What people have told us about Long Covid

September 2020 – March 2022
Introduction

During the COVID-19 pandemic, we received feedback from a number of people about their experiences of Long Covid.

This briefing is informed by the experiences of:

11 local Healthwatch reports which contain the experiences of 736 people

122 members of the public sharing their views directly with Healthwatch England.

122 people took the time to share their experiences of Long Covid with us between September 2020 and March 2022.

Many shared that they felt their GP had been dismissive of their concerns or uninformed about Long Covid. Some people experienced long waiting times to access support at Long Covid clinics, although those who did receive support found it helpful. People told us that Long Covid has an impact on every part of their life, health and wellbeing. We heard from people who have struggled to carry out daily living tasks, as well as people struggling to return to work or care for their loved ones. We also heard about the specific impact of Long Covid on women, children and young people, people with other neurological conditions such as ME and MS, and NHS staff.

Eleven local Healthwatch have completed research and engagement on Long Covid, with more currently undertaking projects and sharing their insight with us.

- Healthwatch Dudley – Our hospital, our care, our future
- Healthwatch Gloucestershire – Post Covid Syndrome: people’s experiences of health care and support in Gloucestershire
- Healthwatch in North Central London – People’s experience of Long Covid in North Central London
- Healthwatch Kingston upon Thames – Living with Long Covid
- Healthwatch Medway – Spotlight on Long Covid
The stories shared with us so far indicate that the goals outlined in NHS England’s Long Covid plan 2021/22 are not yet being consistently achieved. The plan aligns with the concerns which were shared with us, emphasising the importance of continuous, holistic care and enhancing support for GP services. But what we have heard suggests that the policy is not being implemented consistently, leading to failures to provide adequate support for people with Long Covid.

What our evidence shows

GPs are unsure of the symptoms of Long Covid

Many people shared their experiences struggling to access support from GPs. People have not been offered proper investigation of symptoms or been referred to specialist services to manage their condition. There is a concern that the difficulties people face in accessing support are driven by GPs not understanding Long Covid and not being aware of the support they can offer to patients.

We did hear from people who found it difficult to get appointments with GPs because of ongoing pressures on primary care. However, we mostly heard that people can talk to their GP about Long Covid, but GPs were not equipped to support them.

Many people also told us that GPs either dismissed their symptoms or did not understand that symptoms such as fatigue and brain fog were symptomatic of Long Covid. Long Covid is an incredibly changeable condition, with an individual’s symptoms changing over time and symptoms differing between patients. This can make it difficult for GPs to diagnose Long Covid, especially if they are unfamiliar with the condition.

“I had a telephone appointment followed by a face to face appointment with a GP who told me that I didn’t have Long Covid – in his opinion.” (This respondent has been experiencing symptoms
What people have told us about Long Covid

Many felt there was a reluctance by GPs to recognise and diagnose Long Covid. We heard from people who had to persuade their GP over a series of appointments that they had Long Covid, and others who felt their GP was dismissive of their symptoms or misdiagnosed them. Many described GPs as unsympathetic. Some people felt they had been misdiagnosed. Others were prescribed medication for anxiety and depression and offered no further support for their symptoms.

Healthwatch Kingston upon Thames found that nearly half of their respondents with symptoms of Long Covid had not been diagnosed with Long Covid, despite 80% of their sample having experienced symptoms for over 6 months. Healthwatch in North Central London found that 55% of respondents who had spoken to their GP about their symptoms waited longer than four months for a diagnosis of Long Covid.

Some people told us they had blood tests but were told there was nothing wrong with them when tests came back as ‘normal’, resulting in no further treatment or support outcomes for patients. People had to chase up test results and follow-up appointments, which GPs poorly managed.

Patients told us that GPs were reluctant to diagnose patients with Long Covid, particularly if they had not received a positive Covid test in the first place. This created particular difficulties for those who caught Covid prior to or during March 2020, when testing was less readily available. We also heard that some GPs overlooked patients who experienced non-typical symptoms of Long Covid, such as neurological and cognitive symptoms, rather than respiratory symptoms.

Had to fight to get referral to SNELCAS [Suffolk and North East Long Covid Assessment Service], as originally had negative test. Even when referral was submitted by GP, another GP called to warn that my referral was likely to be declined by SNELCAS even though no evidence of this. Appointment had already been received, so when
I attended the appointment, I was anxious about being turned away.

– Quote from Healthwatch Suffolk

People need a diagnosis from their GP to access support, and the lack of understanding of GPs is leading many patients to feel dismissed and overlooked. The lack of a diagnosis impacts those suffering from Long Covid. Some cannot access support from Long Covid clinics. Others told us their GPs would not acknowledge Long Covid on letters for sickness benefits, affecting their ability to access financial support.

GPs are not always aware of what support is on offer

We also heard that, even if GPs acknowledged symptoms, they were not always clear what support for Long Covid was available. Some people were told that their GP simply didn’t know what to do with them. Some GPs were unaware of the existence of Long Covid clinics.

Healthwatch Wandsworth spoke to fifty people who had experienced Long Covid. Only six of these people were referred to a Long Covid clinic, with one person wrongly told by their GP that there were no Long Covid clinics in the borough. One person was told to find a specialist clinic themselves.

‘I have found, since having Covid, that the support is simply not there. Physically or financially. […] My GP surgery have consistently told me they don’t know what to do for me, which I understand, but you do tend to feel like you’re on your own with this.’

– Quote from Healthwatch South Gloucestershire

The public is also unaware of what support is available for Long Covid. Healthwatch Trafford tested the awareness of Long Covid support in their area. They found less than one quarter of their sample were aware of the NHS page “your Covid recovery”.

We heard from 122 people who shared their experiences. One in five of those had contacted their local Healthwatch because they did not know what support was available. Many of these people had spoken to their GP, a clear indication that GPs are not signposting to services to help people manage their symptoms.

However, we did hear from people who felt that when their GP was open and honest about the lack of information about Long Covid, being a relatively new condition, it reassured them that their GP was doing all they could.

‘My COVID symptoms were the same for months – breathlessness, fatigue, loss of taste and smell and nausea. I had been in regular contact with my GP throughout infection and I am still receiving on-going support for Long Covid. I really feel like my GP is trying their best, they have been honest with me and explained that the
virus is so new, they don’t have a specific treatment plan. I’ve had multiple blood tests, an ECG, I have been having chest X-rays – all displaying signs of ‘something’, but a something common to those in my position. It’s been such an incredibly hard time for our healthcare services (I caught COVID working in healthcare, looking after someone much worse off than me). I’m lucky that my GP is supporting me despite their honest admission of not knowing exactly what to ‘prescribe’ so to speak. One thing I have learnt during this time is the importance of holistic healthcare, and in looking after myself to help support my GP as they support me.’

– Quote from Healthwatch Gloucestershire

If GPs are aware of support, they don’t always know how to refer someone for it

We also heard that GPs did not know how to refer a patient to Long Covid clinics.

Some GPs are not correctly managing referral requests to Long Covid clinics and other services. Patients are told they have been referred, but GPs have no record of this. Having to fight to be heard is challenging, especially for those people who may already be lacking resilience.

“I went to my GP and she wanted to refer me to a Long Covid clinic, but the referral process was highly detailed, she suggested that I wait further and see how I feel.”

– Healthwatch Wandsworth

We also heard that some people were referred to a Long Covid clinic, but were never contacted by that clinic. It is sometimes not clear why people find themselves caught between services, but people have told us they were unable to access a clinic that did not have a record of their referral, and unable to speak to their GP for help because they had already been referred.

Had Covid in August 2020, was poorly for about 2 weeks, returned to work and just felt tired. Became ill again about a week later, had trouble breathing, spoke to the GP and 111 but got bounced between the two with no real action being taken for around 2 months. It was taking [her] half an hour to walk up the stairs, very out of breath. A month later, breathing problems getting worse and now having chest pains. GP was meant to refer to Covid Hub four times, but they didn’t do it. [She] got an appointment at the respiratory clinic and got sent straight to A and E, had high blood pressure and spent two days in hospital.
Patients also told us that, even if their GP was aware of what Long Covid support was on offer, there was no monitoring, advice or management of expectations about what support they might receive. People had little idea what a referral to a Long Covid clinic meant.

**These issues mean that people are managing their symptoms themselves**

The scarcity of advice and information from GPs leaves people feeling isolated and frustrated and seeking alternative sources of support and treatment. People rely on their own research and online support groups to obtain information about Long Covid, where they risk finding conflicting information and misinformation.

Healthwatch Richmond found that people frequently sought support and advice through social media or existing groups for Chronic Fatigue Syndrome/ME.

Self-management can also be costly. We heard from some patients who had turned to private treatment. This can widen health inequalities for those who cannot afford it. We heard from many who were suffering financially due to the impact of Long Covid on their ability to work and support themselves and others. Healthwatch Richmond found many people resorted to private healthcare, despite not always being able to afford it.

‘After the GP’s diagnosis approximately 3 months later there was nothing, answers to questions which I was promised were never answered and results were not relayed to me as promised. It was too stressful for me to engage or fight with this blank wall, stress causes instantaneous relapses in symptoms. I self-managed for 4 months using information from social media medics and long Covid groups. I got worse.’

– Quote from Healthwatch Sheffield

**People have mixed experiences of Long Covid clinics**

We heard mixed experiences of care from Long Covid clinics. Many people told us about long waiting times, and it is unclear whether people waiting for care from a Long Covid clinic received support in the meantime.

Once people were able to attend a Long Covid clinic, we heard of short and uninformative appointments. People felt that practitioners did not go into detail about their concerns and often did not offer concrete solutions or treatment.

Waited 3 months for an appointment at the long Covid clinic at UHCW and then had a 5-minute appointment that felt dismissive. Went through a questionnaire and then said you are getting better.
Long Covid is a condition that can cause widely varying symptoms, and people expect support to address the variety of symptoms they have. However, we heard that people were only offered support for respiratory symptoms. Our evidence indicates a lack of support for patients who do not display typical symptoms, such as those affected by ‘non-visible’ symptoms, for example, acute neurological and cognitive issues.

“...My GP confirmed to me that the "Long Covid clinic" was indeed just respiratory, and there was nothing else they could do. Nor could the GP. Thankfully, I am still being followed up by the lung clinic, so far. [...] Long Covid services in Greater Manchester/Trafford are not truly joined up or consistent across the region, are hard to access, and there is no multidisciplinary approach – it starts and ends at respiratory, despite nationwide research into it as a multisystem syndrome. Patient experience and input does not seem to be a part of planning.”

– Healthwatch Trafford

However, we did hear some positive stories saying that the support GPs and Long Covid clinics had offered was helpful. When people can access care, and the care works, it benefits patients. But it’s clear that plans to improve access to care are not being implemented.

[Caller] is slowly working towards returning to a normal level of activity, she must rest when needed and has been advised to work with the condition and not against it, she is increasing her activity by seconds rather than minutes/hours. She is hoping to return to work in November and this will be done in a phased manner, she said she has had good support and understanding from her employer. [She] has had great support from family and friends and has also found the online Long Covid Clinics very helpful. Good understanding and support from her GP as well.

– Quote from Healthwatch Essex

**Long Covid can affect every aspect of life – but patients are not being offered holistic support**

People shared with us the impact that Long Covid has had on their lives.
Many people reported physical symptoms such as joint and muscle pain, chest pains, and breathlessness. For many, these physical problems led to difficulties with daily living. People shared that they found it challenging to complete small tasks such as washing their hair or making a cup of tea.

I am recovering from Covid. Was hospitalised since October 2020. I’ve been home since 2nd February. In the last month I’ve been suffering severe joint and muscle pain. I still cannot walk far without my walking frame. In the past two weeks the pain in my shoulder joints is intense I’m unable to lift my arms. Lifting a kettle and just little things I’m unable to do. I cannot dress myself. If I exert myself, I cannot do anything for a few days.

– Quote from Healthwatch Milton Keynes

Cognitive issues such as memory problems and brain fog also contributed to difficulty with daily living, including difficulty answering voicemail messages or completing paperwork. Several people told us about mobility issues arising from Long Covid, with some relying on mobility aids in order to walk. We heard from people who struggled to lift hairdryers and kettles because of declining strength and others who were severely fatigued following any small task.

Healthwatch in North Central London found that people with Long Covid found it difficult to return to work after their illness, especially if their job relied on skills such as memory or physical fitness, which Long Covid particularly affects.

Severe fatigue led to people spending every hour of free time asleep to recover their energy, having a knock-on impact on their mental health and wellbeing as they could not socialise or otherwise enjoy their free time.

Healthwatch Wandsworth found that 92% of their respondents experienced fatigue, with many saying they had to spend long periods in bed. Sometimes, people felt extreme fatigue following activity, but there was no apparent reason at other times.

Healthwatch Richmond found that 93% of their participants felt Long Covid had had a “significant impact on their lives”. They heard that close relationships suffered, with people struggling to socialise due to their condition. People also shared that tasks required more effort, resulting in only completing necessary tasks.

Many people shared their experiences of anxiety, depression and PTSD following Long Covid. Some state that this is a symptom of Long Covid itself, while others shared that it had arisen from the condition’s impact on their life and relationships. Over three quarters (78%) of Healthwatch Richmond’s and Healthwatch Wandsworth’s respondents, and 85% of Healthwatch Kingston’s respondents, reported that Long Covid had impacted their mental health.

But we heard that when people were able to access support, it mainly focused on physical symptoms. People requested community support with daily living tasks, but their requests were not followed up. People who received support for
physical symptoms, such as inhalers, were often not supported in other areas. We also heard that people were unable to access support for their mental health.

Generally, people told us they expected support to be more holistic, but these expectations were not met.

**Specific groups have issues that are not being addressed**

We heard from women, parents worried about children and young people, people with other neurological conditions, and NHS staff. They all told us they had specific difficulties that healthcare professionals did not address.

It’s important to note that many of these were very small samples. More targeted research into these groups’ experiences – especially those of women and people with other neurological conditions – is needed to fully understand the extent to which their needs are not being met.

**Older women feel practitioners are dismissing their concerns**

While many patients felt their GP was dismissive of their experiences and symptoms, this was especially pertinent for older women. A number of the women we heard from, especially older women, reported that their concerns were dismissed or requests for help were refused.

Many believe that this is due to both their gender and their age. In a *summary of the healthcare issues women face*, the House of Lords reported that the UK has the 12th largest female health gap globally. They report that a variety of studies show that women experience poorer health outcomes in many areas of healthcare, often due to misdiagnosis and dismissal by healthcare practitioners. *Research by the Department of Health and Social Care in 2021* found that women felt they were not being listened to in all areas of the clinical pathway:

*More than 4 in 5 (85%) went on to tell us there have been times they (or other woman they had in mind) were not listened to by healthcare professionals.*

*Tens of thousands of examples were submitted. Based on our thematic analysis of this data, ‘not being listened to’ appears to manifest at all stages of the healthcare pathway. Specifically, many women told us:*

- *Their symptoms were not taken seriously or dismissed upon first contact with GPs and other health professionals*
- *They had to persistently advocate for themselves to secure a diagnosis, often over multiple visits, months and year*
- *If they did secure a diagnosis, there were limited opportunities to discuss or ask questions about treatment options and their preferences were often ignored*¹

¹ Findings from Department of Health and Social Care, 2021

What people have told us about Long Covid
Healthwatch Richmond upon Thames reported a clear gender difference in access to a diagnosis for Long Covid and support.

“74% of the men who answered the survey received a diagnosis against 27% of women. Similarly, 58% of men accessed support for their symptoms (11), against 30% of women (22). This is despite men and women reporting the same severity of symptoms, and men showing marginally more improvement in their symptoms than women.”

– Healthwatch Richmond

They make clear that there were more women than men in the sample, so the findings must be interpreted with caution. However, we heard from several women who believe that their gender contributed to scepticism and dismissal from their GP when they tried to access help. They reported that their symptoms were misdiagnosed as mental health conditions, in one case resulting in a patient’s GP recommending she be detained under the Mental Health Act.

GPs and other practitioners dismissing patients’ concerns is an issue that came up repeatedly in our evidence. From our small sample and work by local Healthwatch, it seems that this may be especially true for women. We have concerns that women are experiencing more dismissive care because of their gender and, in some cases, age. More targeted work in this area, with a larger sample, is needed to see if this is the case.

I suffer with a range of symptoms which vary in time and severity, including moderate pain and extremely debilitating fatigue and malaise. Although I got a diagnosis of presumed Long Covid in August 2020 I was then left with no monitoring, zero advice or management of my expectation of what care I might expect to receive.

... Anxiety was first proposed as the cause for my ailments not surprisingly to the exclusion of other possible causes as basic tests came back negative. This was despite me suggesting otherwise, I was not initially listened to. ... I feel that my narrative as an anxious middle or old age woman was written for me by the first two male GPs who I spoke to regardless of whatever I described to them.

– Quote from Healthwatch Sheffield

**People with long term conditions are worried they will be overlooked**

Many of the symptoms of Long Covid overlap with those of other neurological conditions such as Multiple Sclerosis (MS), Chronic Fatigue Syndrome (CFS/ME), and Parkinson’s. We heard from patients with autoimmune conditions such as Parkinson’s Disease and Vasculitis and CFS/ME. People told us they were concerned about the increased risks associated with COVID infection, including
serious and prolonged illness and the exacerbation of existing health conditions. They felt that they did not have enough information about the potential interaction between their long term conditions and Long Covid.

We heard that some people felt their GP was overlooking their existing condition and its impact on their health following COVID.

People with CFS/ME told us that GP practices prioritised patients suffering with CFS/ME for COVID vaccines at their own discretion. This ‘postcode lottery’ is concerning for those with CFS/ME, as they risk severe illness and long-lasting complications in the event of infection.

Patient with long term Functional Neurological Disorder (FND) developed Long Covid and a relapse of FND with new symptoms. According to patient, they have had up to 200 seizures a day. Patient has now to wait until 1 April 2022 to see a Neurologist. According to the patient, this is the second time they have been left down by the surgery due to referrals been rejected based on insufficient information of symptoms sent by the surgery. Patient has not received any support for long Covid or the recognition of it causing relapse of FND. Patient’s symptoms include dystonia of feet, tics, inability to eat and weight loss of 3 stone in 3 months.

– Quote from Healthwatch North Somerset

There is also a sense of unfairness and worry amongst some people with CFS/ME. Long Covid shares many commonalities with the condition, and those who are diagnosed with Long Covid are referred to specialist services for support. Services are already stretched, and there is a concern that those already living with existing conditions are not getting additional help, and services are not being further resourced.

There’s a feeling among some ME groups that there’s unfairness in this approach – Long Covid is in many ways similar to ME (unexplained periods of fatigue, muscle and joint aches etc) so lots of people with Long Covid are being referred into those services for support, which are already stretched, while people suffering from ME are not getting additional help and the services are not being further resourced.

– Quote from Healthwatch Sheffield

Parents don’t always know what help is available for children and young people

We only heard from a small number of people concerned about the impact of Long Covid on children and young people.
However, those who contacted us were concerned about support provided for children and young people with Long Covid. They also felt that young people were overlooked in information and advice about Long Covid, with some people saying that their children were not taken seriously by their GP.

**My son caught Covid in Dec 2020 from school. [...] The doctors were good and supportive in doing the tests and required investigations. However, I also felt that they were a bit insensitive at a point, where they actually suspected me and the child of making up these stories because nothing had been showing up on the reports, but definitely I've seen my son suffer these 3 months and the lack of trust that our GP started showing made us feel really helpless.**

I think more investigations need to [be carried out] for long Covid issues. There’s not much known and therefore doctors aren’t really in a position to help but definitely there is an issue that needs to be looked into.

— Quote from Healthwatch Harrow

Generally, the people we heard from were worried that their children wouldn’t be offered support if they developed Long Covid or were unclear about what support their children were entitled to. In NHSE’s plan for Long Covid services, they plan to establish fifteen paediatric hubs for children with Long Covid. It would be worthwhile to conduct targeted research to see if parents and children are aware of these hubs and if they have been helpful.

**NHS Staff are worried about returning to work**

We heard from a small number of people who worked for the NHS, some of whom had caught COVID while caring for patients. They were worried about returning to work as they didn’t want to put themselves at risk of reinfection.

While some NHS staff members did have positive experiences of support, sometimes they had to access care through connections at work. One woman told us that her GP did not examine her, but she used contacts in the hospital she worked at to access treatment.

One person told us that a traditional phased return to work does not work for people living with Long Covid, partly because of the fluctuation of symptoms. They felt that this was particularly pertinent for NHS staff and that more thought needed to be given to working with NHS Staff with Long Covid to help them get back to work.
Changes in our evidence over time

The stories we heard indicate that improvements set out in June 2021 by NHS England have not yet been implemented effectively. Our sample spans September 2020 – March 2022. When we compare the overall themes that emerge from the data before June 2021 and after, we see that there are only slight changes.

Our sample suggests some trends before and after the implementation of the NHS plan. We heard more people asking for information about what support was available for Long Covid prior to the implementation of the NHS plan, in September 2020 – May 2021, compared to June 2021 – March 2022 (27% compared to 18%).

Whilst fewer people asked for information about what support was available, more people told us about their experiences with their GP and referrals after June 2021. 44% of experiences were about GPs and referrals between June 2021 and March 2022, compared to 32% before.

<table>
<thead>
<tr>
<th>Themes in our data September 2020 – May 2021</th>
<th>Themes in our data June 2021 – March 2022</th>
</tr>
</thead>
<tbody>
<tr>
<td>GPs &amp; referrals</td>
<td>GPs &amp; referrals</td>
</tr>
<tr>
<td>Information request</td>
<td>Information request</td>
</tr>
<tr>
<td>Other</td>
<td>Other</td>
</tr>
<tr>
<td>Holistic impact</td>
<td>Holistic impact</td>
</tr>
<tr>
<td>Experience of support</td>
<td>Experience of support</td>
</tr>
</tbody>
</table>

What people have told us about Long Covid
The sentiment of the stories in our sample also changed over time. The experiences shared between September 2020 – May 2021 were largely neutral, and mostly comprised of requests for information. In comparison, the experiences shared between June 2021 – March 2022 were more focused on feedback on services and more negative. 55% of feedback in this period was negative.

It is important to note that these findings are drawn from small samples. Forty-four people shared experiences of Long Covid with us between September 2020 – May 2021, and seventy-eight people shared experiences between June 2021 – March 2022. The findings we have are indicative of larger trends but in no way confirm them. A larger dataset would be needed to discover more robust trends.

From this, it seems that slightly more people are aware of the support available for Long Covid since June 2021. The feedback is dominated by experiences of GPs and referrals and is largely negative. This perhaps indicates that, while people are approaching their GPs for help, they are not receiving adequate support. This is supported by the qualitative analysis we have undertaken.

Conclusions

The current NHS plan to tackle Long Covid addresses many of the issues that we heard affected those who shared their experiences with us. It set out to offer an enhanced service to GPs, including education about the condition and knowledge of clinical pathways, to improve patient support and enable more consistent referrals. It also stresses Long Covid’s impact on every aspect of life and acknowledges the importance of holistic care.
What people have told us about Long Covid

Overall, our findings indicate that the support outlined in the Long Covid plan has not yet been implemented consistently. GPs are often seen as dismissive or uninformed, and people struggle to access specialised Long Covid support. When support is offered, it is generally targeted at people diagnosed with Long Covid and people with respiratory symptoms. People not in these groups – for instance, those not diagnosed by their GP or who have cognitive/neurological symptoms – are overlooked.

Specific groups also have concerns. Older women told us that they believe their symptoms are being dismissed, often misdiagnosed as symptoms of menopause or mental health conditions. Our preliminary findings and research from local Healthwatch indicates that the trend here is being driven by poorer care for this group. A more in-depth look women’s experiences, especially older women, is needed to see if this is trend across the population. The context of known poorer care for women in health care settings suggests that this is likely to be the case.

People with chronic conditions such as MS, CFS/ME, and Parkinson’s also have specific concerns that their services will be overloaded with Long Covid patients, reducing their ability to access support. As support for Long Covid moves towards offering support for a chronic condition, thought should be given to ensuring other chronic conditions are not overlooked.

Areas where further efforts should be focused:

• Ensure that GPs understand the variable symptoms of Long Covid and take all concerns seriously.

• Ensure that GPs understand the support that is available and how to refer people to it.

• Ensure that support is truly holistic and people with non-traditional symptoms are offered appropriate care.

• Consider how to ensure people with Long Covid have help with daily living tasks.

• Consider how to ensure people with other chronic conditions are not overlooked and that services have adequate resources to cope with people with Long Covid and other conditions.

• Consider how to ensure holistic support is co-ordinated across services, including data sharing and referrals across services.

• Understand the experiences of women, especially older women, when trying to get help from their GP.