta blockers, but because they haven't monitored my BP or heart rate on many occasions, and I know both my resting heart rate & BP can be quite low at times, I am not convinced that I am on the most suitable medication. I am finding most of my information about managing my condition on the internet, and if I mention some of it to the GPs (e.g. increasing my salt & fluid intake): they seem quite shocked, especially at the salt (I use the advice from POTs UK website for this guidance)"

"My GP has always been sympathetic and always believed me but seem to have little to no knowledge of the condition. Any treatment has come at my insistence which I do find exhausting and frustrating"

"They have learned more over the years and are happy to support treatments suggested by the doctor at the Long Covid clinic. They've always been supportive and sympathetic and have never suggested I have anxiety."

"My GP's have been really good although they had no knowledge of how to treat long Covid they were empathetic and quickly referred me onto the appropriate consultants who on the other hand were dismissive at best the respiratory consultant stating on our first meeting he did not believe in long Covid."

"Not seen the same GP more than once and none of them have any suggestions but all have been understanding. I don't feel they are well informed or know much about the condition."

Study limitations

This was an online survey and participants were recruited via social media. It is therefore unlikely that the study cohort reflects the demographics of the UK Long Covid population. This group is probably more informed about their condition and may expect more from their GPs. There may be some bias in the results since people are more likely to respond to surveys if their experience has been problematic or alternatively particularly good.

Long Covid SOS

March 2024

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