

Experiences of Long COVID Support

Information and awareness in Norfolk



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Who we are and what we do

Healthwatch Norfolk is the independent voice for patients and service users in the county. We gather people's views of health and social care services in the county and make sure they are heard by the people in charge.

The people who fund and provide services have to listen to you, through us. So, whether you share a good or bad experience with us, your views can help make changes to how services are designed and delivered in Norfolk.

Our work covers all areas of health and social care. This includes GP surgeries, hospitals, dentists, care homes, pharmacies, opticians and more.

We also give out information about the health and care services available in Norfolk and direct people to someone who can help.

At Healthwatch Norfolk we have five main objectives:

1. Gather your views and experiences (good and bad)
2. Pay particular attention to underrepresented groups
3. Show how we contribute to making services better
4. Contribute to better signposting of services
5. Work with national organisations to help create better services

We make sure we have lots of ways to collect feedback from people who use Norfolk's health and social care services. This means that everyone has the same chance to be heard.

Acknowledgements

Healthwatch Norfolk would like to thank the Norfolk Community Health & Care Post-COVID Syndrome Service for their help and advice in developing our survey questions.



**Norfolk Community
Health and Care**
NHS Trust

Summary

Healthwatch Norfolk wanted to know what information, advice, and support is available to those living with Long COVID symptoms in Norfolk, as well as how aware people are of these resources. We know from other Healthwatch reports that there is a lack of information and support available for those living with Long COVID.

There are an estimated 2 million cases of Long COVID (symptoms persisting for more than 12 weeks) in the UK as of January 2023. The impact of the condition on people's lives and well-being can negatively affect their health outcomes. It is important that there is support available to help people manage their symptoms and reduce this impact.

We developed and shared a survey to gather public feedback on what information, advice, and support resources are available to those living with Long COVID symptoms in Norfolk. From this we were able to identify themes in the feedback around what is available, how useful it is, and what could be better to improve support.

We heard from 286 people who had experienced Long COVID symptoms in the last year.

We found that knowledge and information about Long COVID and the associated symptoms is lacking. Respondents felt that even some health care professionals are not fully aware or understanding of the range of symptoms. Respondents shared that this made them concerned that they would not be taken seriously and be dismissed by GPs. Updating and improving resources for both public and professionals would help in diagnosis of Long COVID and improve patient confidence in services, knowing that they would be getting the correct support for their symptoms.

There is a lack of awareness for the resources that are currently available, by both public and health care professionals. Many

respondents told us that they were not aware of resources that we had highlighted in our survey including services that professionals should be signposting/referring patients to. More awareness and signposting material, in multiple accessible formats, for what is available would be beneficial in helping patients find the most suitable support for them.

Finally, support needs to reflect the range of symptoms that are associated with Long COVID. Consulting with patients about what they find useful and what they need would help to improve the available resources and identify gaps in support. One example of what patients told us they would like is access to peer support so they can share their experiences and advice.

For NCH&C with potential to work with Healthwatch Norfolk

1. Patient Feedback – Consult with patients on what resources and information is wanted and what needs improving.

For NHS England and Norfolk & Waveney ICB

2. Peer Support – Facilitate access to peer support. Identify sources of peer support and ensure patients are aware of these.

For NCH&C

3. Accessible Information and Signposting – Ensure information and advice resources are in multiple formats that meet accessibility needs and there is adequate signposting.

For Norfolk & Waveney ICB

4. Understanding Long COVID – Increase wider understanding of Long COVID and its symptoms and professionals are aware of the available resources.
5. Resources and Best Practice – Ensure that resources are kept up to date. Ensure resources, best practice, and support for diagnosis of Long COVID is shared with professionals.

Introduction

Read about the background to this work and how we gathered feedback

A hand holding a smartphone with a search bar containing the text 'long covid' and a magnifying glass icon. The background is a blurred crowd of people, and there are decorative teal and pink curved lines at the top of the page.

long covid



Why we looked at this

From other reports, published by local Healthwatch organisations and Healthwatch England, we know that people find that there is a lack of information and support available for Long COVID¹ (Healthwatch England, 2022, and Healthwatch Camden, 2022).

Healthwatch Norfolk wanted to find out what information and support is available to those living with Long COVID symptoms in Norfolk, how aware people are of these, how accessible resources are, and how useful they are.

Additionally, we wanted to use this study as an opportunity to help raise the awareness of local services, support, and advice – including national advice which can be found on the NHS website www.yourcovidrecovery.nhs.uk/.

Long COVID is a condition where the symptoms of a COVID-19 infection continue after the infection has resolved (NHS Your Covid Recovery, 2022). Long COVID can be categorised into two clinical definitions (NHSE, 2023):

- Ongoing symptomatic COVID-19 – for signs and symptoms from 4-12 weeks.
- Post COVID-19 syndrome – for signs and symptoms that continue for more than 12 weeks and are not explained by an alternative diagnosis.

The symptoms of Long COVID vary from person to person, the most common of these include fatigue, shortness of breath, loss of smell, and muscle aches (NHS, 2022). A more comprehensive list of Long COVID symptoms can be found here: <https://www.yourcovidrecovery.nhs.uk/what-is-covid-19/long-covid/>.

Norfolk Community Health and Care (NCH&C) offer a service for those living with Long COVID symptoms (norfolkcommunityhealthandcare.nhs.uk/post-covid-service/). From speaking with their team, they were curious to find out why referral numbers were not as high as they expected them to be. Uncertainty around the condition and lack of knowledge in diagnosing could be linked to this lower than expected referral rate.

According to the Office for National Statistics (ONS) there are an estimated 2 million people in the UK experiencing self-reported long COVID as of January 2023. In the study long COVID status was “self-reported” and therefore misclassification possible (ONS, 2023). We know from the studies by Healthwatch England (2022) and Healthwatch Camden (2022) that there are challenges in

¹ In this report we use Long COVID to refer to COVID symptoms that persist for more than 12 weeks. Others may use other language such as ‘Post-COVID Syndrome’.

diagnosing long COVID, with many people reporting that they found GPs unsure of symptoms and diagnosis.

Long COVID can have a big impact on people’s lives as well as their well-being. It is important that we make sure that there are adequate resources and services available to help people living with Long COVID manage their symptoms to minimise this impact.

Several reports and studies have been published in the last year which highlight the impact that Long COVID is having.

Examples of news headlines:

Headline	Source
‘Long Covid patients face lottery over treatment’	BBC News (June 2022)
‘Long Covid: Early coronavirus sufferer calls for more support’	North Norfolk News (2022)
‘Thousands of NHS staff with long Covid risk losing their pay’	BBC News (2023)
“I’ve had long Covid for two years now”	BBC News (April 2022)
‘Most long COVID patients have organ damage a year later, study finds’	Sky News (2023)

The ONS reported that 72% of adults who had experienced Long COVID said that it had negatively affected their general well-being. Of these 48% said that their ability to exercise had been negatively affected. When looking at working adults only, 50% said that Long COVID had negatively affected their ability to work.

In one study, conducted by the Universities of Southampton and Portsmouth (2022), researchers warned that the long-term effects will have “*significant impact*” on workforces for some time. Their findings note that 5.5% of those who have been infected with COVID-19, and have been vaccinated, will develop “*life-changing chronic illness*”.

We want to make sure that those living with Long COVID, in Norfolk, are supported so to minimise this impact and are able to manage chronic symptoms.

How we looked at this

Approach

The project aimed to collect the views and feedback on the information and support available to those living with Long COVID.

The target audience of this project was all residents in Norfolk and Waveney who have had symptoms of Long COVID in the last 12 months. We did not limit this to those who have been diagnosed with Long COVID as we know from other Healthwatch reports on Long COVID that there are challenges in receiving a diagnosis due to the lack of knowledge of the condition (Healthwatch Camden, 2022).

Survey Design

Healthwatch Norfolk developed a survey to gather feedback on public experiences of accessing information and support for Long COVID in Norfolk.

The survey sought to find out:

- Where participants had tried to find information and support for Long COVID and how useful these were.
- Awareness of NHS and local information and support.
- What information and advice would be most useful to them.
- Their experiences of accessing local support, through a health service, for Long COVID.

Survey responses were collected over a three month period from December 2022 to the start of March 2023. A copy of the survey can be found in Appendix 1.

Participant Involvement and Consent

To encourage participation in the survey Healthwatch Norfolk developed promotional materials, which were distributed through Healthwatch Norfolk's well-established network, with a goal of reaching as many individuals, and groups as possible, including those seldom heard.

Healthwatch Norfolk promoted the project by means of social media posts, videos, a dedicated webpage on the Healthwatch Norfolk website, in the Healthwatch Norfolk newsletter, and through local media coverage.

All survey and interview participants had to give their consent for their answers and feedback to be shared in this report anonymously.

Analysis

The survey was comprised of a range of questions (including multiple choice, closed-ended, and open-ended); therefore, analysis was broad to reflect this, and results and comments are reported on in the next section. To ensure originality any comments used as direct quotes in this report have been left unchanged, only names have been removed to keep anonymity.

A copy of the survey questions can be found as Appendix 1.

Additionally, we collected demographic data to better understand the reach of this survey, help us make sure that we engage with people from different backgrounds and that we understand the needs of different groups in our community. A summary of this demographic data can be found as Appendix 2.

Please note that numbers are rounded to nearest whole number and therefore percentages may not add to 100%.

Limitations

There were some limitations in collecting data and feedback for this project.

Whilst the option was available to contact Healthwatch Norfolk to complete the survey in an alternative format (either over the phone or by requesting a paper copy) all responses received were online. The survey was shared through various means to try and reach as many people as possible however, due to capacity issues, no in-person engagement was conducted for this project so reach of those digitally excluded was limited. This is something that could be addressed in future work.

We did not specify that symptoms/diagnosis had to be 'new' and therefore responses could reflect older experiences of resources and services which may have improved since the time of the individuals experience. Additionally, as with the ONS estimates, responses include self-reported cases rather than just diagnosed cases.

Key Findings

Read how people responded to our survey, and what they told us about their experiences of Long COVID.



What we found out



344

people took part in our survey, of which 286 told us that they had experienced symptoms of Long COVID/Post COVID syndrome in the last 12 months.

We received a total of 344 responses to the Long COVID survey from across Norfolk and Waveney. Of these 83% (286) told us that they had experienced symptoms of Long COVID in the last year, while 13% (44) were 'not sure' and a further 4% (14) told us they had not.

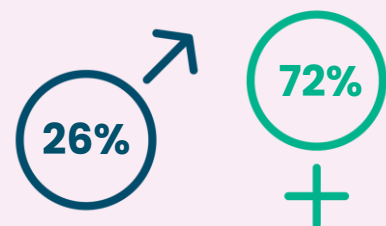
Those who responded that they were 'not sure' or that they had not experienced symptoms are not included in the analysis for this report.

Demographics

For the 286 that told us that they had experienced symptoms in the last year:

- Nearly three quarters (72%, 205) were female, 26% (75) were male, one person identify as non-binary, one as genderfluid, and four preferred not to say or did not respond.
- The majority of respondents (70%, 201) were aged over 45.
- Most (92%, 264) identified as 'White British/ English / Northern Irish / Scottish / Welsh'.
- Just under half (46%, 132) considered themselves to have a long term condition.

For more detailed information regarding the demographics of survey respondents see Appendix 2.



26% of our sample was **male** and **72%** was **female**.



One person identifies as **non-binary**, **One** as **genderfluid**. Four preferred not to say.

Information and advice

Publicity and awareness of resources

We wanted to know where people have tried to find information and advice resources on Long COVID. The majority of respondents (76%, 218) told us that they had tried to find resources in more than one place, and just under half (48%, 137) had tried more than two options. Most (62%, 176) told us that they had looked on the NHS website for resources, followed by at their doctor's surgery (50%, 143).

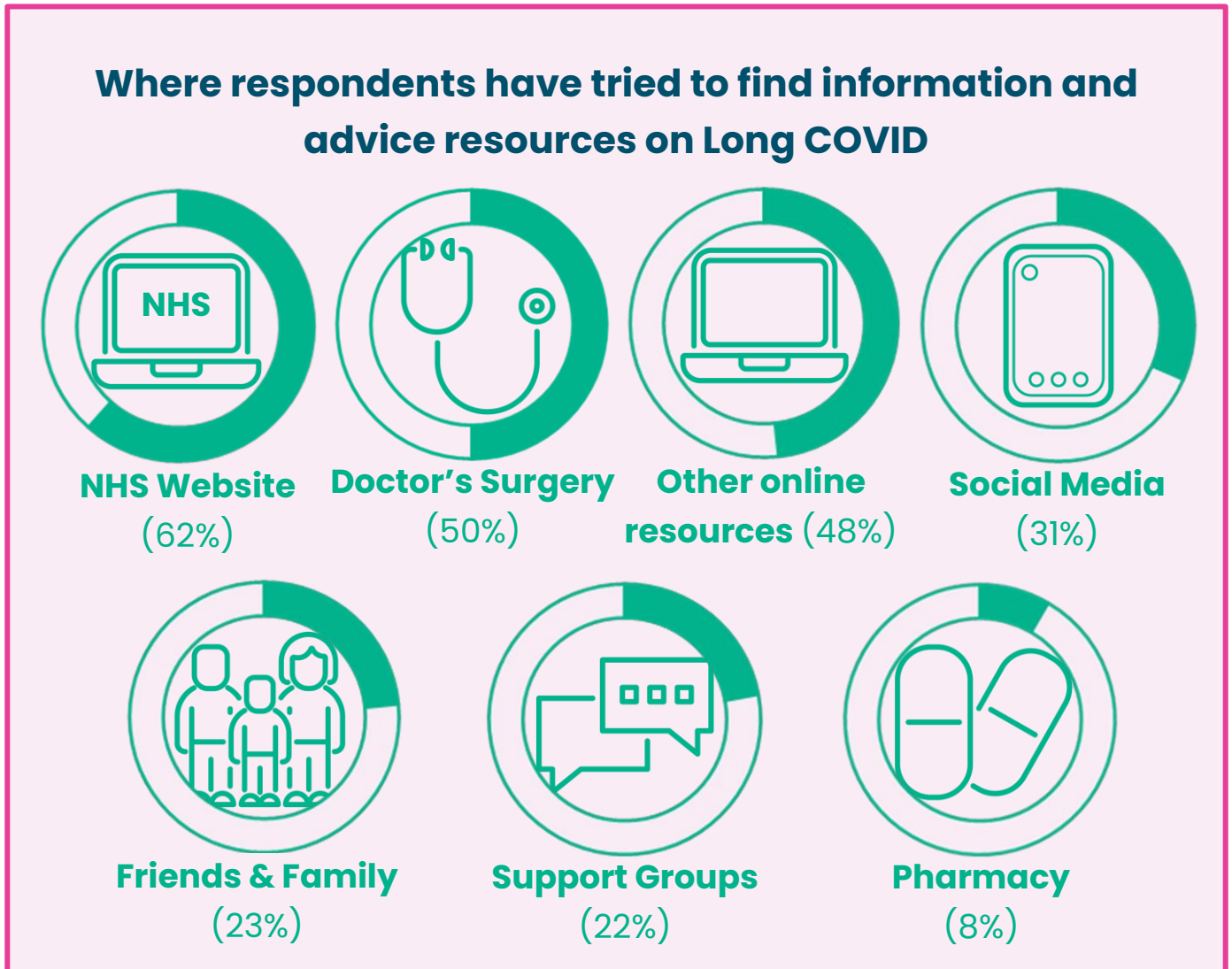


Figure 1. Responses to the question 'Where respondents have tried to find information and advice resources on Long COVID'. Respondents were able to select more than one option.

A number of respondents, (24, 8%), told us where else they had looked for resources, which included the Long COVID clinic, employers/occupational health, and other services (a full list can be found in Appendix 3). One in ten respondents (10%, 29) told us that they did not look for any resources.

Several survey respondents shared with us that they were unaware of information and advice resources which were available to them telling us “I have not seen any”, that they “had no idea this website existed or any other official resources”, and “resources are virtually unheard of and I work in a hospital”. We heard that there needed to be “more public information locally” and greater awareness of the resources which are already available.

“Making access easy to find so we all know what and where to find it. Plus having more information about what advice support and help is available. As myself and others knew nothing about it.”

Your COVID Recovery website

We wanted to know about public awareness of the ‘Your COVID Recovery’ website, which is provided by the NHS. Most respondents (67%, 192) told us that they were not aware of the website, and just under a quarter (24%, 69) were aware of and had used the website (Figure 2).

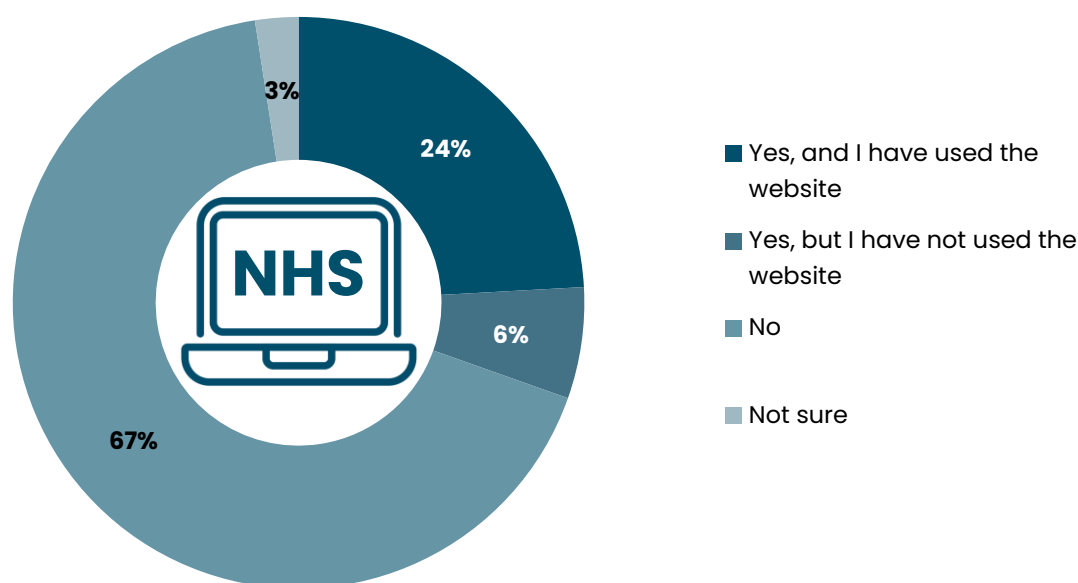


Figure 2. Responses to the question ‘Were you aware of the Your COVID Recovery website currently provided by the NHS and includes information and advice for people with Long COVID to use?’

Some respondents who were not aware of the ‘Your COVID Recovery’ website told us that they thought it should be publicised further suggesting that “perhaps putting [the website link] on surgeries website” would increase

publicity. Alternatively, others suggested that the website could *“have been sent to me when I had my assessment at the long covid clinic”* or that *“patients that require a sickness beyond a month-2 month duration should be made aware of this website.”* Interestingly, one respondent told us that the Long COVID clinic in Norfolk simply provided *“a password to access NHS YCR [Your COVID Recovery]”* website and was surprised that there's a website *“which looks completely different but has the same name, that anyone can access without a password”*. We found that Your COVID Recovery offers a publicly available website as well as an online, interactive rehabilitation platform that requires a login (NHSE, 2020).

Easy and clear access to information and resources

Within this theme respondents also told us there was the need for *“easy access”* to resources and *“clearer information”* for people with Long COVID symptoms. Suggestions included *“a single access point. Containing information on various aspects of LC”, “leaflets at doctors”,* and *“leaflets sent out in the post”*

One respondent highlighted needing more information available offline telling us:

“People unable to use the internet should have access to the same level of resources as those who are able to; I have felt somewhat excluded and undervalued as I cannot afford the internet at home. I was provided with some printouts, some of which had websites for further information.”

Doctors' surgery knowledge and awareness

Even though 50% of respondents told us that they went to their doctor's surgery for information and advice, we heard that their doctors' surgery was often unaware about Long COVID symptoms or services available to them.

We heard from some that *“my gp didn't off [sic.] any help as didn't know enough to advise me”* and that *“more information in gp surgeries and on gp website would be very helpful”*. Another respondent told us that their GP *“was not aware of The Long Covid clinic when I asked to be referred in February 2022”*.



“I think people should be made aware of the symptoms of long covid. I felt like my diagnosis was very rushed and felt like they weren't really sure about it.”



Variety of information needed

Based on the information available on the 'Your COVID Recovery' website, we asked respondents what they felt would be the most useful for them. Most (87%, 249) told us that information about the effect that Long COVID has on the body and mind would be the most useful to them, this was followed by information on 'How to manage daily activities' (37%, 106) and 'Advice on when to seek help' (37%, 107) (Figure 3).

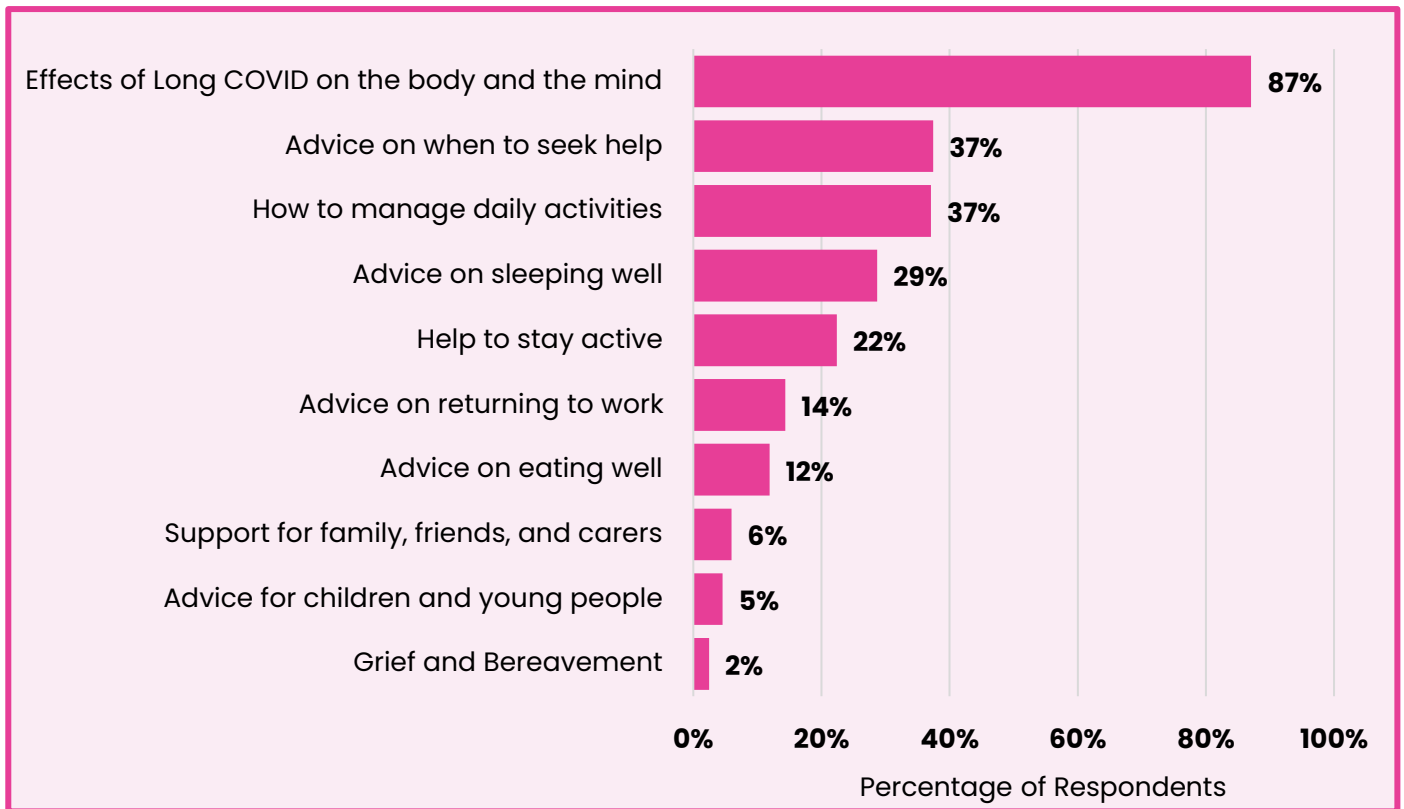


Figure 3. Responses to the question "Your COVID recovery' website provides information on the following topics. What information and advice is/do you think would be most useful for you?" Respondents were able to select more than one option.

We saw the same trend with the 69 respondents who were aware of the 'Your COVID Recovery' website and had used it, with 90% (62) telling us that they would find information on the 'Effects of Long COVID on the body and mind'. Followed again by information on 'How to manage daily activities' (45%, 31) and 'Advice on when to seek help' (36%, 25).

"All the advice is good but that is all it is..advice. What I need is help with getting rid of the symptoms and not just controlling them. [...] I just don't know how long I can continue with the symptoms without trying some kind of treatment to try and rid my body of them."

We heard from survey respondents that their Long COVID symptoms and experiences could vary significantly and several had very specific needs for information and support; as one respondent explained they would like *“as much information as possible it’s difficult because anyone is different”*. Others told us that the information and advice resources they have used *“didn’t go into as much depth as I expected”* and that *“it’s very basic, without the range of combinations of effects that people experienced”*.

These experiences highlight that a variety of information or individualised signposting to useful information and advice already available may be helpful.

Some examples of information respondents wanted included:



- Breathing help: “After the initial really bad, breathless period, I was not really able to do anything without having to sit down until it settled [...] maybe breathing exercises could be helpful and reassuring[sic].”
- Practical help: “Practical information on where I can access practical help with everyday activities would be good”.
- Alternative therapies: “the possible benefits of safe dietary and therapeutic practices”
- Financial advice: “gaining financial support when I cannot commit to a regular work pattern due to Long covid symptoms which can be unpredictable in nature and severity of impact”.



“ Thank you for enlightening me to the two web sites and services available”



Experiences of health services

Access to health services

We asked respondents if they had sought support and contacted a health service about their Long COVID symptoms. The most common response (41%, 116) was that they had and as a result had been diagnosed with Long COVID, a further 23% (67) of respondents had contacted a health service but were not given a diagnosis. A third of respondents (33%, 95) told us that they had not contacted any health service about their symptoms (Figure 4).

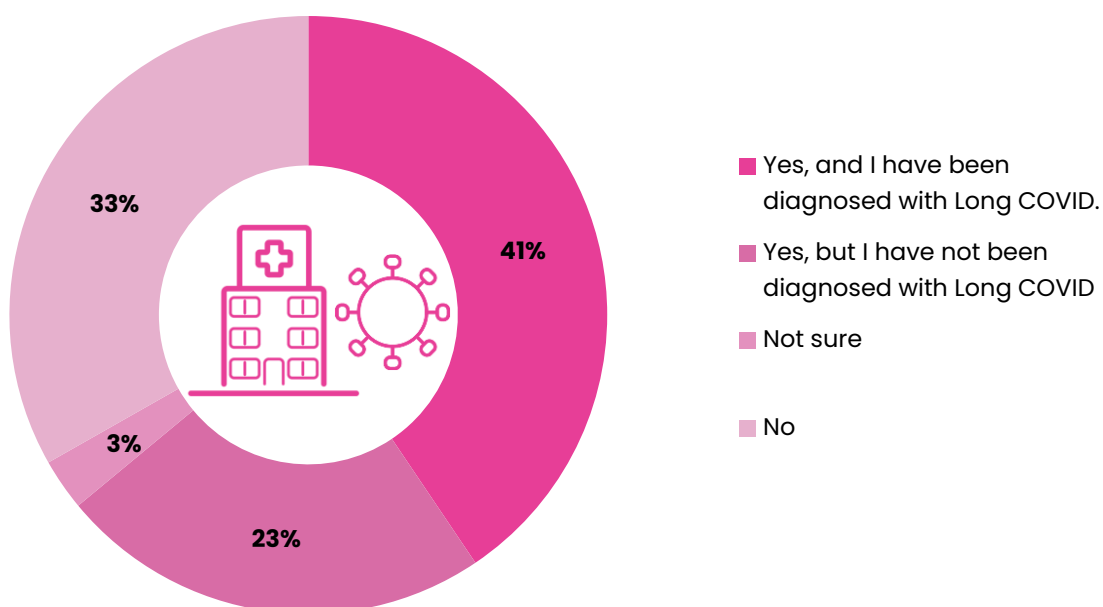


Figure 4. Responses to the question 'Have you contacted a health service (such as your doctors' surgery) about Long COVID symptoms?'

Some respondents told us they found it difficult to access health services or that *"it all takes too long"*. This included difficulties getting an appointment with their doctors' surgeries, for example one respondent told us that they felt *"most things could be improved if my G.P. would actually see me"*.

Another respondent, who has had Long COVID since April 2020, shared how they would like to have more regular contact with their doctors' surgery telling us that they *"felt my GP has just abandoned me"*. They also said that they *"would have liked to have had regular follow ups every 3-6 months"* and that they *"have not had any Long Covid appts with my GP since June 2021"*.

For the 95 who did not contact a health service about their Long COVID symptoms, we asked why they had chosen not to. Almost half (49%, 47) told us this was because they did not think they would receive additional help/support. This was followed by respondents worrying that they wouldn't be taken seriously (46%, 44) (Figure 5).

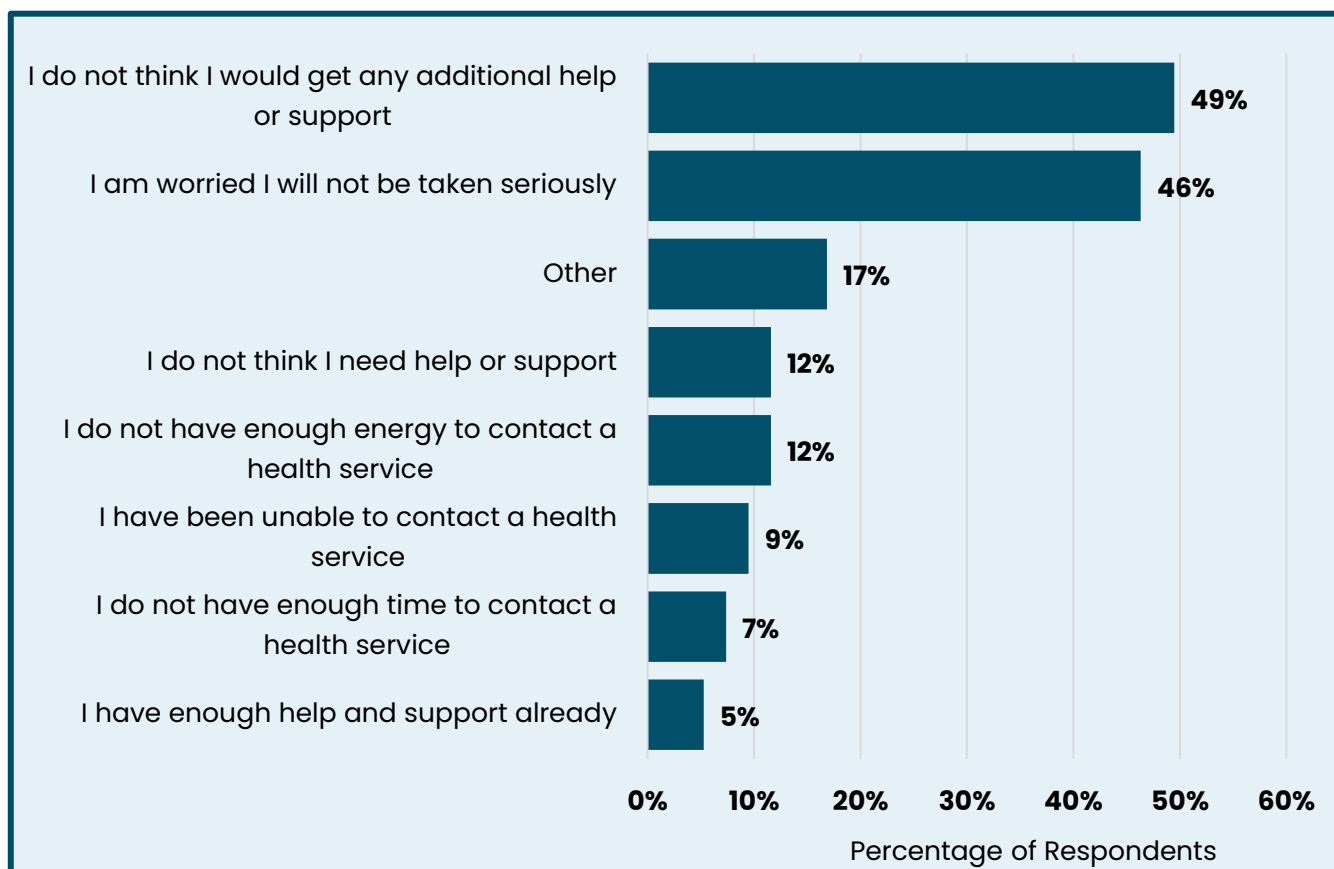


Figure 5. Responses to the question ‘Why have you not contacted a health service for help and support for your Long COVID symptoms?’ Respondents were able to select more than one option. (100%=95)

Other reasons that respondents gave included not being able to see a doctor, uncertainty about symptoms and if they could be related to another condition, thinking that nothing can be done for their symptoms (e.g., loss of taste) and feeling that NHS and doctors are busy so their symptoms don't seem as important.

“I have M.E, so I believe my symptom's will be attributed to M.E and not long covid”

The Post-COVID Syndrome Service, which is offered by Norfolk Community Health & Care, provides support and advice for those living with Long COVID. GPs are able to refer patients to this service for their Long COVID symptoms and diagnosis. However, over half of respondents (55%, 156) were not aware of this service, and only 24% (68) told us that they had been referred. Of those who

were not aware of the service 60 said that they would use it if it were offered to them, 20 were not sure if they would, one answered that they would use the service but were also unsure, and one said that they would not use the service. 74 did not answer if they would or would not use the service.

We also heard from some respondents that it took them a long time to get a referral to the post COVID clinic from their doctors' surgery: *"after 2 years and several gp visits I finally got a referral"*.

Alongside this, we heard about patients being on the waiting list for referrals or the Post COVID service for several months and the impact this had on them. For example, one school aged respondent told us that *"the GP told me just to wait for the referral"* they explained how *"12 months has been a long while to just live with symptoms and wait for referrals. Had huge impact on my education"*. This is also illustrated in the following experience and the stages involved in a referral which all contributed to how they felt the service was slow for them:

"This has been an horrendous 9 months for me ... and yet I feel completely isolated and with nowhere to go for help. The system has not helped me at all. Once your GP has diagnosed you with Long Covid - you are referred to the Long Covid Clinic. You then have to fill in a number of questionnaires before having a telephone interview. You are not "seen" but referred on and put on waiting lists (such as for the respiratory specialist or the Long Covid Rehabilitation Clinic). This takes weeks / months and no one seems to care how you are managing or about the impact on your life and wellbeing."

Being taken seriously

Many respondents discussed feeling that they were *"dismissed too easily"*, that they wished *"they'd take me seriously"*, *"symptoms were brushed off"*, and that *"dr's need to be more aware, and be willing to help more"*. Some told us they were unhappy with how Long COVID was sometimes *"treated more as an "in your mind" illness"* and seen *"as a psychological issue"*. Others shared that they felt dismissed because *"I am of menopausal age and symptoms can be similar"* or they were told *"that I am too fat and it is all in my head"*.

We asked respondents if they felt that they had been listened to, by health professionals, regarding their Long COVID symptoms. Of the 183 who told us that they had contacted a health service. Only a small number (14%, 26) told us they felt completely listened to compared to 54% (99) who felt 'somewhat' listened to, whilst 32% (58) felt that they weren't listened to at all (Figure 6).

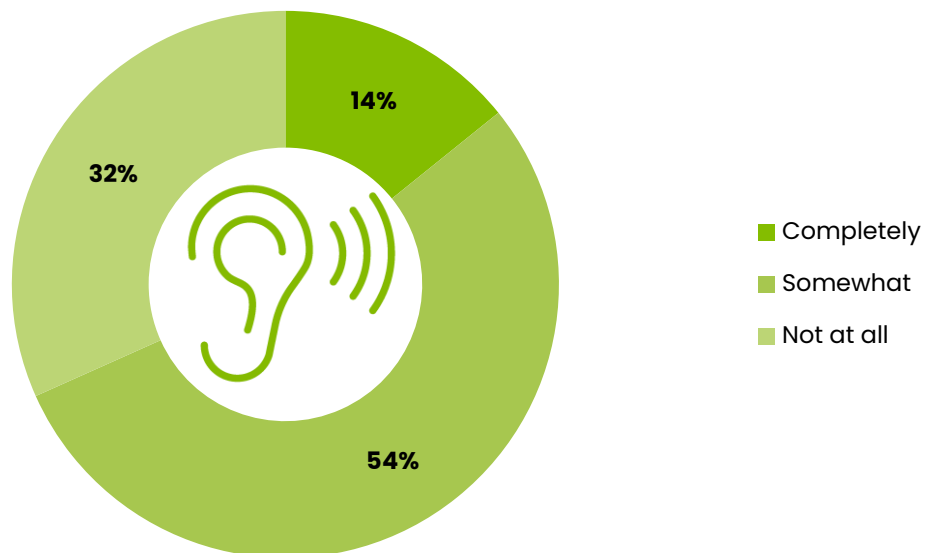


Figure 6. Responses to the question 'Do you feel listened to by health professionals about your Long COVID symptoms?'

Consequently, we heard that patients wanted health services to *"listen to what I'm telling them"* and how they sometimes had to *"insist"* on having tests.

This was reflected in the good experiences reported to us where they felt health services *"have listened to me"*. For example, one person told us that *"until recently my experience has been negative and upsetting"* and how *"since speaking to the post covid team I feel listened to for the first time"*. Similarly, we heard that for some the *"long COVID service are amazing [...] extremely knowledgeable, it was a breath of fresh air being believed, offered practical support and referral to correct services and asking gps to do correct tests"*.



"The support received from The Long Covid clinic was very good. They listened and understood."



Limitations of Long COVID support

We wanted to know how useful respondents found the information and advice resources they had used. Over half (55%, 158) of respondents told us that information and advice they had used was 'Somewhat useful', and only 9% (26) found what they had used 'Very useful'. Some (21%, 61) did not find information and advice resources useful at all, and a further 13% (38) told us they were not provided with, or found, any resources and three people (1%) did not answer.

Of the 68 respondents who told us that they had used the NCH&C Post COVID Syndrome service a higher proportion, 21% (14) told us that the resources they had used were 'Very useful' and 65% (44) said they were 'Somewhat useful'.

Personal stories: Resources need updating



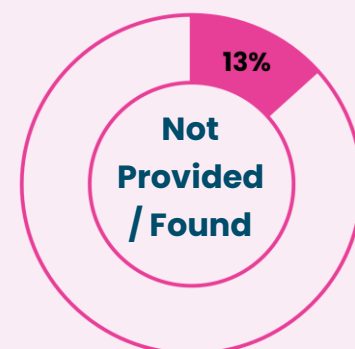
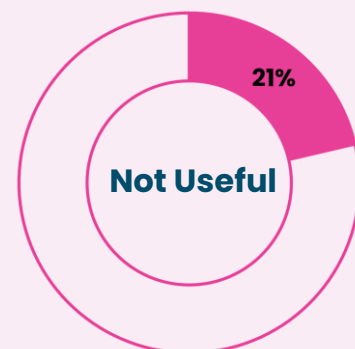
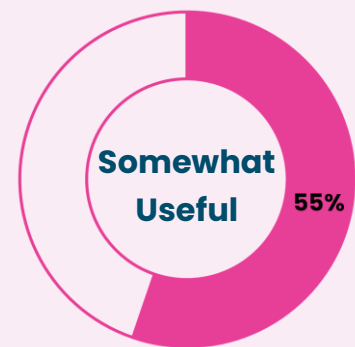
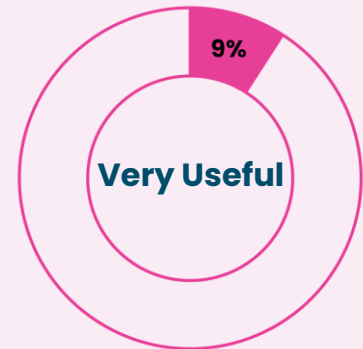
“Resources for NHS need updating as they are based on traditional knowledge of ME type illness which many patients find inadequate.

There are many research theories now which are not being used in practice or even considered.”



In terms of the support respondents, who contacted a health service, received from health services to help manage their symptoms, more (53%, 96) told us they did not feel the support helped them at all. Only 8% (15) told us they felt the support helped them 'A lot' and 39% (72) said it helped them 'Somewhat' (Figure 7).

How useful are the resources you have used?



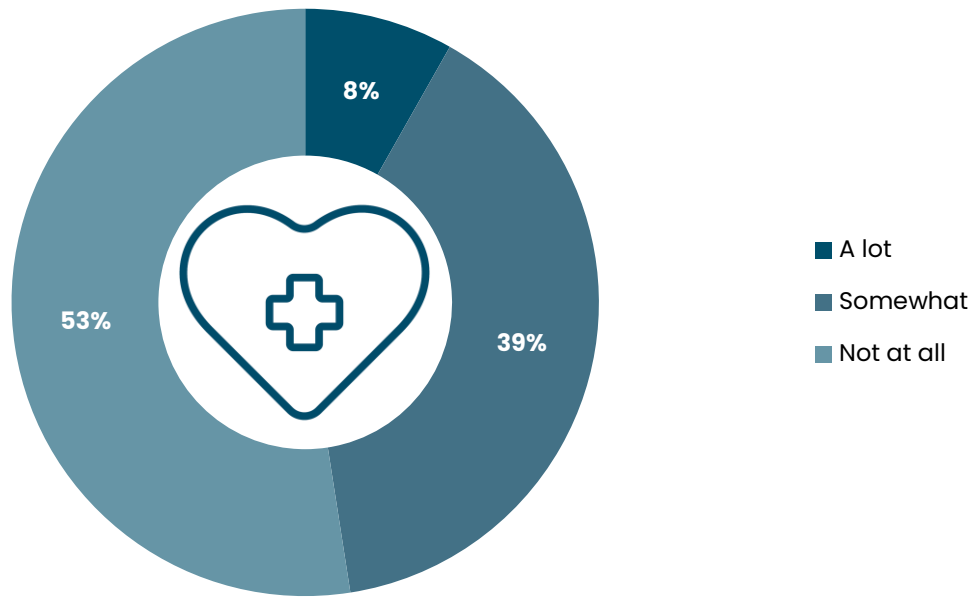


Figure 7. Responses to the question 'How much do you feel the support from your health service has helped you to manage your symptoms?'

For the 68 respondents who told us that they had used, or been referred to, the NCH&C Post COVID Syndrome service almost half (49%, 33) told us that they felt the general support they had received from health services was 'Somewhat' helpful for managing their symptoms. A further 38% (26) told us that the support was 'Not at all' helpful and only 9% (6) felt it helped them 'A lot'.

Some patients who had used the Post COVID service told us that the support they received was limited and for some *"it was really more of a box ticking exercise rather than anything useful for me"*.

In particular there seemed to be a lack of communication for some patients. For example, we heard from respondents that support was *"sporadic esp at height of pandemic which was understandable but frustrating"*, that their support stopped without warning: *"had long Covid clinic ringing me then stopped for no reason"*, and another told us that they *"have had one meeting so far and not heard anything since. Nor did they send the information that they said they would"*. To improve communication, one respondent suggested that *"it would be more beneficial if you were not contacted by multiples different staff members on different emails and numbers as there is no continuity"*.

"What can they do to help? The NHS is in crisis. The country is in crisis. We are just all trying to stay afloat."

Alongside this, some respondents explained to us why they might be reluctant to use a Post COVID service if they were offered it. Again, it appears that more communication about the service and what is available would be beneficial. Some told us that they would use the service if it was local to them, for example one respondent told us that *“when I looked I could only find somewhere near Norwich”* they then chose not to pursue it with their GP because *“I am unable to drive [...] I'm sure if I could Get there it would be helpful”*. Other uncertainty about the service included being *“not sure which of my symptoms are due to long Covid and which may have other causes”* or that they *“suffer from depression and anxiety and find it difficult to deal with unknown people”*.

From other respondents we heard how they understood *“the Long Covid clinics can only really offer CBT and advice on living with the condition”* and that *“if the clinic offered a way to take part in trials for treatments such as blood thinners I would be interested”*. This is also illustrated in the following extract.

“I have been seen in the clinic and they were very nice but its all just talk on how to cope with the symptoms. I would like there to be some treatments given even if I'm just a guinea pig. I would much rather try something than just accept that this is what I have now off you go and use your breathing exercises. I know how to control my breathing but this does not stop me from coughing continuously”



“ I feel that there is a lot of information but GP's are very busy and do not have the time so [sic.] support me further than providing a sick note but I will definitely ask to be referred to this service”



Personal stories: Support is good but needs to be ongoing.



"It [the NHS website] is a good place to go to remind myself how I can manage different symptoms. It is very general and doesn't consider the symptoms in conjunction with each other. Long covid is very individualised and different people have different range of issues. It helps us manage our illness but not to get better.

This [the Post COVID Syndrome service] was a face to face service and I felt listened to by the health professional and it was specific to my needs. I also had help from OT in the service to help me get back to work but this has not been possible yet. All of the advice I was given was good and has helped me manage my symptoms but I am still functioning at a very low level compared to before covid. All staff have been lovely, understanding and helpful.

Suggestions were sent to Gp for follow up- GPs are not understanding conditions such as POTs, MCAS etc that are associated with Long covid and not able to advise, refer on to specialists, treat. GPs either need more education in these conditions or specialised doctors need to be accessible through clinic. Diagnosis are important for us to get benefits, adaptations at work etc. We also need to feel we are working towards getting back to full health not just accepting functioning at a lower level in the long term.

I feel that people shouldn't be discharged from the service if the clinic feels there is no more they can do for them, if they still have symptoms. If we are successfully managing symptoms so to have some quality of life, it does not mean we are better.

Understanding is continuously evolving and people need to be registered with the clinic and recalled if treatments come available in the future. We should not be discharged until we are back to pre-covid health. If it is to be a long term health condition then people need to have support available to them in long term."



What this means

We heard from 286 individuals, who are living with Long COVID symptoms, about the information and advice resources available to them in Norfolk. There are some consistent themes in the experiences of those who have given feedback concerning what is known about Long COVID, what support there is, and what that support looks like.

Knowledge & Information

Overall knowledge of Long COVID is currently lacking. As a relatively recent condition that is emerging from the COVID-19 pandemic there is still a lot of on-going research in to understanding the Long COVID, its symptoms, and how best to treat and manage those symptoms.

Patients feel that some GPs are not fully aware of the range of symptoms associated with Long COVID, and are therefore unable to offer the most appropriate help. This lack of clinical knowledge results in patients becoming concerned that they will not be taken seriously about their Long COVID symptoms and would be dismissed by health professionals. Development of guidance, and other resources, to help with the diagnosis of Long COVID would help to get patients appropriate support. Additionally, this would improve confidence in health services with patients knowing that their condition and symptoms are being recognised and acknowledged.

As there is still a lot unknown about Long COVID, information about the condition and symptoms is continuously being updated. Ensuring health professionals are kept up to date with the latest research, resources, and advice for Long COVID is key to helping patients and preventing health outcomes worsening. We would like to see evidence that regular updates to information is being shared as best practice to health care professionals.

General information for the public should also be kept up to date and made readily available for anyone living with Long COVID. Even though responses to the survey conducted were all online, respondents suggested paper based information would be beneficial. We assume that there are others who did not/were not able to complete this survey so it would be of benefit to also work more to reach out to these communities and discover their needs too.

There is a need to make sure that information and resources come in a variety of accessible formats both online and offline. Making information available in these

formats will help patients access the advice and support they need to manage their symptoms and also reduce the chance of their health outcomes becoming worse.

Awareness & Signposting

Awareness of the available resources and services for information, advice, and support is poor. Not only are members of the public unaware of what is available to them, they feel that health professionals themselves are not aware.

A significant number of people were unaware of the 'Your COVID Recovery' website, which would indicate that it has not been well publicised or that people with symptoms are not being directed to the website for advice. As more cases of Long COVID start to present resources such as the 'Your COVID Recovery' website should be signposted to by health professionals. We know that some patients may have initially had symptoms of Long COVID before the website and specialist clinic were available and were unaware of these when they were first introduced. It is therefore also important to make sure patients are kept up to date of any new services and resources as and when they are introduced.

Similarly awareness of services such as the NCH&C Post COVID Syndrome service could be improved. Ensuring that health professionals are aware of services and know the referral process is important for getting patients the support they need. Referrals to such services is determined by the knowledge and information available to health professionals and in turn, the correct diagnoses being made.

Where patients are being referred to the appropriate service they are then able to be further signposted to the best support. However, this means that those not being referred slip through a gap and are unable to get appropriate support for their specific symptoms. We would like to see more signposting and awareness material made available for resources and services in Norfolk to help patients find suitable support for their needs and symptoms.

Range and Limitations of Support

We know that there are a wide range of symptoms associated with Long COVID, and not all cases are the same. This means that the information, advice, and support available to patients needs to reflect this. Not only this, but it also needs to be communicated clearly so that patients know what is available and what would be beneficial to them.

Finding out from patients what information they would find useful for their experience is key to ensuring that any advice and support is appropriate for them. Whilst it would not be possible to tailor information for each individual

case of Long COVID we would like to see patient feedback influence the information available rather than generic information for the most common symptoms.

In the recent work from Healthwatch England, it was found that due to similarities in symptoms with Chronic Fatigue Syndrome (CFS/ME), Multiple Sclerosis (MS), and Parkinson's there are worries and concerns of existing support and resources, that are already stretched, worsening. It is important that provision of support should be given to help those living with the symptoms of Long COVID whilst not taking away from other conditions such as CFS/ME.

The usefulness/effectiveness of the available support needs to be reviewed. With patients who have used resources finding it only somewhat useful or very generic it is clear that there needs to be patient consultation into what is working well and what is not. We would like to see patients being involved, through a feedback system, to highlight what support is beneficial to their health and wellbeing and improve resources that are not working well. One thing that would benefit patients is access to peer support, where patients can share their experiences, tips, and advice, and let them know that they are not alone.

Recommendations

From the findings of this piece of work several recommendations can be made for health care services in Norfolk to consider regarding improving the available information and advice resources for Long COVID and the access to these.

1. Patient Feedback (for NCH&C with potential to work with Healthwatch Norfolk) – Consult with patients on what resources and information is wanted as well as what is working and what needs improvement for helping them manage their Long COVID symptoms.
2. Peer Support (for NHS England and Norfolk & Waveney ICB) – Facilitate access to peer support. Some respondents felt that being able to talk to others living with Long COVID, sharing experiences, and tips/advice would be beneficial to them. Identifying sources of peer support, both locally and online, and making sure health services are able to signpost to these so that patients are aware of them.
3. Accessible Information and Signposting (for NCH&C) – Develop and adapt information and advice resources in multiple formats that meet accessibility needs, both online and offline. Ensure that the information is in suitable locations such as GPs, clinics, hospitals, pharmacies, libraries, Walk-In centre, etc. to improve access for all.
4. Understanding Long COVID (for Norfolk & Waveney ICB) – Ensure that efforts are made to increase wider understanding of Long COVID and its symptoms both publicly and professionally. Ensure that health professionals (e.g., GPs) understand the range of symptoms, take all concerns seriously, and are aware of the available support and referral process.
5. Resources and Best Practice (for Norfolk & Waveney ICB) – Ensure that resources are kept up to date with latest national guidance and research. Ensure that resources and best practice, as well as support, for diagnosis of Long COVID is shared with health care professionals.

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Appendix

Appendix 1: Survey



Experiences of Long COVID in Norfolk

Who is Healthwatch Norfolk?

Healthwatch Norfolk is the independent voice for patients and service users in the county. We gather your views of health and social care services to ensure they are heard by the people in charge.

What is this survey about?

Healthwatch Norfolk is collecting feedback about information and support available for Long COVID in Norfolk.

There are different definitions of Long COVID or Post COVID syndrome. For this survey we are interested in hearing from people who live in Norfolk and have experienced symptoms in the last 12 months.

We are interested in hearing from patients who continue to show signs or symptoms of COVID-19 for more than 12 weeks and the symptoms cannot be explained by a different diagnosis. Patients usually have more than one symptom at a time. These can change or progress over time and can affect any part of the body. Symptoms may include general pain, fatigue (tiredness) breathing difficulties, difficulty concentrating and mental health problems such as Anxiety or low mood.

We want to find out what patients would like Long COVID services to look like and why people may not have accessed services currently available. We are interested in hearing from people who have and who have not been diagnosed or accessed

services for Long or Post COVID

The survey should take approximately ten minutes to complete.

How the survey results will be used

Survey responses are being collected and analysed by Healthwatch Norfolk. You can read our full privacy policy at:
www.healthwatchnorfolk.co.uk/about-us/privacy-statement.

All responses will be anonymous and will be used to make recommendations to health and social care providers. The report will also be publicly available on our website and may be used in other Healthwatch Norfolk communications.

Want to keep in touch?

To stay up to date with what we are doing at Healthwatch, you can sign up to our newsletter via our website: www.healthwatchnorfolk.co.uk

If you do not use email, you can call Healthwatch Norfolk on 01953 856029 to ask to receive our newsletter via post.

Survey closing date: 3rd March 2023

If you would prefer to do this survey with us over the phone, please call Healthwatch Norfolk on **01953 856029** and we will arrange a time to ring you back to complete the survey. Alternatively, please email: enquiries@healthwatchnorfolk.co.uk for further support.

Please note: questions marked with an asterisk (*) require a response.

Please tick to confirm *

I have read and understood the above statement

Have you experienced symptoms of Long COVID/Post COVID syndrome in the last 12 months? *

Yes

No

Not sure

Healthwatch Norfolk produce newsletters about health and social care in Norfolk. If you'd like to receive this newsletter please leave your email here:

**If respondents answered No or Not Sure about having symptoms in the last 12 months they were directed to this message:*

Thank you for your interest in our survey. This survey is exploring experiences of Long COVID in the last 12 months. You have indicated that you have not experienced symptoms in the last 12 months.

We still would like to hear your experiences so please visit our website to leave feedback on services: www.healthwatchnorfolk.co.uk/services. Alternatively you can contact us by email on enquiries@healthwatchnorfolk.co.uk or call us on **01953 856029**.

Information about Long COVID

These questions are about information and advice resources for Long COVID for example websites and leaflets. Later questions in the survey will explore experiences with health services such as your doctors' surgery.

Where have you tried to find information and advice resources on Long COVID?

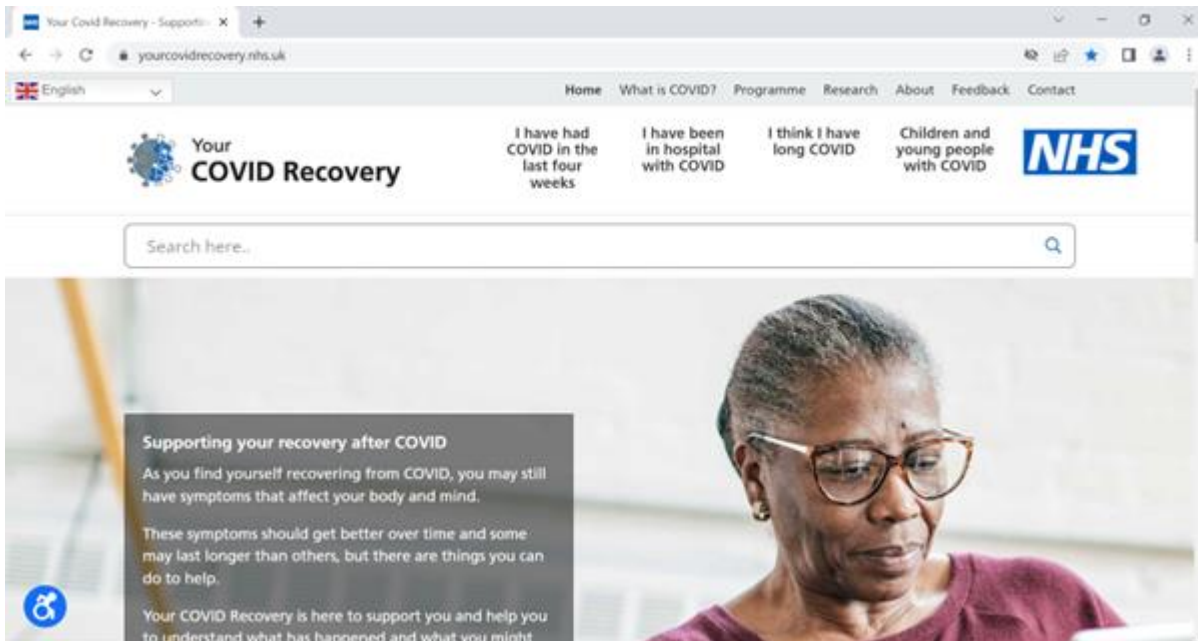
Please select all that apply.

- Doctors' surgery
- Pharmacy
- Friends and family
- Support groups (online or offline)
- NHS website
- Social media
- Other online resources (for example Google search)
- I haven't tried to find out information about Long COVID
- Other (please specify):

How useful are the information and advice resources you have used?

- Very useful
- Somewhat useful
- Not useful
- I have not found or been provided with any information or resources

This website 'Your COVID Recovery' is currently provided by the NHS and includes information and advice for people with Long COVID to use:
www.yourcovidrecovery.nhs.uk/



Were you aware of this website?

- Yes, and I have used the website
- Yes, but I have not used the website
- No
- Not sure

'Your COVID recovery' website provides information on the following topics.
What information and advice is/do you think would be most useful for you?

Please choose up to three options.

- Effects of Long COVID on the body and the mind
- Advice on eating well
- Grief and Bereavement
- Advice on sleeping well
- Help to stay active
- How to manage daily activities
- Advice on returning to work
- Advice on when to seek help

- Support for family, friends, and carers
- Advice for children and young people

What is good and what do you think could be improved about information and advice resources for Long COVID?

Experiences of Health Services for Long COVID

Have you contacted a health service (such as your doctors' surgery) about Long COVID symptoms? *

- Yes, and I have been diagnosed with Long COVID.
- Yes, but I have not been diagnosed with Long COVID
- No
- Not sure

Norfolk and Waveney Post COVID Syndrome Service is offered by Norfolk Community Health & Care NHS Trust.

The post COVID-19 service offer support to patients suffering the ongoing effects of COVID-19. The service brings together healthcare professionals from multiple areas of specialty for example physiotherapy, occupational therapy, SLT, nurse, respiratory, mental health to make sure that patients are seen by the clinical team(s) who are best able to support management of their symptoms.

Please select all of the following which apply to you:

- I have used or been referred to this service
- I was already aware of this service
- I was not aware of this service
- I would use this service if it was offered to me
- I would not use this service if it was offered to me
- I am not sure if I would use this service if it was offered to me

Please explain your answer:

Experiences of Health Services for Long COVID

Do you feel listened to by health professionals about your Long COVID symptoms?

- Completely
- Somewhat
- Not at all

How much do you feel the support from your health service has helped you to manage your symptoms?

- A lot
- Somewhat
- Not at all

What was good and what could have been improved with support you have received from health services for your Long COVID symptoms?

Do you have any further comments about information and support for Long COVID in Norfolk?

Why have you not contacted a health service for help and support for your Long COVID symptoms? Please choose all that apply.

- I do not think I need help or support
- I have enough help and support already
- I am worried I will not be taken seriously
- I do not think I would get any additional help or support
- I have been unable to contact a health service
- I do not have enough time to contact a health service
- I do not have enough energy to contact a health service
- Other (please specify):

Do you have any further comments about information and support for Long COVID in Norfolk?

About you

In this next section we will be asking you some questions about yourself and your life. All these questions are optional. Your answers help us make sure that we hear from people from different backgrounds and that we understand the needs of different groups in our community. Remember: all your answers are strictly confidential and the survey is anonymous.

What is the first half of your postcode?

How old are you?

What is your gender?

- Male
- Female
- Non-binary
- Genderfluid
- Genderqueer
- Intersex
- Prefer not to say
- Prefer to self-describe:

What is your ethnic group?

Arab

- Arab

Asian / Asian British:

- Bangladeshi
- Chinese
- Indian
- Pakistani
- Any other Asian / Asian British background

Black / Black British:

- African
- Caribbean
- Any other Black / Black British background

Mixed / Multiple ethnic groups:

- Asian and White
- Black African and White
- Black Caribbean and White
- Any other Mixed / Multiple ethnic groups background

White:

- British / English / Northern Irish / Scottish / Welsh
- Irish
- Gypsy, Traveller or Irish Traveller
- Roma
- Any other White background

Other:

- Any other Ethnic Group
- Prefer not to say

If other, please specify:

Please select any of the following that apply to you:

- I have a disability
- I have a long term condition
- I am a carer
- None of the above
- I prefer not to say

Where did you hear about this survey?

- Doctors' surgery website
- Healthwatch Norfolk Event

- Healthwatch Norfolk Newsletter
- Healthwatch Norfolk Website
- News (website / radio / local newspaper)
- Search Engine (e.g. Google)
- Social Media (e.g. Facebook / Instagram / Twitter)
- Through a friend or co-worker
- YouTube
- Other (please specify):

Appendix 2: Demographics

		Percentage of Respondents	Number of Respondents
Age	0-15	1%	3
	16-25	3%	10
	26-35	7%	19
	36-45	16%	47
	46-55	26%	74
	56-65	27%	78
	66-75	14%	39
	76-85	3%	8
	86-95	1%	2
	No Answer	2%	6
Gender	Male	26%	75
	Female	72%	205
	Non-Binary	0%	1
	Genderfluid	0%	1
	Prefer not to say	1%	2
	No Answer	1%	2
Ethnic Group	British / English / Northern Irish / Scottish / Welsh	92%	264
	British / English / Northern Irish / Scottish / Welsh (Greek Cypriot descent)	0%	1
	Any other Mixed / Multiple ethnic groups background	1%	2

	Any other White background	3%	10
	Caribbean	0%	1
	Indian	0%	1
	No Answer	1%	3
	Prefer not to say	1%	4
Do you consider yourself to have any of the following? (Respondents could select more than one option)	I have a disability	18%	51
	I have a long term condition	46%	132
	I am a carer	9%	25
	None of the above	38%	108
	I prefer not to say	4%	11

Appendix 3: List of additional places respondents found information and advice resources for Long COVID

Where respondents found information and advice resources
At work at the hospital
Work Occupational Health
medical publications
Zoe research programme
alternative therapies
Hospital
ME/CFS Service
Post Covid team at bowthorpe community hospital
Gez Medinger You Tube - https://www.youtube.com/channel/UCIn_SCEd4JiGkHIUZdIVIXw
Purchasing the long covid handbook
Occupational health
Long COVID clinic

Norwich covid support team nhs

Long covid clinic

Long Covid clinic appointment by telephone

Occupational therapy, oxygen nurse

Long covid clinic

"The Long Covid Handbook"

Occupational Health - Work

Hospital consultant

Long Covid book

research papers

newspaper and New Scientist magazine.

Through employer



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