NHS
Greater Manchester

Service Design Engagement Report -

Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) and Long Covid Service

July 2025 v1.1

Part of Greater Manchester Integrated Care Partnership

Contents

Date	Version	Record of changes made to document
24 July 2025	1.0	First version
25 July 2025	1.1	Definition of CBT updated to mirror the NHS website definition at section 4.9 (page 9)

1. Introduction and Background

The NHS Greater Manchester (NHS GM) engagement team engaged with people living with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS), and/or Long Covid, to support the development of a new single service in Greater Manchester to help people of all ages manage these conditions.

A new service was needed because it was not possible to continue with separate services in different areas of Greater Manchester due to resources and clinical workforce availability. In some areas there was no service at all.

The engagement helped us understand more about how people live with these long-term conditions, their experience of using primary care and other NHS services, along with the type and effectiveness of any therapy or treatment they had had. We also wanted to hear about people's interactions with healthcare professionals and what they needed to support them to manage their long-term condition and live a better quality of life.

2. Aims

The aim of this public engagement was to find out what people thought a new ME/CFS and Long Covid service should look like. NHS GM wanted to make sure the views and lived experience of people living with these health conditions were heard in supporting the design and development of a new service. We wanted to contribute to creating a fair and consistent offer and approach across Greater Manchester, that would meet the individual needs of people living with these conditions.

3. Approach

The NHS GM engagement team and other NHS GM colleagues worked closely with members of existing support groups, including Stockport ME Group, Bury and Bolton ME/CFS and Fibromyalgia Support Group, Greater Manchester Long Covid Support, Long Covid Support and the ME Association. It was felt that those connected to these groups were best placed to give insight on the current services available in Greater Manchester and what they needed from a new one. Thank you to all the groups and their members for their contributions to the engagement workshops and the online survey.

The groups supported NHS GM to reach people with ME/CFS and Long Covid through their networks and promoting the online survey on social media channels. Family members and carers of people living these long-term conditions were also invited to take part.

Six one-hour workshops were arranged across three weeks during April 2025 to enable as many people to get involved as possible, with afternoon and evening sessions available. Some of the support groups we worked with helped with the design of the workshops.

One-to-one telephone interviews also took place to give people more opportunities to have their say. For those unable to join a workshop or telephone interview, an online survey was created, with paper copies made available on request.

The focus of the workshops was to understand people's experiences of living with ME/CFS and Long Covid, dealing with their GP, getting a diagnosis, and being referred to NHS and other health services. We also wanted to understand what patients thought about the treatment or advice they were offered to help manage their conditions, their communication with healthcare professionals, and what they wanted to see in the new service.

We spoke to a wide range of people from different backgrounds and ages, males and females, patients, parents and carers. Some people were retired or had had to give up work because of their condition, others were still working but struggling. Some were diagnosed 30 years ago and others as recently as 2024. We heard from people who had severe ME/CFS and were at crisis point, whilst others were trying to learn to live with their condition whilst concerned about their future.

Table 1: Numbers of people reached and/or engaged with

Method of engagement	Public engagement numbers
Online survey	54 completed
Six online workshops	18 people engaged with
One-to-one telephone interviews	7 people engaged with

4. Findings

We spoke to a mix of people with both ME/CFS and Long Covid at the workshops. Of the people who filled in the online survey around 80% had ME/CFS and 20% had Long Covid. Some people were living with other long-term conditions, such as postural orthostatic tachycardia syndrome (POTS), which is when the heart rate increases very quickly after getting up from sitting or lying down, often making people feel dizzy or lightheaded.

The people we met were encouraged by the prospect of a new ME/CFS and Long Covid service and they wanted to play their part in making it the best service possible. They were generous with their time, and many were grateful for the opportunity to have their say and share their experiences.

They were also passionate and honest about their own lives and how ME/CFS and Long Covid has affected them and their families. They told us there was a social stigma around these conditions which made dealing with the physical symptoms even more difficult.

The main themes from the engagement were:

4.1 Getting a diagnosis

It was clear that those who were able to self-advocate and be more persistent with their GP were more likely to get a diagnosis in the end. One person told us "I went multiple times over 18 years. Never any diagnosis until I asked directly regarding ME/CFS. Then I was diagnosed within two weeks".

It was felt by some that the emergence of Long Covid meant ME/CFS was being taken more seriously due to similarities in some of the symptoms of the conditions, and how to manage them. Whilst people were generally pleased about this, there was also disappointment that ME/CFS wasn't taken seriously by many health organisations before now.

Overall, we heard that getting a diagnosis for ME/CFS had been a difficult journey for most, often taking months or even years. Those diagnosed with Long Covid had similar challenges but over a shorter period of time.

4.2 Overall experience of being diagnosed

Almost everyone we spoke to with ME/CFS told us they spent much of their lives feeling not listened to, not believed and not taken seriously about their condition. They told us most health professionals, who they had met over many years, were not knowledgeable enough about ME/CFS or, worse still, didn't believe it was a real condition.

The survey responses suggested the average wait for diagnosis was around two years. It usually required persistence, self-advocacy, direct requests for ME/CFS or Long Covid assessments, or seeing multiple specialists and undergoing extensive tests to rule out other conditions.

This matched what we heard from people during our face-to-face engagement, where we were told about how chance encounters or conversations with family members, friends, or other health professionals helped people realise they might have one of the conditions. This gave people the confidence to challenge and push their GP to listen and be more open to recognising the symptoms of ME/CFS. Without that persistence it appeared some of the people we spoke to might not have been correctly diagnosed or diagnosed at all.

These findings raised the question of the potential number of undiagnosed people, or even diagnosed with the wrong condition or illness, and not getting the help they needed. Data reviewed by the NHS GM's ME/CFS and Long Covid steering group suggested people from ethnically diverse backgrounds were less likely to be diagnosed with one of these conditions, again indicating there might be more undiagnosed people that needed help. It was the view of some people that the absence of ME/CFS and Long Covid services, and available support in some areas of GM, might be a reason for this.

Those with children with one of more of these conditions found the journey to a diagnosis even more difficult. Not only did they feel unheard, but they felt they were being held responsible for their children’s conditions. We heard from one family where social services were involved because it was believed that a mental health condition was the cause of the children’s issues, whilst the parents felt they were not listened to. This case led to the children being placed in a psychiatric unit with limited access to family. The situation was only made better through expensive legal support, privately paid for counselling and working with local support groups. However, the trauma for the family was still evident now.

For those with Long Covid we heard getting a diagnosis was usually more straight forward. However, there was a compulsory 12-week period between testing positive for COVID and being eligible for referral to a Long Covid clinic. During this period, many people felt isolated and alone, and struggling to deal with everyday life.

We heard praise for the ME/CFS service in Salford and the existing Greater Manchester Long Covid clinics. One person told us they saw a doctor in 2024 and was referred immediately to the ME/CFS Service in Salford and diagnosed with ME within a few weeks. This might be evidence that awareness of the conditions had increased in recent years, resulting in better outcomes for some patients. It should be noted however, the same person was told they might have had ME for 17 years and only went to their GP after a family member suggested they might have the condition. They took the latest National Institute of Health and Care Excellence (NICE) guidance with them to the appointment to support the conversation. This was a good example of someone being informed and prepared before going to their GP to give them the best chance of making progress with their condition.

4.3 Misdiagnosis

A common theme in our discussions was people’s symptoms being dismissed as something else. People with both ME/CFS and Long Covid often felt their symptoms were put down to depression or anxiety, the menopause, or lifestyle. This was despite them being vocal and clear it wasn’t the case, and they knew their own bodies. This led to people being prescribed inappropriate treatment or medication. It also left them feeling confused and angry. More than one person told us they felt like they had to follow the medical advice because, if they didn’t, they felt they would not get any more help or support in the future.

4.4 Wider impact on people’s lives

We heard from people who said they had nowhere to go for help and felt alone and isolated. They told us friends and family treated them differently because, from the outside, it looked like there was nothing wrong.

Being in the workplace was particularly difficult because of the expectation to get a job done and perform to the level they did before they had ME/CFS or Long Covid. In many cases people had to give up or leave work before any real adjustments had been made to help them. It was felt many of these people may have been able to stay in work had the right support been available.

This all made people feel sad, angry and like there was no light at the end of the tunnel. Because of this we found people with the conditions were likely to push through their limitations to try and keep up with the demands of society, despite it being potentially worse for their health.

There was a suggestion that a wristband could be created for people to wear which might help other people know they have an invisible condition.

4.5 Dealing with health professionals

People felt disbelieved and not listened to as a direct result of interactions with health professionals and the language used at those appointments. We asked what sorts of things had been said or done to create a breakdown in the relationship between the patient and health professionals:

- “You’ll get better.”
- "You need to try, even on a bad day."
- “Just push through.”
- “There’s nothing I can do.”
- "Most people recover if they try or want to."
- “It would be better or easier (for the doctor to help) if you had another condition.”

People wanted more positive, constructive and knowledgeable conversations. They wanted health professionals to work with them and make them feel it was possible to live a better quality of life with the right advice and treatment.

Being believed by a healthcare professional and being spoken to with empathy was important to almost all the people we spoke to and really made a positive difference to the way people managed their condition. Fighting to be believed was a drain on people’s energy.

We also heard about the value and importance of accurate and up-to-date patient records to enable better conversations between patients and healthcare organisations. This was especially true when there were multiple people involved over a long period of time.

4.6 Advice and treatment

People's experiences of their advice and treatment varied. We also found some people were paying for private healthcare to help manage their symptoms, creating inequalities in access to services and patient outcomes. Those that could afford private treatment considered themselves to be in a fortunate position compared to others.

Long Covid clinics were generally viewed as a positive experience, and a good source of information to support people living with this long-term condition. We heard positive stories about Long Covid clinics making referrals for help with breathing.

For those with ME/CFS there were fewer positive views about the advice and treatment they received, which in some cases they felt had made their condition worse in the long-term. Most people we heard from put this down to being given wrong or outdated advice.

4.7 Physical therapies

Most people we heard from told us their physical therapy (PT) and graded exercise therapy (GET) were not the right solutions for them. GET is a physical exercise program that increases the duration and intensity of exercise slowly and gradually.

Therapy usually involves going to group sessions at gyms and leisure centres. Many people talked about the negative impact GET had on their symptoms, particularly on the days following therapy, with many people saying it made their condition worse.

People also talked about the lack of follow up support after treatment, to see how they had responded to the treatment and monitor the impact of physical therapies. People also said that accessing GET was very difficult due to their own lack of energy and long waiting lists.

Several people told us the courses were too early in the day, too intense, and not tailored to their needs. One person said: "The 9am start told me it wasn't suitable for me, and I was unable to drive home after the session as I had used up all my energy and it made me ill for a long time after".

Another told us the therapists followed them into the toilet to ask why they weren't taking part in the therapy session, despite them clearly struggling. They found this experience humiliating.

Another said: "Physical therapy led to a deterioration which I've never recovered from. I am now severe and housebound and bedbound for years. I blame the initial advice given by doctors".

It should be noted that some people said they benefited from some physical therapy, but everyone acknowledged the importance of adapting any therapy to the individual's needs. Those with Long Covid were more likely to say this, which might be another indication that awareness and approach to treating ME/CFS and Long Covid might be improving, given that Long Covid is the more recently discovered condition.

Many people with ME/CFS told us that inappropriate physical therapy in the past had made their condition worse and made them more cautious about trying it in the future, at any level.

We heard mixed opinions on the effectiveness of the Perrin Technique, an osteopathic approach that aimed to manually drain toxins from the cerebrospinal fluid into the lymphatic system. Not everyone had tried it, but some expressed an interest if it would help them, but there was not an informed view about this overall, more a willingness to try something else that might help.

4.8 Pacing and energy management

Pacing is a strategy to manage energy limiting conditions by monitoring the heart rate and helping people balance rest and activity.

For many people, pacing and energy management advice was very useful and helped manage their condition and day-to-day life better. General advice, tips and establishing a baseline was useful, including learning about counting energy and being encouraged to rest.

There were lots of positive comments about using online apps such as Visible and Garmin, although these often required a paid subscription and were not the solution for everyone.

Some people were struggling to change the lifestyle they had been used to previously due to having less energy. For some, it was simply a case of having to continue to try and meet responsibilities such as family or work. However, most could see the benefit of using apps like these and were open to using them in the future, with the right support.

One person said about the Visible app: “It is brilliant for pacing and showing to other people, so they understood my condition. It was an eye opener to what energy was being used on certain tasks. It also helped with sleep hygiene and getting a deep sleep and checking my pulse and heart rate”.

We heard different accounts about patients being asked to keep a diary with limited results. People didn't always find it easy to do that amongst their day-to-day living. One person said: “The only advice that was useful was how to pace and how to let go of what was once important, for example, ironing or cleaning. My consultant openly told me he didn't know a lot about the condition and that research at the time (2018) was poor. He advised me to keep a diary and to learn about myself but did not suggest this would help me manage the condition or burden me with the need to get better on my own. Instead, he focused on learning to live with the fatigue and preventing over-exertion”.

Early morning appointments for people at hospitals and GP practices were not suitable for everyone in terms of energy management, especially those without support to travel to and from appointments. Most people we spoke to would like to see an online option for some appointments, depending on how severe their symptoms were.

4.9 Cognitive Behavioural Therapy (CBT)

Cognitive behavioural therapy (CBT) is a type of talking therapy where a therapist helps people to change the way they think and act. CBT should be used in a supportive capacity to help people live with symptoms and improve their quality of life. It does not directly treat the symptoms of ME/CFS.

There was frustration that the physiological basis of ME/CFS and Long Covid was ignored in favour of psychological explanations, with many people stating they felt as though their symptoms were being attributed to a mental health condition. Lots of people with ME/CFS told us about being prescribed anti-depressants which they didn’t really want but felt they had to take them to comply with the medical advice. They also told us that these experiences had made them resistant to CBT and other talking therapies.

We found those that had been seen at Long Covid clinics were more positive about the benefits of CBT as part of an all-round treatment plan.

4.10 Medication and supplements

There were lots of different examples of the medication and supplements people were taking to manage their condition. Some people were following medical advice and taking prescribed medicines from their GP or a private healthcare provider.

Others were trying supplements such as aspirin, magnesium, nicotine patches, vitamins B3 and C to find what might work for them, based on anecdotal information from peer and support groups.

People talked about the challenge of using private health care as the medication prescribed was very expensive. Some patients were reliant on having a supportive and understanding NHS GP who was prepared to prescribe the medications recommended by private doctors on the NHS. Some people were worried about losing this option.

One person told us: “I would like to be offered some drugs that have been researched as improving symptoms, like low dose naltrexone and nicotine patches, but these aren’t available via my GP”.

Another said: “I have to buy a lot of supplements and medications to keep going. Many aren’t on prescription but my trials of them on/off have curated the ones that do. I spend about £50 per month on medicines."

We also heard about the impact of prescribing anti-depressants and Hormone Replacement Therapy (HRT), with some people feeling totally dismissed because their symptoms were being put down to anxiety, depression and the menopause.

4.11 Post treatment and therapy support

Several people described being discharged from their treatment too quickly or receiving only time-limited support, with little or no follow-up. Some were told to self-refer for further help but found waiting lists very long.

Others mentioned advice was too general or not tailored to their individual needs. Practical support, for example home visits, occupational health and nutrition advice, was not usually an available option.

This all meant that people were not always getting the help they felt they needed and were trying to cope the best they could, making them feel alone and isolated.

5. What people need and want from a new service

5.1 Staff

First and foremost, people wanted experienced and supportive staff, willing to listen to everyone, and give them timely and ongoing support when they needed it. Patients wanted open conversations rather than being the subject of a checklist or a set of instructions.

They also wanted consistency in seeing the same GP or healthcare professional. Getting to know and understand a person properly was seen as key to being able to find out what people needed, and sooner.

Several people also suggested a multi-disciplinary team should be part of the new service which should include physio, psychologist, specialist nurse and clinical consultant. A multidisciplinary team (MDT) is a group of health and care staff who are members of different organisations and professions that work together to make decisions about the treatment of individual patients.

Other suggestions about the type of staff and teams that should be involved were:

- A named lead consultant.
- Specialist nurse led service with a named person who has a specialist interest in ME/CFS and Long Covid.
- Named expert or single point of contact in each GP practice or primary care network.
- A physiotherapy team that specialises in ME/CFS and Long Covid to help specifically with breathing techniques.

- Hospital at home teams to help patients at home during a crisis.

5.2 Treatment

One-to-one pacing training and support was considered essential by most. It was suggested physiotherapists and occupational therapists should be involved in this.

Not setting physical therapy goals was a popular suggestion with people wanting the impact of exercise therapy to be properly monitored.

Therapy courses needed to meet the patients' needs, such as not starting too early or lasting for two hours or more, which was considered too long by most. It was felt that patients should also not be discharged from a course of treatment or management if they were too unwell to make two consecutive appointments. There needed to be more understanding about why people might not be able to attend.

Most people wanted to see individual care plans with regular reviews built into the plan. Opinions on the frequency varied from six months to one year. Most people felt one year was enough, but only if they could access further support if they needed it.

Those with severe symptoms wanted the option of treatment, support and advice to be available at home.

5.3 Information, advice and guidance

People wanted information to be available in one place and accessible by all. Lots of the best tips and advice came from informal or chance conversations, but often only the individual that heard it got the benefit. It was felt a single service should be able to pull everything people needed to know into one place, available online and on paper. This should include practical solutions to help people manage their energy and advice on how to sleep better, also known as sleep hygiene.

By way of examples, some of the things we heard that might help people manage their energy better were: Having everything they needed within reaching distance, drying hair at night, doing some shopping online or using computer software to read. These would not suit everyone but were examples of individual pieces of advice that helped certain individuals.

The MyMFT app at Manchester University NHS Foundation Trust was highlighted as a good example of how to communicate with patients online.

Regarding individual patient records, most people agreed that information needed to be full and accurate with patient comments included and not just clinician's summary notes.

Other points and ideas raised were:

- Help with signposting to trusted support services, rather than relying on informal social media peer groups.
- People should have access to the 2022 edition of the ME Association's Clinical and Research Guide, known as "The Purple Book".
- Provide more information about heart rate monitoring, which was described by a participant as one of the few objective measures available.
- People wanted information and advice about post exertion malaise (PEM) as over-exertion could cause permanent harm.
- A regular newsletter to keep people up to date about the new service, with an option for an audio file to be sent via WhatsApp.
- A podcast affiliated to the new service to provide the latest information on ME/CFS and Long Covid including practical tips and advice.

5.4 Wider support

Lots of the people wanted to see a wider support offer as part of the service to help people with the following:

- Support people with referrals for assessment for co-morbidities such as Postural Orthostatic Tachycardia Syndrome (POTS), fibromyalgia, dysautonomia, orthostatic hypertension and Ehlers-Danlos Syndromes (EDS).
- Meditation and mindfulness.
- Advice, guidance and support to manage motion illness.
- Monitoring and management of asthma and other respiratory conditions.
- Blood pressure monitoring equipment at home to support patients to monitor their own.
- Dealing with employers and coping at work.
- Access to befriending and voluntary services to help with daily tasks and provide respite for some families, especially for those who were housebound with severe symptoms.
- Financial support information for things like personal independence payments (PIP). including providing clinical supporting documentation to support applications.
- Educational signposting specific to an individual child's needs including online schooling information and advice.
- Support for parents in dealing with schools to create the best conditions for their children to learn.

5.5 Location

There were lots of opinions on where a new service should be located, with no overall preference, except the need for an online option. People agreed they didn't want the service to be part of, or added onto, a psychology department or unit. They thought it would send the wrong message to those using the service by suggesting they had a mental health condition.

Some people felt very strongly that there should be a physical clinic in a central location to make it feel real and to become a centre of excellence. Others thought there should be clinics spread across Greater Manchester to make the service easy to access.

However, it was also felt that if people could access expert advice from dedicated professionals, they would be happy to go to a local GP practice in their area to get help and support from a named expert.

Most people agreed the new service needed to have a strong online offering, from finding information to having telephone and online appointments. Those with more severe symptoms said that travelling to and from physical appointments could be counter-productive and could take up too much energy.

Consideration should be given to limiting the distance and time people needed to travel with the option for appointments outside of rush hour times, as travelling during busy periods can be exhausting. A difficult journey often impacted people's ability to be able to take part in an appointment or assessment properly. A possible solution was to include a patient transport option to and from appointments, in addition to home visits for those with severe symptoms.

It was also mentioned that any physical clinic should be suitable for those whose symptoms included extreme physical sensitivity to substances or conditions such as light, sound, touch, taste, smell, temperature and particular chemicals.

6. Conclusion

The people we engaged with were generous with their time and openness. Despite most of them feeling left behind and ignored by the health care system, especially those with ME/CFS, they wanted to contribute to making the new service the best it can be and a centre of excellence.

People wanted NHS GM to treat each condition separately, whilst recognising there were some similarities, and patients needed to be dealt with according to their individual needs. For them, it was about the service and knowledgeable staff listening to patients, believing them and adapting to individual needs. This was particularly important when it came to pacing, energy management and talking therapies.

The service needed to be open, honest and transparent about what it could or couldn't do. It was acknowledged that a new service might not be perfect at the beginning, but it needed to stay up to date with latest guidance and research, and not be afraid to try new initiatives and ideas.

People also expected NHS Greater Manchester to work with other integrated care boards and private health care providers to find out what was already working well and could be introduced in Greater Manchester.

Availability and accessibility of information, advice and guidance was key. People wanted somewhere trusted and reliable, so they were not reliant on finding things out by chance or through non-clinical routes. They also wanted a wider support offer around things like living with other conditions, dealing with employers, education and access to financial support.

More needed to be done to identify undiagnosed people with ME/CFS and Long Covid and those who might not be aware of the conditions or that they have it. We found people were more likely to make progress with managing their condition if they were part of a support group or able to speak up for themselves.

Almost all the people we engaged with will be users of the new service and they want to help shape it now and in the future. If we work together and listen to each other there was a belief this new service would enable people to manage theirs and their families' day-to-day lives easier.

7. Recommendations and key considerations

Based on what we heard, NHS Greater Manchester commissioners should consider the content of this report and the following points when designing and developing this new service:

- The culture of the new service will be very important. Consideration should be given to how the new service will ensure users feel safe, listened to and cared about. Capturing positive and negative patient insight gained through everyday clinical interactions will help with the smooth implementation of the service. It should allow the public to have a say on potential improvements once the service is up and running.

- We should be mindful of the debilitating nature of these conditions on people, which can impact their ability to interact with the service, including attending appointments or taking part in specific treatments or therapies.

- It may help people manage their condition better if they knew where and when to get support and information when they needed it. A dedicated website, webpage or information phoneline were all suggested by those we engaged with.

- The service needs to consider how it will communicate well with its patients. The people we spoke to want their story and their information to be available to the health professionals that need it.
- Communication between healthcare professionals at the new service and its patients will be key, especially those waiting for appointments who still need advice and support whilst they wait. This also applies to those with ongoing or completed treatment plans, so that patients always know where to go for help when they need it.
- Existing technology should be used to help meet the individual needs of patients to attend appointments. People want to see a range of options for appointments and attending therapy sessions.
- The people we spoke to support a multi-disciplinary team approach, with a suggestion that patients should have individual care plans to ensure that any treatment and therapy is suited to their needs and severity of condition.
- Consideration should be given to including a wider support and/or signposting offer for non-medical support such as help dealing with employers or applying for benefits.

8. Next Steps

August 2025

- A further engagement session will take place on Tuesday 12 August 2025 to review a proposed patient pathway. The pathway has been designed with the help of healthcare professionals and people with lived experience of living with ME/CFS or Long Covid from across Greater Manchester. This additional session is primarily for those people and service user groups that were involved in April’s engagement workshops but is also open to people in Greater Manchester who might use the service in the future. It will focus on explaining the patient journey in the new service and inviting feedback from those in attendance.

September 2025

- Subject to approval of the new model of care and service pathway, a communications plan will be created to keep service user groups and the wider population informed of the progress and development of this new service.

October 2025 and beyond

- Further public engagement will be planned to support the implementation of the new service. This is to make sure the voices of those who will use it are heard and considered before and after the service is launched.