



**Long COVID support services
across Cheshire and Merseyside**

Report into patient questionnaire findings

Report Prepared for:

NHS Cheshire and Merseyside Integrated Care Board (ICB)

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1.0 Introduction

NHS Cheshire and Merseyside Integrated Care Board (ICB) held a period of public engagement about long COVID Services in Cheshire and Merseyside. The main mechanism for collecting responses was a questionnaire, which opened on 14th February 2025 and closed on 16th March 2025.

Praxis Community Interest Company CIC was appointed to analyse the feedback from the questionnaire and produce a report which could be used to inform decision-making about future provision of long COVID support.

2.0 Public engagement

The following information outlines NHS Cheshire and Merseyside's approach to involving patients and the public in planning for future provision of long COVID services.

Introduction and background

Long COVID services launched in 2020, to support patients who were suffering ongoing effects of the virus months after being infected, with symptoms including breathlessness, poor sleep, fatigue, a cough, or anxiety and low mood.

Dedicated national funding was allocated to run these services. In Cheshire and Merseyside, they were accessed through a GP referral, and provided through a number of hubs, run by the following trusts:

- Warrington and Halton Hospitals NHS Foundation Trust
- Mid Cheshire Hospitals NHS Foundation Trust
- East Cheshire NHS Trust
- Cheshire and Wirral Partnership NHS Foundation Trust
- Wirral Community Health and Care NHS Foundation Trust
- Mersey Care NHS Foundation Trust

Due to the significant drop in referrals, and as national funding was no longer ring-fenced for these services from 1 April 2025, NHS Cheshire and Merseyside is reviewing how long COVID support is provided in the future.

As a result, the current long COVID hub arrangements have ended, meaning that these services are no longer taking referrals. While the wider review is underway, GPs will refer patients to alternative services, depending on their clinical needs.

NHS Cheshire and Merseyside wants to find the most effective way of supporting people with long COVID in the future, while ensuring that it makes the best use of NHS resources. By involving the public, patients and staff in the review process, it aimed to gather a wide range of views and insights to help inform next steps.

The involvement objectives for this work were:

- Communicate the fact that changes are being made to local NHS long COVID support services, and that there is an opportunity for people to share their views about how this care looks in the future.
- Gather feedback from patients, carers, the wider public, staff and key stakeholders to understand what the core components of any future long COVID support should consist of. This will include key areas of support required, and preferences for how this is delivered.
- To compile and analyse findings so that they can be used to develop a proposal for how services might look in the future.

Methods of engagement and materials

[NHS Cheshire and Merseyside has published information about changes to long COVID services on its website](#). This includes links to support materials (including self-help information, and signposting to resources such as the ORCHA App library), and the intention is to continue building this content over time.

Between Friday 14th February and Sunday 16th March 2025, people were able to complete an engagement questionnaire, containing both qualitative and quantitative questions, designed to gather views and perspectives on long COVID support. The questionnaire is shown in appendix number twenty-two.

Printed copies of both the information and questionnaire were available on request, as were alternative formats and languages. People who were unable to complete the questionnaire were able to provide their feedback over the telephone.

Wider partners and stakeholders, including NHS providers, Healthwatch, and voluntary, community, faith and social enterprise (VCFSE) organisations were asked to share details of the engagement using their own channels.

NHS Cheshire and Merseyside also attended local long COVID support groups to discuss the changes and understand more about what patients need to support their ongoing and future recovery. Participants were encouraged to complete the main engagement questionnaire, but we also captured a summary of the key themes which arose during these sessions. While not covered in this report, the key themes which arose during these sessions were captured by NHS Cheshire and Merseyside to inform the development of potential service options for the future.

3.0 Analysis and reporting

NHS Cheshire and Merseyside ICB required support with the following:

- a) Analysis and reporting of responses to the engagement questionnaire identifying different views/needs of particular groups, including differences by equalities groups, geographical area (the nine local authority footprints within Cheshire and Merseyside and a further category of “out of area”) or other groups defined by the data. Data was provided as a single data sheet. Closed questions were analysed descriptively and statistically where relevant and possible. Open questions were analysed qualitatively.
- b) As part of this engagement there was need to understand any equalities implications by exploring information presented by groups with protected characteristics. This required responses to be cross tabulated with each protected characteristic to better understand any differences of view. This is clearly identified in the report of findings to inform development of a full Equalities Impact Assessment.
- c) The profile of respondents indicating their interest in this engagement are shown in appendices one to three. Equality Monitoring profiles are also shown in the appendix.

4. Summary of findings

- 4.1** This engagement was based on a self-completed questionnaire by 516 respondents. Of these 353 respondents indicated that they currently have or have had long COVID in the past. A further 27 respondents were members of staff working in a long COVID service role.
- 4.2** Of the 353 long COVID patients and carers 22% are aged between 18 and 44, 60% are aged between 45 and 64 and 18% aged over 64. Again, based on more limited data 23% are male and 77% female. These percentages are based on those respondents who answered both the question about whether they currently have or had long COVID and the questions about their age and gender profile.
- 4.3** The two long COVID symptoms respondents most frequently cited as the reasons they sought support were 'fatigue' (91% of respondents) and 'problems with memory and concentration' (82% of respondents).
- 4.4** All six of the defined long COVID symptoms that prompted respondents or their carers to seek support were recognised by a minimum of 60% of those who reported having long COVID.
- 4.5** On average, each of the 353 respondents with long COVID had approximately 4 of the recognised symptoms prompting them to seek medical help.
- 4.6** 59% of patients with 'fatigue' said they needed the 'highest level of support' to deal with this symptom. This compares with just 22% who identified 'shortness of breath' as the symptom needing the 'highest level of support'.
- 4.7** 110 respondents between them added a whole range of other health symptoms that prompted them to seek support for long COVID. These are shown in appendix four.
- 4.8** When presented with different potential options set out in the questionnaire for managing long COVID symptoms only 31 respondents said they had not received any additional support. Of the remaining 322 long COVID patients, each had accessed, on average, three of the listed support routes or services.
- 4.9** Of the ten different support services to manage long COVID symptoms, the most popular were GP Practice (60% using), Talking Therapies (43% using) and Community Therapies (38% using).
- 4.10** The most important sources of help in accessing long COVID support were 'face to face' appointments (85% selecting) and 'telephone appointment' (70% selecting).

4.11 Respondents were asked for additional comments, and particularly how changes to NHS long COVID services might impact those with long COVID and their carers. 259 individual comments were received. A thematic analysis identified four broad categories of responses. These are described below together with the number of individual responses allocated to each category. It should be noted that many of the responses selected for each of the three categories were abbreviated to aid analysis and presentation.

- 26% of responses were critical of the service they had received or the lack of accessible services.
- 44% of responses were concerned about the withdrawal of long COVID services at a time many people were still suffering with the condition.
- 28% of responses were satisfied with the quality of service or the options available to people with long COVID.
- 2% of responses were classified as providing a statement with a neutral stance on how changes to the long COVID service might impact them.

MAIN FINDINGS

5. Profile of respondents with long COVID

5.1 The number of respondents identifying with long COVID is shown below in Table 1.

Table 1. Respondents with long COVID or carer of someone with long COVID.

Respondents long COVID profile	No.	%
I have long COVID and I am currently accessing an NHS long COVID service	209	59.2
I have/had long COVID and have previously accessed an NHS long COVID service	83	23.5
I have/had long COVID but haven't received support for my condition	39	11.1
I am a carer of someone with long COVID	22	6.2
Total	353	100

5.2 To provide a more detailed profile of long COVID respondents, an age and gender profile is shown below. Caution is needed in interpreting these profiles because respondents were not required to provide their gender and age and therefore the totals are less than those shown in Table 1.

Table 2. Respondents with long COVID or carer of someone with long COVID by age

Respondents long COVID profile by age	18-44	45 - 64	64 +	Total
I have long COVID and currently accessing NHS long COVID service	49	112	24	185
I have/had long COVID and previously accessed NHS long COVID service	9	48	18	75
I have/had long COVID but haven't received support for my condition	6	12	9	27
I am a carer of someone with long COVID	2	10	6	18
Total	66	182	57	305

Table 3. Respondents with long COVID or carer of someone with long COVID by gender

Respondents long COVID profile by gender	Male	Female	Total
I have long COVID and I am currently accessing NHS long COVID service	37	129	166
I have/had long COVID and have previously accessed NHS long COVID service	22	44	66
I have/had long COVID but haven't received support for my condition	4	23	27
I am a carer of someone with long COVID	2	16	18
Total	65	212	277

6. Symptom(s) which prompted respondent to seek support for long COVID

6.1 Respondents were required to describe the symptom, or symptoms that prompted them, or the person they care for, to seek support for long COVID. They could choose as many options as applied. The results are shown in Table 4 below.

Table 4: Symptom(s) Prompted Respondent to Seek Support for long COVID

Symptom	No	%
Shortness of breath	249	70.5
Fatigue	321	90.9
Problems with memory and concentration (“brain fog”)	289	81.9
Heart palpitations and dizziness	214	60.6
Joint pain and muscle aches	249	70.5
Depression, anxiety and mental health	215	60.9
Other (See 6.2 Below)	110	31.2

(n=353.) These are respondents who have/had long COVID or a carer of someone with long COVID.

6.2 The 110 respondents who answered ‘other’ provided an extensive list of symptoms associated with long COVID. These are listed in appendix four.

7. Level of support needed for different symptoms

7.1 Respondents were required to select from five options the level of support they needed to manage the following symptoms.

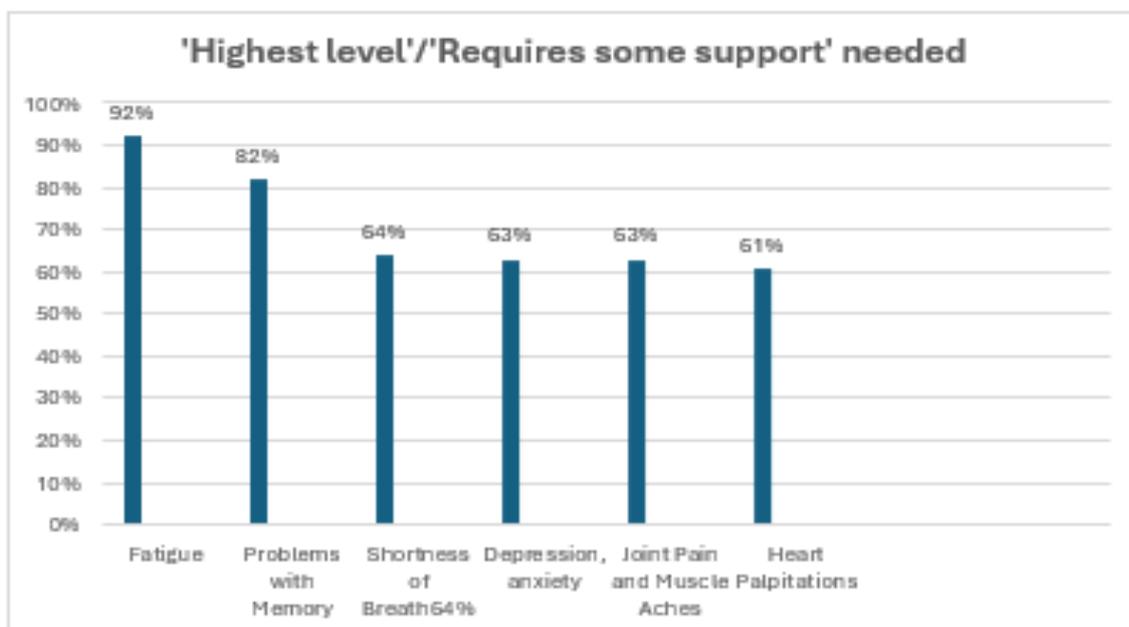
Table 5: Level of support needed for different symptoms

Symptom	Highest level of support	Requires some support	Lower level of support	Lowest level of support	No experience of this symptom
Shortness of breath (n = 303)	68 22%	127 42%	48 16%	33 11%	27 9%
Fatigue (n = 320)	188 59%	104 33%	20 6%	7 2%	1 -
Problems with memory and concentration (n = 313)	102 33%	153 49%	35 11%	14 4%	9 3%
Heart palpitations and dizziness (n = 298)	83 28%	97 33%	42 14%	30 10%	46 15%
Joint pain and muscle aches (n = 306)	117 38%	106 35%	38 12%	21 7%	24 8%
Depression, anxiety and mental health (n = 307)	98 32%	124 41%	29 9%	27 9%	29 9%
Other symptoms (n = 196)	74 38%	49 25%	14 7%	7 4%	52 26%

N.B The total number of respondents answering this question were the 353 identified in Table 1. However not all respondents answered each section of the question. Therefore, the percentages are based on the number of respondents answering each individual question.

7.2 To identify the symptoms requiring most support Table 6 ranks them according to the level of support required.

Table 6: Long COVID symptoms requiring most support



8. Support received to manage long COVID

8.1 Respondents were asked to identify, from a range of different support services, the ones they had used to manage their long COVID symptoms. The results are shown below in Table 7.

Table 7: Support received to manage long COVID

Support services	No	%
Your GP practice	193	54.7
Talking therapies (Psychological treatments for mental and emotional problems)	138	39.1
Pain management	52	14.7
Respiratory/pulmonary rehabilitation	100	28.3
Community therapies (OT/Physio)	121	34.3
Chronic fatigue/ME (Regional service operated by Liverpool University Hospitals Foundation Trust)	62	17.6
Medical specialities relevant to individual clinical symptoms including Cardiology, Rheumatology, Gastroenterology, Neurology	98	27.8
Local wellbeing and support organisations e.g. wellbeing hubs, disability support.	102	28.9
Local social prescribing services e.g. in your GP practice	50	14.2
Online resources	103	29.2
I haven't received any additional support	31	8.9
Other	61	17.3

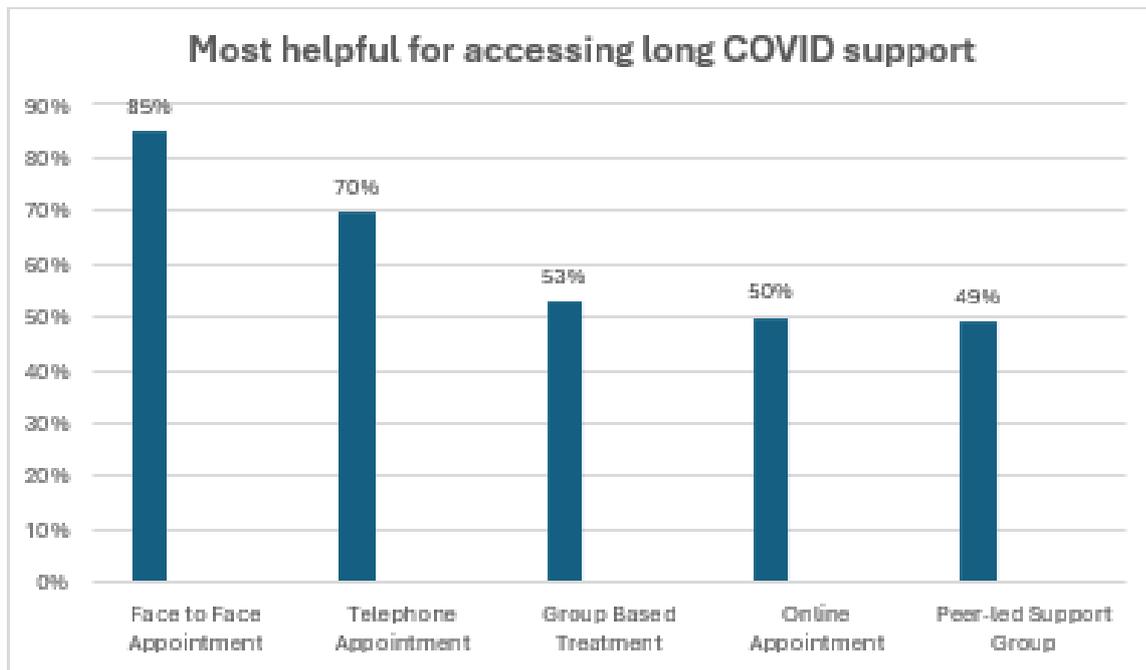
N.B. (Base = 353. These are respondents who have/had long COVID or a carer of someone with long COVID.)

8.2 Respondents were required to select from five options the level of help they received to access long COVID support.

Table 8: Long COVID support received

Symptom	Very helpful	Somewhat helpful	Somewhat unhelpful	Not very helpful	No experience of this symptom
Face to face appointment (n= 316)	228 72%	42 13%	8 3%	10 3%	28 9%
Online appointment (n = 305)	81 27%	69 23%	17 5%	26 8%	112 37%
Telephone appointment (n = 317)	110 34%	113 36%	19 6%	34 11%	41 13%
Group-based treatment (n = 307)	116 38%	47 15%	6 2%	18 6%	120 39%
Peer-led support group (n = 301)	107 36%	40 13%	11 4%	15 5%	128 42%

Table 9: Most helpful long COVID support



9. Opinions about long COVID support

9.1 Respondents were asked for additional comments, and particularly how changes to NHS long COVID services might impact those with long COVID and their carers.

9.2 259 individual comments were received. A thematic analysis identified four broad categories of responses. These are described below together with the number of individual responses we allocated to each category. It should be noted that many of the verbatim quotes selected for each of the four thematic categories have been abbreviated.

Table 10. Classification of responses about long COVID support

Classification of responses about long COVID support	No	%
Respondents who were critical of the service they had received or the lack of accessible services	67	26
Respondents concerned about the withdrawal of long COVID services at a time when many people were still suffering with the condition	114	44
Respondents who were satisfied with the quality of service or the options available to long COVID patients.	73	28
Statement with neither positive nor negative sentiment	5	2
Total	259	100

n=259: respondents who responded to the request for additional comments

9.3 The following is a random selection of comments from the three main classifications, and which provide deeper insights into the feelings of respondents.

Table 11. Respondents who were critical of the service they had received or the lack of accessible services

Respondents who were critical of the service they had received or the lack of accessible services
1. Feel symptoms are dismissed as being Long COVID and assumed to have other causes. I have had Covid 3 times and am very aware of how different symptoms are to other viruses.
2. I think the biggest issue with not having a dedicated portion of the NHS for long COVID is that some members of the individual departments don't have the belief that such a thing even exists, and you get fobbed off onto somewhere else. The only place where I have felt believed and supported is the long COVID dedicated department run by Warrington Disability Partnership, which I eventually got referred to via my GP.
3. Inaccurate information and derogatory comments were made about me from people who are supposed to be healthcare 'professionals', mocking my mental health and bowel issues. As a former nurse who caught Covid at work, I am disgusted and feel like I've just been dumped and my health needs, and that I, do not matter.
4. I don't feel it was taken seriously enough by health care professionals plus no referral was made to Liverpool clinic.
5. I feel abandoned in the system, for 3 years the attitude has mainly been to get on with it and very little support has been signposted by health professionals apart from the long COVID service which is being discontinued.
6. I have been suffering, unknowingly, with Long COVID since 2022. In early 2024 I approached my GP 6 weeks after my second infection to discuss the crippling fatigue I was experiencing and my inability to return to work. I was told I hadn't been unwell long enough to be referred to the long COVID clinic. By December 2024 I had become progressively more unwell and disabled by Long COVID symptoms.
7. There is nothing available to help support and prescribe for my symptoms of chronic fatigue and challenges with my immune system. it's only ever been about respiratory issues.
8. Knowing how isolating a disease such as long COVID is, I fear for the lives of those severely affected. The lack of knowledgeable support I am sure will lead to tragic mental health consequences. I am also very aware of the gaslighting effect of the disjointed and uneducated effect of using the individual specialities.
9. Many people are alone with their symptoms and need positive reinforcement from others with similar long lasting and confusing symptoms. Most GPs are totally in the dark as to how to treat people with long COVID symptoms.
10. What long COVID patients most need is medication, not 'support'. It is extremely difficult to access this via the NHS, in part due to prescribing guidelines, and in part due to lack of knowledge.

Table 12: Respondents concerned about the withdrawal of long COVID services at a time when many people were still suffering with the condition

Respondents concerned about the withdrawal of long COVID services at a time when many people were still suffering with the condition
1. I would like to see the service still going ahead they have been great support, got me through very dark days I still have these days, but I know I have got the support still where will we go for support; I would be lost without it
2. I'm sorry to hear the long COVID clinic is closing. I think the two biggest benefits for me were the recognition of long COVID as a condition. Secondly, the instructor led classes were great for leading me to peer support and almost incidentally the instructor identified Mast Cell Activation Syndrome as a condition I potentially had and was thus able to address with the clinic GP.
3. It's a shame the service is going to finish it has been very helpful not sure where to go now
4. I will struggle without the service; the service has gone above and beyond to help me. Assessing us, teaching and guiding us through talking and tools to help us manage long COVID.
5. It will be devastating to lose this invaluable provision - from the experts with answers to our questions and our peer group who support and help us.
6. I'm extremely concerned that without the long COVID service, not only will I not be able to access the level of support that I've received this far, but it will also leave me having to seek support from others who don't have the level of knowledge, understanding or expertise about the condition and what this means for us. This has been an absolute lifeline.
7. Please do not end the Liverpool long COVID service. As a thirty-four-year-old facing a potentially lifelong disabling condition, the support I have had from the service's GPs and nurses has been the lone light at the end of a very long and extremely exhausting tunnel. My GP practice does not provide any support for my long COVID aside from issuing medication prescribed by the long COVID service. I am extremely worried for myself and other patients if the service closes. It has been the only truly holistic care I have received since I was diagnosed in 2020. I feel extremely distressed and despairing since receiving the letter.
8. I will struggle without the service, the service has gone above and beyond to help me. Assessing us, teaching and guiding us through talking and tools to help us manage long COVID. They started a Peer Support Group so we could meet our patients. Had guest speakers to enlighten us with taster sessions.
9. The closure of the long COVID clinic will leave me vulnerable and open to falling through the cracks in the system, there will be no continuity of care. Our physical, mental and emotional wellbeing will be affected. We do not have the energy or capacity to co-ordinate multiple appts.
10. It's a smack in the teeth that valuable services are being withdrawn because there not popular. Already various agencies are saying goodbye so if like me you need multiple disciplines were screwed.

Table 13: Respondents who were satisfied with the quality of service or the options available to long COVID patients

Respondents who were satisfied with the quality of service or the options available to long COVID patients
1. Long COVID service is a vital part of ongoing support for so many of us, myself included. There is no known cure for us and no medication that can be prescribed so the help and support received from long COVID service is vital.
2. The long COVID clinic have been the only referral that have understood my conditions down to a T. For 3 years I had absolutely no support from GPs, or any referrals as they had no way of helping and no understanding. A lot of them treated me like an inconvenience and like I was overreacting or just needed therapy due to their complete lack of knowledge on the condition.
3. Meeting people who have suffered and sharing our experiences has been lifechanging! I don't feel so isolated and alone.
4. The holistic approach the clinic has provided has been most important. Advice given to GPs is also vital as they have very little knowledge of long COVID. The long-term cost of treating people living with long COVID will increase as we are passed from one specialist to the next, rather than being treated by one team.
5. The long COVID service have provided me with support and direction to help I did not find anywhere else nor did I know was available. I felt listened to and felt like the staff understood me and my condition.
6. NHS led support groups are very helpful. Long COVID clinic is the first medical place that looks at you as a whole person it's a crime to close these down. I assume referring us means putting us on a waiting list which is awful and once again each specialty will look at only that part of us and not the overall picture. The news that the clinics are closing has had a significant impact on my mental health and overall wellbeing it's an absolute disgrace.
7. The long COVID service had a huge impact on my life when I was deep in the midst of long COVID and was struggling to understand what was happening to me and how to move forward. The team were incredibly helpful when I was at the worst point in my life and helped find me the tools I needed to manage my condition.
8. The long COVID team got me from unable to work to returning part-time in a new career. Without them, I would be unemployed and claiming benefits with a very poor quality of life. They looked at my health holistically, which I have never experienced with the NHS before and this was key to getting me working again.
9. The long COVID Service provides me with invaluable support. I was seen within 3 months of GP referral. They immediately prescribed medication which improved my symptoms. They also provide excellent OT and physiotherapy support. They have provided these services in my home as I have been too exhausted to attend clinic. The level of advice, support and understanding of the condition is exceptional and I believe has helped me to cope with a profoundly disabling condition.
10. The long COVID Team have been an absolute lifeline to me. They are the only service to completely understand my condition, its symptoms, and how it impacts upon me, my life, family, and mental health. They are absolutely invaluable. I am absolutely desperate for the service to continue. Without it, I feel abandoned and like there will be no help for me, and not even any understanding from health professionals I see, and especially the Physio and OT are exceptional professionals and the best I have ever met in the NHS.

10. Views By health professionals not working in the long COVID service

10.1 Health professionals completing the questionnaire, were asked to share their views about long COVID in an individual capacity. There was a range of differing opinions, and which were classified as either scepticism towards the validity of long COVID or support for continued and accessible community and collaborative services. These are much abbreviated extracts from the comments made by health professionals but do represent the most frequently occurring themes.

Classification of responses about long COVID support
Scepticism towards the validity of long COVID services
Support for continued and accessible community and collaborative services

Table 14. Responses which show scepticism towards the validity of long COVID services

1. I think the support should be used elsewhere. The staff who carry out this service need to be back into the main hospitals help reducing patients waiting times, whether that be in clinic setting or A&E. Helping with the backlog of patients getting sicker because they are not getting seen quicker enough.
2. It is very clear that 'long COVID' is being used as an excuse for our patients who have actually being injured by the 'vaccinations'.
3. Long COVID is a poorly defined syndrome. Screening is poor. A diagnosis is typically given without properly excluding other causes. It is often diagnosed in individuals with no previous diagnosis of COVID.

Table 15. Support for continued and accessible community and collaborative services

1. As a clinical psychologist I am very aware of the multiple and wide-ranging health (physical, neurological, psychological and neuropsychological) and mental health effects that can be precipitated by long COVID - including many distressing medical symptoms that can further fuel dynamic cycles of mental and physical health symptoms.
2. As the long COVID service is winding down, we have several patients who are still very unwell and need ongoing specialist care.
3. Long COVID services need to be available for face-to-face engagements close to home.
4. The long COVID hubs must be accessible for patients who are navigating this condition and need good quality advice and guidance from professionals who are knowledgeable and willing to work collaboratively.
5. The long COVID service has been delivered out of my Health and Wellbeing proactive since 2022 and the team have built the service up with expertise and also resources in the form of workshops in the studio and rooms for clinic time. This has been very well attended and has provided a community hub for the community to get support from each other and from other specialist speakers.
6. The loss of a centralised service where patients can access all the support they need will be devastating and highly detrimental to these individuals

11. Views by members of staff working in long COVID services

11.1 Staff working in long COVID services completing the questionnaire, were asked to share their views about long COVID in an individual capacity. These respondents were all concerned about the negative consequences for patients created by the end of hub services for long COVID. They describe the most frequently occurring concerns for multi-disciplinary support and highlight the value of long-term support and understanding. These are a selection of abbreviated comments made by members of staff working in long COVID services.

Table 16: Comments by members of staff working in long COVID services

1. The loss of a centralised service where patients can access all the support they need will be devastating and highly detrimental to these individuals
2. Ending the long COVID services without first consulting with staff and patients and without assessing costs is wrong. Many patients will only have their GP surgery to turn to.
3. I believe that the current model is sufficient. Patients need access to a multi-disciplinary team. As most people do not understand the complexities of long COVID, it is hard for patients to receive the support they need from other practitioners.
4. I think the current model works well for patients and their families. I think the decision to close the service is short-sighted.
5. Long COVID support fundamentally needs not to be a year-on-year service provision.
6. No other services available for this cohort of patients to provide the holistic and timely approach that they need.
7. Patients need support for coping with their symptoms, from people who understand the condition and the impact it has on every aspect of their life. people are broken physically and mentally when they come to the service

Appendices

1. Profile of respondents indicating their interest in long COVID questionnaire

Personal interest of respondents	No.	%
I have long COVID and I am currently accessing an NHS long COVID service	209	40.4
I have/had long COVID and have previously accessed an NHS long COVID Service	83	16.1
I Have/had long COVID but haven't received support for my condition	39	7.6
I am a carer of someone with long COVID	22	4.3
I am a health professional working in another service and would like to share my views in an individual capacity.	24	4.7
I am a member of staff working in long COVID Service	27	5.2
None of the above apply to me but I would like to share my views	88	17.0
Other category.	24	4.7
Total	516	100

2. Home location of respondents

Home location of respondents	No.	%
Cheshire East	88	17.1
Cheshire West	123	23.8
Halton	33	6.4
Knowsley	17	3.3
Liverpool	54	10.5
Sefton	33	6.4
St Helens	35	6.8
Warrington	52	10.1
Wirral	56	10.9
Outside of Cheshire and Merseyside	25	4.8
Total	516	100

3. Where did you hear about this engagement

Where did you hear about this engagement	No	%
From GP practice	4	1.0
From local pharmacy	0	0
Sent a letter by an NHS long COVID service	115	27.6
Social media	71	17.0
NHS website	37	8.9
Patient group/Voluntary sector	49	11.8
NHS staff communication	38	9.1
Friend or family member	26	6.2
Other	77	18.5
Total	417	100

N.B. 99 Respondents did not answer this question.

4: Other symptom(s) prompted respondent to seek support for long COVID

Abnormal breathing pattern
 Adrenaline rushes, tinnitus,
 Affected senses e.g. auditory overload
 Among others: tinnitus, noise sensitivity, light sensitivity, movement sensitivity, gastrointestinal issues, dizziness, light-headedness, derealisation, blood pooling, pins and needles, numbness, skin rashes, skin dryness, skin irritation, insomnia,
 Asthma
 Balance problems (4)
 Blood pressure
 Blurred vision, jerky movements of limbs, pins and needles, vertigo, loss of smell, change in taste, headaches, sensation to skin, intolerance to noise, light, busy areas, trouble swallowing, loss of appetite, nausea, gastrointestinal issues, poor balance/stability, peripheral neuropathy, sleep problems, clenching jaw, TMJ, spasms in hands /feet, cramps, rib pain, chest pain, tinnitus, overall body stiffness, fainting, abdominal pain/bloating, etc
 CFS/PEM/Autonomic dysfunction – now registered disabled from COVID
 Chronic migraines/Constant headaches
 Constant headaches
 Constipation, blackouts, sleep impact, no taste or smell (2)
 Damaged nerves, weight and muscle lost, poor balance
 Difficulty sleeping – short spells
 Digestion issues, sinus issues, mouth issues
 Digestion/histamine intolerance
 Digestive/bowel issues along with nausea. (2)
 Dizziness tinnitus and disorientation and dramatic changes in hr and bp (3)
 Dryness mouth throat, sore lungs
 Dysautonomia, ataxia, MECFS, MCAS
 Electric shocks
 Extreme Food/medication intolerance
 Eye migraines. Double vision. Infected toes
 Fibromyalgia
 Gastrointestinal issues (4)
 Hair loss
 Headaches (4)
 Hearing, eyesight, feet and skin problems
 Heart pain, costochondritis, blood clots, Dysautonomia, fibromyalgia, chronic fatigue, ovarian failure and hormone problems
 Hypertension, hot flushes, raised ALT levels, signs of nerve damage
 Increase in blood pressure, cholesterol and breathing pattern disorder
 Increased allergy symptoms
 Inflammatory flare ups
 Insomnia
 Left side weakness, walking into walls,
 Loss of appetite
 Loss of smell and taste, confusion with coordinating, tinnitus, headaches, rashes, shakes in hands, tremors, light sensitivity, hair loss, brain fog, concentration problems,
 Loss of smell and taste, tinnitus, digestive issues including diarrhoea, sleep issues, headaches, mental health (3)
 Loss of voice
 Lost all my teeth bar 2. Itchiness. Fluctuating blood pressure
 Mast Cell Activation Syndrome
 Mood swings and can't be bothered syndrome
 Multiple new health conditions following covid – Raynaud's, High Blood Pressure, Eczema, Silent Reflux, Subclinical Hypothyroidism, Bell's Palsy and various AI markers (elevated inflammation, CRP, etc). Also, multiple new deficiencies (Vit D, Iron, B12 and Folate and others) and food intolerances.
 Muscle tension and panic attacks
 Neuropathic pain

Nose bleeds, pale/flushed, feeling ill, wheeze, recurrent viral illness, mood swings/violence, pins n needles, diarrhoea,
 Not being able to walk, insomnia, voice dysphonia, sensory overload, headaches, severe memory loss, post exertional malaise, change of taste-smell, obesity, muscle weakness
 Numerous ME/CFS symptoms (e.g. reduced exertion capacity, headaches, abdominal pain, disrupted sleep, PESE), POTS
 Ongoing diarrhoea and bowel incontinence
 Peripheral neuropathy, poor stamina, unpredictable low energy levels, need for a lot of sleep
 Photophobie, vertigo, tinnitus
 Pots, fainting, gastritis, chronic migraine, chronic fatigue (2)
 Pots, heart damage
 Prostatitis,
 Pulsatile tinnitus.
 Regular diarrhoea and sickness
 Sensory overload, autism traits, extreme lethargy, neurological
 Sensory symptoms
 Skin condition
 Sleep apnoea
 Stomach pain and hair loss
 Stutter. Don't always understand what is being said. Can get lost
 Tinnitus (4)
 Trouble walking, possible seizures, tachycardia, bradycardia, could feel temperature, felt euphoric for 14 months despite illness, strong chest pains, trouble sleeping, sudden high cholesterol, infections that won't clear up.
 Urology issues, Vocal problems, social anxiety and agoraphobia
 Vertigo
 Vertigo and balance problems
 Voice loss
 Weakness, Facial Numbness, Stomach Pain, Altered proprioception
 Weight gain, heart failure
 Weight loss, loss of physical strength, cardiac.
 Widespread pain, pins and needles, external tremors, internal tremors, PEM, imbalance, clumsiness
 Worsening of CFS/Fibromyalgia symptoms after contracting COVID

N.B. The above is an extensive selection of symptoms from the 110 respondents selecting the option 'Other' in Table Four above.

5. Ethnic group of respondents

Ethnic group of respondents	No	%
White: English/Welsh/Scottish/Northern Irish/British	362	90.7
White: Irish	3	0.8
White: Gypsy or Irish Traveller	0	0
White: Any other White background	15	3.8
Mixed/Multiple Ethnic Groups: White and Black Caribbean.	0	0
Mixed/Multiple Ethnic Groups: White and Black African	2	0.5
Mixed/Multiple Ethnic Groups: White and Asian	3	0.8
Mixed/Multiple Ethnic Groups: Any other Mixed/Multiple Ethnic background	2	0.5
Asian/Asian British: Indian	2	0.5
Asian/Asian British: Pakistani	0	0
Asian/Asian British: Bangladeshi	0	0
Asian/Asian British: Chinese	2	0.5
Asian/Asian British. Any other Asian background	2	0.5
Black/African/Caribbean/Black British: African	0	0
Black/African/Caribbean/Black British: Caribbean	0	0
Black/African/Caribbean/Black British: Any other background	0	0
Other ethnic group: Arab	0	0
Prefer not to say	6	1.5
Total	399	100

6. Age group of respondents

Age group of respondents	No	%
Under 18	0	0
18 – 24	3	0.7
25 – 34	33	8.3
35 – 44	56	14.1
45 – 54	112	28.1
55 – 64	111	27.9
65 - 69	43	10.8
70 – 74	13	3.3
75 - 79	17	4.3
80 and over	6	1.5
Prefer not to say	4	1.0
Total	398	100

7. Religious belief of respondents

Religion or belief of respondents	No	%
No Religion	137	34.9
Christian	231	58.9
Buddhist	3	0.8
Hindu	1	0.3
Jewish	0	0
Muslim	0	0
Sikh	0	0
Other religion	0	0
Prefer not to say	20	5.1
Total	392	100

8. How respondents identify

How respondents identify	No	%
Male	94	23.8
Female	292	73.9
Trans-Man	0	0
Trans-Woman	1	0.3
Non-binary	2	0.5
Gender-Non-Conforming	0	0
Other	0	0
Prefer not to say	6	1.5
Total	395	100

9. Sexual orientation of respondents

Sexual orientation of respondents	No	%
Heterosexual	343	87.7
Lesbian	9	2.3
Gay	5	1.3
Bisexual	8	2.0
Asexual	3	0.8
Other	0	0
Prefer not to say	23	5.9
Total	391	100

10. Relationship status of respondents

Relationship status	No	%
Married	201	50.4
Civil partnership	5	1.3
Single	64	16.1
Lives with partner	42	10.6
Separated	11	2.8
Divorced	33	8.3
Widowed	18	4.5
Other	0	0
Prefer not to say	24	6.0
Total	398	100

11. Day to day activities limited because of health problem or disability which has lasted, or is expected to last, at least 12 months.

Day to day activities	No	%
Yes, limited a lot	261	65.9
Yes, limited a little	77	19.5
No	58	14.6
Total	396	100

12. Respondents consider themselves to have a disability (As defined by The Equality Act 2010)

Respondent considered to have a disability	No	%
Physical disability	105	27.6
Sensory disability	13	3.4
Mental health condition	34	8.9
Learning disability or difficulty	4	1.1
Long-term illness	116	30.6
Prefer not to say	18	4.7
Other	0	0
No, don't consider themselves to have disability	90	23.7
Total	380	100

13. Respondents providing care

Providing care for someone	No	%
Yes – For person aged 24 and under	42	10.6
Yes – For adults aged 25 to 49	18	4.5
Yes – For older person(s) aged 50+	43	10.8
Prefer not to say	18	4.5
No	276	69.6
Total	397	100

14. Respondent pregnant at time of questionnaire completion

Currently pregnant	No	%
Yes	2	0.5
No	386	97.2
Prefer not to say	9	2.3
Total	397	100

15. Respondent recently given birth

Recently given birth	No	%
Yes	0	0
No	388	97.7
Prefer not to say	9	2.3
	397	100

16. Respondent served in Armed Services

Served In Armed Services	No	%
Yes	11	2.8
No	383	95.7
Prefer not to say	6	1.5
Total	400	100

17. Those with long COVID by area

	I have long COVID and currently accessing NHS long COVID service	I have/had long COVID and previously accessed NHS long COVID service	I have/had long COVID but haven't received support for my condition
Cheshire East	34	27	2
Cheshire West	52	13	16
Halton	7	6	2
Knowsley	4	4	1
Liverpool	21	5	4
Sefton	15	3	2
St. Helens	14	4	2
Warrington	22	10	5
Wirral	25	7	4
Outside	15	2	2
Total	209	81	40

18. Those with long COVID by age

	I have long COVID and Currently Accessing NHS long COVID Service	I have/had long COVID and previously accessed NHS long COVID Service	I have/had long COVID but haven't received support for my condition
18-24	2	1	0
25-34	19	2	2
35-44	28	6	4
45-54	47	27	7
55-65	65	21	5
65-69	13	11	4
70-74	5	3	1
75-80	3	3	2
80+	3	0	1
Prefer not to say	0	1	1
	185	75	27

19. Those with long COVID by gender

	I have long COVID and currently accessing NHS long COVID service	I have/had long COVID and previously accessed NHS long COVID service	I have/had long COVID but haven't received support for my condition
Male	37	22	4
Female	129	44	23
Trans-woman	1	-	-
Non-binary	1	-	-
Prefer not to say	1	-	-
Total	169	66	27

20. Those with long COVID by relationship status

	I have long COVID and currently accessing NHS long COVID service	I have/had long COVID and previously accessed NHS long COVID service	I have/had long COVID but haven't received support for my condition
Married	93	33	8
Civil partnership	1	2	1
Single	21	12	4
Lives with partner	16	10	6
Separated	5	2	3
Divorced	17	4	3
Widower	6	3	1
Prefer not to say	9	1	1
Total	168	67	27

21. Those with long COVID by disability

	I have long COVID and currently accessing NHS long COVID service	I have/had long COVID and previously accessed NHS long COVID service	I have/had long COVID but haven't received support for my condition
Physical disability	65	20	6
Sensory disability	4	4	1
Mental health condition	20	6	3
Learning disability or difficulty	2	2	-
Long-term illness	72	17	7
Prefer not to say	6	2	2

N.B. Some respondents had more than one disability.

22. The survey

The survey was hosted online by Survey Monkey.

Survey questions:

Long COVID Services in Cheshire and Merseyside

Introduction and Privacy Statement

This questionnaire is for you to share your views on NHS long COVID support services in Cheshire and Merseyside. You can find background information about this on the [NHS Cheshire and Merseyside website](#).

The questionnaire will close on Sunday 16th March 2025.

This questionnaire is for individual responses. If you would like to share views on behalf of a charity, support group or similar organisation, please email engagement@cheshireandmerseyside.nhs.uk

How will my information be used?

NHS Cheshire and Merseyside is coordinating responses for this engagement. Your responses to these questions are anonymous - we don't link this information with any that identifies you.

Your data will be treated confidentially and stored in accordance with Data Protection law and NHS Cheshire and Merseyside Privacy Notice. You can read NHS Cheshire and Merseyside Privacy Notice at [Privacy Notice - NHS Cheshire and Merseyside](#)

**Questions marked with a * require an answer before you can move on.
Thank you.**

1. Where do you live?

- Cheshire East
- Cheshire West
- Halton
- Knowsley
- Liverpool
- Sefton
- St Helens
- Warrington
- Wirral
- Outside of Cheshire and Merseyside (please specify)

* 2. Please tell us about your interest in this questionnaire (please tick as many as apply):

- I have long COVID and I am currently accessing an NHS long COVID service
- I have/had long COVID and have previously accessed an NHS long COVID service
- I have/had long COVID but haven't received support for my condition
- I am a carer of someone with long COVID
- I am a health professional working in another service and would like to share my views in an individual
- capacity
- I am a member of Staff working in a long COVID Service
- None of the above apply to me but I would like to share my views
- Other (please specify)

My experience:

3. What symptom, or symptoms, prompted you, or the person you care for, to seek support for long COVID? Tick all that apply.

- shortness of breath
- fatigue
- problems with your memory and concentration ("brain fog")
- heart palpitations and dizziness
- joint pain and muscle aches
- depression, anxiety and mental health
- Other (please specify)

4. What level of support do you feel you, or the person you care for, needs/needed for the following symptoms:

	Highest level of support	Requires some support	Lower level of support	Lowest level of support	I have no experience of this symptom
shortness of breath	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
fatigue	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
problems with your memory and concentration ("brain fog")	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
heart palpitations and dizziness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
joint pain and muscle aches	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
depression, anxiety and mental health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other, as stated in previous question	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

5. To help you manage your long COVID, have you received support from any of these other services?

- Your GP practice
- Talking Therapies (psychological treatments for mental and emotional problems)
- Pain Management
- Respiratory/Pulmonary Rehabilitation
- Community Therapies (OT/Physio)
- Chronic Fatigue/ME (regional service which is operated by Liverpool University Hospitals Foundation Trust)
- Medical Specialties relevant to your individual clinical symptoms including Cardiology, Rheumatology,
- Gastroenterology, Neurology
- Local wellbeing and support organisations e.g. wellbeing hubs, disability support
- Local social prescribing services e.g. in your GP practice
- Online resources
- I haven't received any additional support
- Other (please specify)

6. How do/did you find it most helpful to access long Covid support?

	Very helpful	Somewhat helpful	Somewhat unhelpful	Not very helpful	I have no experience of this kind of support
Face-to-face appointments	<input type="radio"/>				
Online appointments (video)	<input type="radio"/>				
Telephone appointments	<input type="radio"/>				
Group-based treatment sessions	<input type="radio"/>				
Peer-led support groups	<input type="radio"/>				

7. Please use this space to provide any additional comments. For example, you could share details of how changes to NHS long COVID services might impact you/people you care for, or what wider support you feel is needed for people with long COVID.

Comments

8. Please use this space to share your views about how NHS long COVID support should look in the future. This could include how changes to NHS long COVID services might impact you or people you care for.

Equality monitoring questions

All the information that you give will be recorded and reported anonymously. NHS Cheshire and Merseyside collect this as part of its duty under the Equality Act 2010.

Your data will be treated confidentially and stored in accordance with Data Protection law and NHS Cheshire and Merseyside Privacy Notice. You do not have to answer these questions if you do not want to. Thank you.

* 9. Are you happy to complete this section to help us better understand who we are reaching? *

- Yes
- No

Equality monitoring questions

10. What is your ethnic group? Choose one option that best describes your ethnic group or background.

- White: English/Welsh/Scottish/Northern Irish/British
- White: Irish
- White: Gypsy or Irish Traveller
- White: Any other White background (please specify below)
- Mixed/Multiple ethnic groups: White and Black Caribbean
- Mixed/Multiple ethnic groups: White and Black African
- Mixed/Multiple ethnic groups: White and Asian
- Mixed/Multiple ethnic groups: Any other Mixed/Multiple ethnic background (please specify below)
- Asian/Asian British: Indian
- Asian/Asian British: Pakistani
- Asian/Asian British: Bangladeshi
- Asian/Asian British: Chinese
- Asian/Asian British: Any other Asian background (please specify below)
- Black/African/Caribbean/Black British: African
- Black/African/Caribbean/Black British: Caribbean
- Black/African/Caribbean/Black British: Any other Black/African/Caribbean background (please specify below)
- below)
- Other ethnic group: Arab
- Prefer not to say
- Any other ethnic group (please specify below)

11. How old are you?

- Under 18
- 18-24
- 25-34
- 35-44
- 45-54
- 55-64
- 65-69
- 70-74
- 75-79
- 80 and over
- Prefer not to say.

12. What is your religion or belief?

- No religion
- Christian (including Church of England, Catholic, Protestant and all other Christian denominations)
- Buddhist
- Hindu
- Jewish
- Muslim
- Sikh
- Prefer not to say
- Other (please specify)

13. How do you identify?

- Male
- Female
- Trans-Man
- Trans-Woman
- Non-binary
- Gender-non-conforming
- Other (please specify)

14. What is your sexual orientation?

- Heterosexual
- Lesbian
- Gay
- Bisexual
- Asexual
- Prefer not to say
- Other (please specify)

15. What is your relationship status?

- Married
- Civil Partnership
- Single
- Lives with Partner
- Separated
- Divorced
- Widowed
- Prefer not to say

16. The Equality Act 2010 protects people who are pregnant or have given birth within a 26-week period. Are you pregnant at this time?

- Yes
- No
- Prefer not to say

17. Have you recently given birth? (Within the last 26-week period)

- Yes
- No
- Prefer not to say

18. Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months?

- Yes, limited a lot
- Yes, limited a little
- No

19. Do you consider yourself to have a disability? (The Equality Act 2010 states a person has a disability if they have a physical or mental impairment which has a long-term (12month period or longer) or substantial adverse effects on their ability to carry out day-today activities).

- Physical disability (please describe)
- Sensory disability e.g., Deaf, hard of hearing, Blind, visually impaired (please describe below)
- Mental health condition
- Learning disability or difficulty
- Long-term illness e.g., cancer, diabetes, COPD (please describe below)
- Prefer not to say
- No, I do not consider myself to have a disability
- Other (please specify)

20. Do you provide care for someone? A carer is defined as anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support (Tick as many as appropriate)

- Yes - Care for young person(s) aged 24 and under
- Yes - Care for adult(s) aged 25 to 49
- Yes - Care for older person(s) aged 50 and over
- No
- Prefer not to say

21. Have you ever served in the armed services?

- Yes
- No
- Prefer not to say

Thank you - before you go.

22. Where did you hear about this questionnaire?

- From my GP practice
- From a local pharmacy
- I was sent a letter by an NHS long COVID Service
- Social media (Facebook etc.)
- NHS website (for example, NHS Cheshire and Merseyside or hospital trust website)
- Through a patient group and/or voluntary sector organisation I am connected to
- NHS staff communication
- Friend or family member
- Other (please specify)