healthwatch Knowsley

healthwatch Liverpool

healthwatch St Helens

healthwatch Sefton

Long Covid Tier 3 Assessment and Treatment Services Review

October 2022

Contents

Introduction

About Healthwatch

This engagement was carried out collectively by **Healthwatch Liverpool, Knowsley, Sefton, and St Helens** at the request of the service. The local Healthwatch had heard from people about their experience of long covid and were keen to see how the new multidisciplinary teams were working and if they were meeting the needs of patients.

Healthwatch is the independent champion for people who use health and social care services. There is a local Healthwatch in each area of England. We're here to make sure that those running services, put people at the heart of care. One of our main purposes is to understand the needs, experiences and concerns of people who use health and social care services and to speak out on their behalf.

- We focus on ensuring that people's worries and concerns about current services are addressed. We work to get services right for the future.
- We listen to patients of health services and users of social care services, along with their family members or carers, to find out what they think of the services they receive.
- We advise people how to get the best health and social care for themselves and their families.
- We provide help and information about all aspects of health and social care.
- We make sure that service user views are heard by those who provide health and social care.
- Wherever possible we try to work in partnership with providers to influence how they make improvements.

About Mersey Care and the Long Covid Tier 3 Assessment & Treatment Services

Mersey Care is an NHS Foundation Trust which provides a range of community and mental health services. Mersey Care was appointed lead provider for Cheshire and

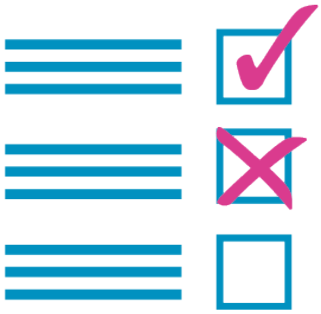
Merseyside Tier 3 Long Covid Assessment and Treatment Service and from 1 December 2021, referrals for Long Covid Assessment and Support from patients in Liverpool, Knowsley, Sefton and St Helens were made into the Mersey Care service. Previously a Tier 4 Long Covid service had been provided from Aintree by Liverpool University Hospitals Foundation Trust (LUHFT). This service will be referred to as the Aintree Long Covid Clinic henceforth in this report. More information on the service can be found on https://www.merseycare.nhs.uk/our-services/liverpool/long-covid-service

NHS
Mersey Care
NHS Foundation Trust

Community and Mental Health Services

About this engagement

Mersey Care asked the local Healthwatch (Healthwatch Liverpool, Knowsley, Sefton, and St Helens) to engage with patients to learn from their experiences of using the service. We believed that with long covid being a new condition there was also a lot to be learned from the experiences of patients affected earlier, some of whom had been referred to the Aintree Long Covid Clinic. For that reason, we had asked for the consent of the Aintree Long Covid Clinic to also speak to their patients, but this was not agreed. This has left a gap in our collective knowledge. Questionnaires were sent out to patients of the Long COVID Tier 3 Assessment and Treatment Service and paper copies of the survey given out at the clinics. Information was also shared on social media and on Healthwatch websites and with people who contacted the local Healthwatch in this period about Long Covid. This wider sharing was an attempt to fill the gap in knowledge from the Aintree Long Covid clinic not being party to the engagement.



Who we heard from

Overall, we engaged with 54 people, (5 interviews, 49 survey results). We asked people who had been seen by both the Long Covid Tier 3 Assessment & Treatment Services and the earlier Aintree Long Covid Clinic to identify which service they were talking about. Not all respondents did this. It is understandable that, especially when dealing with a service by telephone, some patients are not clear who was treating them. For most respondents, other information in their response (e.g. dates, names, clinics) make it possible to work this out. For respondents who were only seen by the Aintree Long Covid Clinic we included their feedback on page 14 rather than in the other sections of this report as it doesn't reflect on the Long Covid Tier 3 Assessment & Treatment Service but does provide lived experience of the condition.

We also heard separately from 3 people who hadn't been referred to a Long Covid Clinic yet but believe that they have long covid. Their responses have been reported separately on page 16.

The patients we spoke to were mostly female (**68%**), described their ethnicity as White: British / English / Northern Irish / Scottish / Welsh and all had English as their first language. Most of the respondents were aged between 51-60 (**40%**), followed by 41-50, and 61-70. This probably reflects those accessing the service. Given that even this cohort of people reported that getting referred to the service had often been difficult, it is likely that people from more diverse backgrounds, especially those without English as their first language, would have faced greater barriers. The planned provision of information on long covid in other languages and format might, if it reaches community members, help ensure a wider reach.

What did we hear?

Experiences of Referral from Primary Care to Long Covid Clinic

General experience of referral

As expected, people's experiences getting a referral to the clinic, from their GP or other primary care health professional, are varied. This presumably comes down to individual GP practices and GPs varying in how they deal with and see patients and their own practices of diagnosing and treating health conditions.

Just over a third of people we engaged with had a positive experience getting a referral from primary care to Long Covid services. Most of these people felt they didn't have to wait very long to be referred and the contact from the service was initially what they had hoped for. They felt an initial relief that their condition was recognised and felt staff were helpful and friendly during the process.

> *"It was quite simple; it took one appointment with my GP to get a referral and diagnosis (Brownlow Student Heath was my GP)"*

Around a third of the people that we engaged with had mostly a negative experience. This was mainly due to having to wait very long periods of time before actually being referred to the clinics. Some people felt the wait was unnecessary and their symptoms got worse in the meantime, or they were not initially believed by GPs who doubted that their symptoms were related to Long Covid. A few people said that they were sent for a lot of tests to confirm they had long covid and then had to wait for their results before being believed. Pre-referral tests are part of the required referral process to rule out other possible causes, but it is important to note that if not carefully explained to patients the process can lead to them feeling disbelieved.

Some people reported that they heard about the Long covid service from another NHS service such as A&E or a walk-in centre who advised them to ask their GP for a referral. If this visit and conversation hadn't had happened, they may not have even known to raise the question with their GP

Referral delays

In a small number of cases, there had been such a significant wait or barrier when getting an initial GP appointment that people reported waiting months before being seen by their GP to discuss a referral.
Even after seeing their GP, the referral was not always straightforward.

> *"GP has been understanding but admits that they are still learning about long covid."*

> *"The GP referred me to the wrong clinic and didn't put the correct information on the form further delaying everything that I then had to chase up with the long covid team"*

The delays caused by required tests caused some frustration for some patients. Some patients reported needing to do quite a bit of chasing to make sure that the referral and tests went through which could be challenging given their own fatigue or cognitive issues.

> *"I attended my GP for various tests I.e. BP/pulse/O2 stats/chest x-ray/ECG and then were told that none of my results were received, so I was the 'middle' man chasing results, going back for BP check again. In all, not a very smooth ride."* - Knowsley patient

A patient who moved house and changed GP during the referral period reported that the tests took a year to be carried out after an initial attempted referral to the Aintree Long Covid Clinic service (LUHFT) due to breakdowns in communication between practices. After their eventual referral to the service however they were seen promptly.

One person told us that the service once accessed was good and they thought more people should be referred but their GP had commented that it was a long referral form to fill in.

Time taken between referral and first contact with service

Again, the answers to this question varied. The shortest amount of time mentioned was just one day after a GP referral that the Long Covid service contacted them, whilst the longest waits people mentioned to be seen by the Long Covid Tier 3 Assessment & Treatment Services were around 6 months. 14 people said that they didn't have to wait more than 2 weeks which they were happy about.

10 people said that they had to wait 6 months or over between getting a referral and having first contact from the service. Some of these people had also been seen by the Aintree Long Covid Clinic service, therefore answers over 6 months may have included wait times from this service as some patients do not clearly distinguish between the two services – from a patient perspective they are both the NHS long covid service. Analysis of people's reported wait time and the reasons for this are interesting. Respondents who are clearly describing referral to the Long Covid Tier 3 Assessment & Treatment Services had a significantly lower wait time than patients referred earlier in time to the Aintree Long Covid Clinic service (LUHFT). Some patients however still report waiting times of weeks or months, but their text responses suggest this is due to the referral process and the time taken for the required tests to be carried out, rather than a delay on being seen once this had been done.

Treatments given in the meantime/ progression of symptoms

Due to the wait times before being seen, either because of GP appointment pressures or referral times, many people said that their symptoms got worse. Some had been prescribed different treatments by their GP to manage symptoms or improve their condition such as antibiotics or pain medication. Some had been sent for various tests at hospital departments such as ENT, X-Ray, Phlebotomy, Physiology, Occupational health, Cardiology, Rheumatology, and community respiratory services. One person said they were referred quicker due to the severity of their symptoms, a few others said they were not accepted for a referral to the clinic until they had many tests confirm their symptoms. In the time they waited between tests and results they had to suffer with their symptoms which they feel was not necessary.

What were/are people hoping the Long Covid service could do for them?

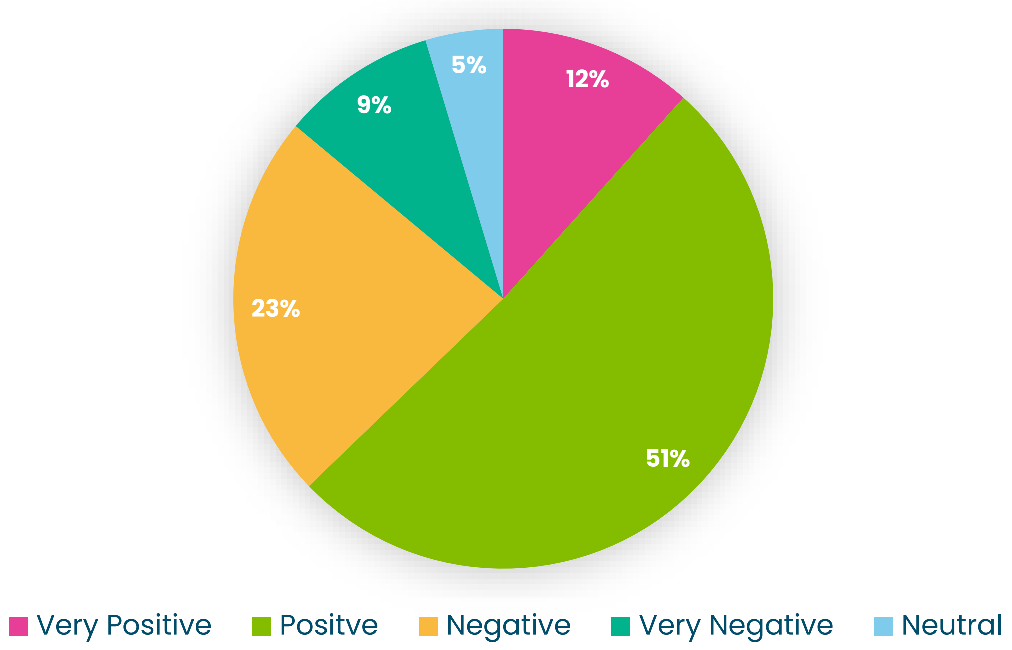
When we asked about what people had expected or hoped the service could do for them, obviously the main answer was to help people get better and get back to their old selves again. Several people admitted they weren't sure what the service could do, or whether it would be able to help at all. However, some more specific answers are included below:

- A planned approach to recovery
- Explanations as to why they were ill for so long/a diagnosis
- Treatments/ medications for symptoms
- Help and advice on how to manage symptoms that couldn't easily be treated
- Reassurance / rule out that their symptoms were not any other condition
- Help to understand the condition

- To be heard, understood, and believed

> *"Help me get my life back, I have lost my life since covid I have lost myself and there has been nobody to talk to the GP have made it clear they don't have time and also don't understand what I am experiencing"*

General experiences of the Long Covid services so far



Due to the nature of people's responses, some of these experiences could be regarding the Aintree Long Covid Clinic, however, we believe the majority were referring to the Multidisciplinary teams in local clinics.
Over half of respondents had positive or very positive experiences so far, mainly as they felt listened to and had information explained to them in a clear and understandable format. They felt they had been given enough time to explain themselves and felt thoroughly supported throughout.

> *"Holistic approach- doctor consulting with other doctors and researching. Clinic couldn't have been nicer… Not a good experience for others I heard as it's a postcode lottery"* – Southport clinic
>
> *"The team at Marian square were amazing"* Netherton clinic

> *"Initially relieved. I was actually understood by the Covid GP. First time I felt believed that my symptoms were real. I broke down and felt less alone. … My symptoms were recognised and understood by somebody else. Extremely open minded. I was treated as an individual in a non-judgemental way. I was given practical guidance in terms of energy conservation and the activity diary has been a great help. I was sign posted to some very good websites. Advice from these websites gave me more control on how to manage my symptoms." -* Southport clinic

> *"Very good. Well informed and explained everything simply. The team has done a good job."* Liverpool clinic

About a third of respondents had a negative or very negative experience. Some of these people were dissatisfied because they had been offered only psychological help when they felt their symptoms were physical. Some were frustrated at a lack of contact from the service and felt that they hadn't had not been listened to and supported adequately. A few people mentioned lack of follow up after appointments and a couple of people also mentioned that the attitudes of the doctors were dismissive and unhelpful.

> *"Bad. I was told to take a photo of 2 leaflets, told to download an app (that I cannot find on the app store) and then will be contacted in a few months." - Southport resident*

> *"I feel like I got nothing out of it. It was a really hard experience for me. Being told the key to problems was exercise and healthy eating. Before covid I had no issues. Mentally found it extremely hard not being helped and feeling again like no one believed me or no one cared enough to help. I had placed a lot of hope in the long covid service, and I was really sad after the experience." -* location not stated

What do people like about the service?

The most common answer for this question referred to staff attitudes. Many people said that the staff at the Long Covid clinics were very helpful, kind, caring, , reassuring, and put them at ease. People mentioned specifically that the staff listened and believed what they were telling them about the condition, which a few people compared to their GPs who they believed did not. Other people said that they thought the service was comprehensive, professional and well planned. A few people also mentioned that they liked how quick the referral was and that their follow up appointments were not too far apart.

> *"Friendly and welcoming staff put me at ease and explained everything so I could understand what was being said"* – Liverpool clinic
>
> *"Accessibility- quick referral- team [were] personable-[I] enjoyed working with them- I have another appointment due in 3 months to see progress which is helpful to see what advice, support…[and] see progress. No appointment received yet."*- Netherton clinic
>
> *"Very good friendly staff that don't dismiss the long-term effects of virus. All staff polite and helpful"* - St Helens clinic
>
> *"The Doctor in the long covid centre Speke was very good"* - Speke clinic
>
> *"I was always made to feel like I mattered. And that my symptoms were taken seriously…. overall, it's been a good and informative experience. They provide information on how to live as best you can with it. And that going forward you should make progress with your recovery. And that they are learning new things about why it effects some people differently."* - Liverpool clinic
>
> *"I appreciate the telephone calls checking on how I am doing and offering the Life Room activities."* - Netherton clinic
>
> *"Planned approach to helping patients like myself rethink their approach to fitness. … Being ex RAF then a nurse I was fitness minded prior to virus. Gleaning information to help me move forward is valuable".* - Southport clinic

There were 8 people who had a negative experience and therefore said that they didn't like anything about the service.

What do people think could be improved?

15 (38% of people who answered) people said that they didn't think there was anything that could be improved as they were happy with what they had experienced so far. Other than this, people mostly reported that they would have like more information and advice post and pre appointment about treatments, procedures and test results. Some people felt they were being left in the dark in between appointments and no follow up procedures were being carried out and they were unsure about why this was.

> *"More information, being given an actual leaflet with some information on and a more hands on approach. Advice on alternative medicines/therapies i.e: vitamins, herbs, diet etc."*

> *"More information [and] more testing to see why I still don't have any taste/smell after nearly 2 years"*
>
> *"I did feel a bit pressed for time almost feeling as if I had to rush at the appointment to get everything I wanted covering" -* Liverpool clinic.

Some patients commented on clinic locations:

> *"The only criticism I have was the time getting seen to was almost four hours. Also the distance, there's no bus route and had to rely on friend to take me which they had to wait to bring me home." -* Knowsley clinic.
>
> *"The location of the clinics are inconvenient" -* unspecified area

- Support for multiple symptoms

Reflecting the variety of long covid presentations, some respondents talked about the need for support to cover the range of symptoms.

> *"Offer more specific advice on what to try to relieve symptoms even when the standard advice isn't applicable, and keep in mind that long covid has multiple symptoms so to offer support to all aspects not just one"*

- Waiting times

Several people mention that the waiting times in between referral and appointments were too long, the administration could be improved, and communication between services.

- Lack of answers

There were a couple of people who said that they hadn't even been properly seen by the service and were very unhappy about this. They mentioned being passed from service to service with no answers or outcomes or just being told to 'go back to your GP' once they got to finally see someone.

- Specific tests

Some people were also disappointed that they hadn't been sent for more or regular tests or symptom specific testing. A few people wanted to have more treatments or therapies along the way that could help with symptoms in the short term. A few people mentioned the topic of psychological support and not being sure about how it could help them. This could factor into people's suggestions for improvement centred around more information about the service and what it can offer.

- Other therapies

Two people mentioned having accessed and felt benefit from sessions of hyperbaric therapy accessed privately in one case and via a charity in another. They felt that the NHS should invest in a hyperbaric oxygen chamber.

What other support have people been accessing for Long Covid?

Mostly, people reported that they had not been getting any other support other than the Long Covid service. Of those who had received other support the most common was additional medical help from their GPs or other specialists to help manage symptoms. After this, people said that they were mostly receiving informal support from their family and friends, either emotional or physical support like caring duties. Some people said they were accessing Long Covid support groups or accessing help and advice online. A few people were using the voluntary, community and social enterprise sector to attend support groups or receive one-to-one support. Several people said that they had received help via their workplace, through schemes that were set up to support health and wellbeing or from occupational health. A couple of people were receiving support privately to manage their symptoms and mental health. Some people mentioned having researched the condition themselves and having accessed

Peer Support

We did not specifically ask people about whether they would like to access peer support. Some of the responses however suggest that it might be useful. For one person meeting other people with long covid was the best part of their visit to the Long Covid Tier 3 Assessment & Treatment Service:

> *"Actually meeting other people with long covid and realising that the symptoms I have are the same for lots of people."-* Knowsley clinic

Another patient suggested they could learn from other patients:

> *"Maybe give details on same problems others have to see if the symptoms we have are common, for example I have problems with Covid fingers and only*

> *seen one other person with it. If anyone has unusual problems would help to let us know how they cope and if there's help.”*

We asked people if there was anything else they wanted to share about their Long Covid experience. Mainly people wanted to share how severely the condition had affected their life.

> *“There have been a variety of symptoms that have affected my breathing and intestinal tract mainly, though I have also experience tinnitus and joint pain. I feel 20 years older, in January I was playing football twice a week, now I feel out of breath climbing the stairs at home.”*

> *“It’s life changing. I was a fit outdoor person who worked to live. 14-hour ward shifts. Then days off hill walking wild camping mountain bikes kayaks etc. It really has taken me by surprise how it’s impacted my life and not bouncing back. ... I am suffering depression ... I have developing type 2 diabetes / hypertension/ low energy. Muscle aches pain. Complex memory problems."*

> *“It's a frightening experience not knowing what is going on in your life, even though you know what the problem is caused by. I think some people don't get it, long covid is real and by my experience it turns your life into an existence only.”*

> *“If I didn't experience these symptoms of extreme fatigue which renders me bed bound, and totally dependent on my family. I would find it hard to believe that these symptoms would follow what is a viral illness.”*

Some people wanted to emphasise the need for research and learning.

> *“As a scientist, I think there should be a research centre and more physiological testing and collecting more data to look at the range of symptoms and look at what has worked- a local borough approach. More medical research is needed. More Covid research is needed. Long covid support needs to be coordinating support, in partnership with Hospital Trusts and medical trials should be offered. I would take part.”*

Summary

People have generally had good experiences with the Long Covid Tier 3 Assessment & Treatment Service. The main issues seem to be getting the referral itself, and the communication between referral and appointments. Some people feel disappointed that it took so long to get to the service and didn't feel initially heard and believed. Nevertheless, feedback from first contact with the service appears very positive, even if the patient acknowledged nothing has 'changed' yet or had only had 1 appointment. They have felt reassured and relieved that the staff have made them feel like they have hope by just believing, seeing, and hearing them and their problems. Some patients feel frustrated that their health hasn't improved for them as quickly as they had hoped. Some are frustrated that health professionals still seem unclear about how to diagnose and treat their condition, however some view this as understandable. Patients feel it would help if they were kept in the loop and provided with more feedback on test results and more advice and information that can put their minds at ease between appointments and give them things to work on themselves. People have spent so long wondering what was wrong with them and getting told that there is nothing that can be done for them that they are wary of feeling left in the dark about their condition.

Some of our respondents had been ill for some time, including when the NHS had no long covid provision and since been referred to 2 NHS long covid services. It is to be hoped that patients developing long covid more recently, with the services established and staff teams more settled and experienced will report fewer delays and smoother care. We would be happy to speak to patients at a later date to see if this has been the case.

People who had been seen only by the Aintree Long Covid Clinic (provided by LUHFT)

We received some feedback from people who had only accessed the Aintree Long Covid Clinic. We have not included their feedback on services in the analysis above. With the service now being closed there is no scope for the service to learn from their experiences. This service was set up when less was known about long covid and there were few dedicated resources. It is perhaps not surprising the feedback from people on this service was less positive including longer wait times.

> *"I was referred by my GP in June 2020. I didn't actually get any contact with a Long covid clinic for 12 months. During which Time I was really suffering with severe fatigue, brain fog, breathing problems, palpitations, chest pains. Insomnia."*

These patients however having developed long covid early now have a lot of lived experience of the condition, so we have drawn on their comments below.

> *"I wish that there is more help for people who are suffering with long covid. On a good day it's liveable on a bad day it's exhausting, frustrating, frightening & depressing. And there doesn't appear to be any help."*
>
> *"I have dysautonomia symptoms, feels like a twitchy nervous system, have been adrenaline surges and immune issues but I have no diagnosis for this and no tailored advice around it. They can't offer any insights on autonomic issues. No understanding of what is happening at the cellular level."*
>
> *"I am very grateful for the NHS and know the staff mean well, they just don't have the tools and expertise needed."*
>
> *"My assessment included a depression score and I was aware of being very careful of my answers – it includes points for being tired but in my case that isn't caused by depression. NHS doesn't seem to have a very sophisticated understanding of long covid. Patients learned like mad out of necessity. Lots of patient led research. There is also lots of academic research but it doesn't seem to have fed down into patient facing work."*

On why some people, including those with previous trauma may be more prone to developing long covid:

> *"It's complex. It would help if the NHS could recognise that some people are perhaps more susceptible without stigmatising them or victim-blaming e.g. saying something like 'Past experience of trauma can alter a person's physiology and leave them vulnerable to a range of health issues. This is of course really unfair as it's an additional challenge on top of the trauma itself. Here are some ways to reverse these physiological changes as far as possible and increase your physical resilience...'*

People who have not been seen by a long covid service

We received 3 questionnaire responses from people who believed they had Long Covid, however, had not been referred to a Long Covid clinic thus far. We asked about their experiences of seeking help from their GPs for their symptoms and two out of three respondents said that their symptoms had been dismissed or played down. One was told to wait to see if it got worse and the other was told her symptoms were just anxiety and had to resort to seeking help privately. The third respondent said she was prescribed things by her GP to deal with the symptoms such as secondary infections. None of them had received any sort of medical help, other than prescriptions, to help them with their symptoms. None of the respondents were aware of any Long Covid Clinics in their area and none of them had been referred anywhere for tests or consultations related to Long Covid clinic referrals.

These respondents would have like to have received help for their Long Covid symptoms such as genera advice and information about symptoms related to Long Covid; fatigue, loss of smell/taste and breathlessness. One respondent said they just wanted validation around what was going on in their body and some more proactive support instead of short-term fixes. These respondents relied on friends and family, support groups and private appointments with counsellors or doctors to help them manage their condition. They expressed feelings of isolation, being a burden, and being hopeless about their future and their symptoms improving. Some of the responses correlate with others received from patients who had been seen by the Long Covid Tier 3 Assessment & Treatment Services, in that they were initially not believed or taken seriously, which is an anecdotal common theme amongst Long Covid sufferers.

Potential learning points

- Continue to liaise with GPs who are not/rarely referring to the service to ensure awareness and smooth referrals
- Consider providing GPs with a patient friendly explanation of the reason for the pre-referral tests to reduce the risk of patients feeling they are tests they need to “pass” in order for their Long Covid to be believed.

- Continue to develop and evaluate patient resources so that patients have reference information and recovery activities they can try between appointments.
- Ensure that patients can access information about Long covid and the service in community languages and other formats

Response from Mersey Care

Thanks to Healthwatch Liverpool, Sefton, St Helens and Knowsley for their commitment and attention to detail collating this report on the provision of Long-Covid Assessment & Treatment services provided by Mersey Care NHS Foundation Trust.

It provides a valuable insight into successes and challenges in care delivery across Liverpool, Sefton, St Helens & Knowsley over the last year and the information shared in the report provides essential learning to help improve areas of need, but also to highlight what's working well, ensuring we continue to develop and deliver quality care that genuinely helps people.

Dr Chris Barker, Clinical Director – Long Covid,

Mersey Care NHS Foundation Trust

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