ME ASSOCIATION

Annual Report

Health and Social Care Pilot

2025

ME Association
Healthcare Team

Healthcare 4 ME
TRANSFORMING HEALTHCARE TOGETHER

Contents

Working with the NHS and social care services to improve healthcare for people with ME/CFS.

Introduction

This report presents the findings of the 2025 Health and Social Care (HASC) pilot project conducted by the Healthcare Team. The primary objective of the project was to evaluate the services available for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and Long Covid. The aim was to demonstrate how these findings can inform policy changes and influence strategies to enhance service provision and understanding.

The pilot project, which began in October 2024, emerged from six months of dedicated research. The pilot area was strategically selected, recognising that existing services in some regions of the county could serve as a foundation for our efforts. This extensive area encompasses nearly two million people.

Despite the National Institute for Health and Care Excellence (NICE) 2021 recommendations advocating multidisciplinary, patient-centred services for ME/CFS, significant barriers persist. Many clinics remain hard to access, and some patients face waiting times of up to two years to get the help they need. These issues make it difficult for individuals across the county to access consistent and equitable care.

Additionally, the project aimed to include specific services for patients with severe ME/CFS or Long Covid. This was to ensure the needs and concerns of people affected with severe/very severe ME/CFS were appropriately acknowledged and addressed.

One of our main challenges was convincing local healthcare leaders of the urgent need for better services and funding, both to enhance existing provision
and establish new services. Alongside this, the project focused on raising regional awareness of the demand for services related to ME/CFS and Long Covid, helping to bring together stakeholders and foster a shared sense of responsibility.

Ensuring that NICE guidelines were implemented correctly was a key priority. To achieve this in practice, we have advocated for specialist clinics to be adequately resourced, so that everyone in the area, no matter where they lived, could access the support they needed.

Aims

Overall Aim: To foster positive engagement with healthcare services and residents.

1. Engagement with Health and Social Care Services

The first objective of the pilot was to ensure that individuals with ME/CFS and Long Covid are able to access reliable, specialist assessment, care, and management, regardless of their geographical location. This included identifying barriers to access and promoting more equitable service provision across the region.

2. Adopting NICE Guidelines:

The second objective was to encourage and support NHS services, Integrated Care Boards (ICBs), and associated support services to adopt and implement the NICE guidelines for ME/CFS (NG206). The project provided guidance, practical advice, and collaborative support to assist existing services in aligning with best practice and ensuring compliance with national recommendations.

3. Addressing Individual Patient Concerns

The third objective was to engage with individuals and healthcare professionals (HCPs) to address and resolve individual patient concerns, ensuring that every voice is heard and issues are resolved both within and beyond the pilot region.

Our plan was to review the current state of ME/CFS and Long Covid services, assess gaps in service provision, and provide recommendations for improvement. This process aimed to enhance our understanding of how NHS and social care services support individuals with these conditions and identify steps for advocacy.

We also sought to collaborate with the NHS to ensure better service provision for individuals with severe cases, ensuring that everyone affected by ME/CFS and Long Covid has access to the specialist teams and referral services recommended by NICE guidelines.

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Key findings

68% of respondents in the working group rated their overall NHS ME/CFS care as 'poor' or 'very poor

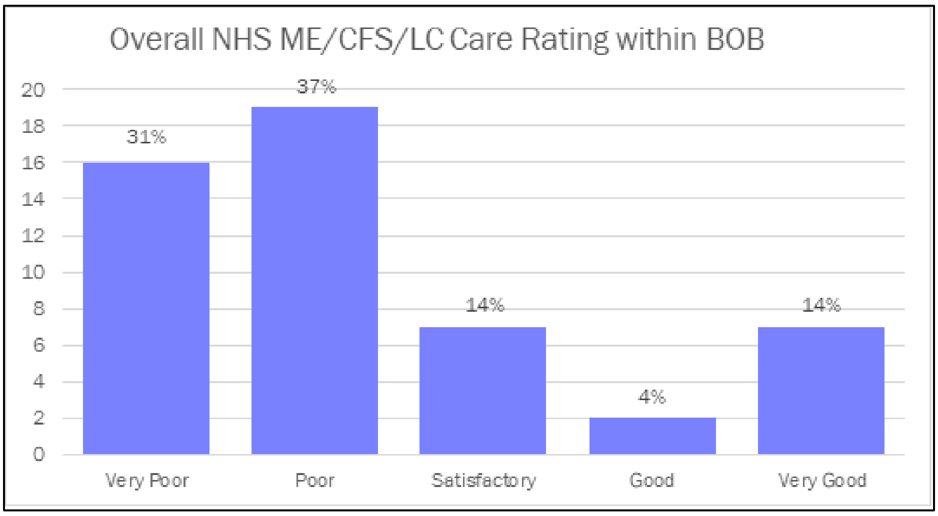


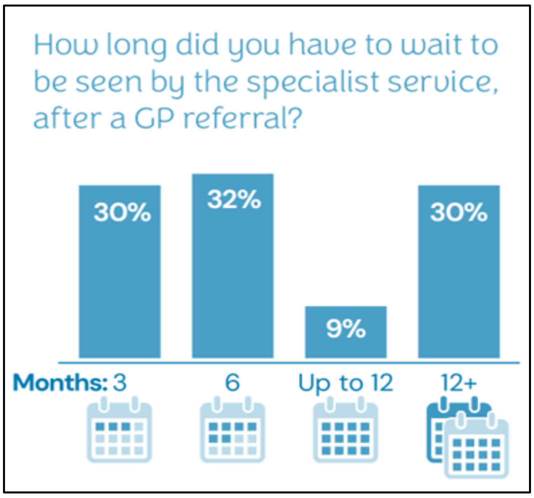
Fig 1 Overall NHS ME/CFS and LC Care Rating within pilot ICB. Working Group care rating

None of the working group participants have received an annual ME/CFS review since the publication of NICE NG206 in 2021.

Inappropriate exercise-based and psychogenic treatment models continue to persist in some areas of the Integrated Care Board (ICB).

Severely affected ME patients in the region lack adequate support.

There are significant inconsistencies in diagnosis, treatment pathways, and professional understanding.



On average, individuals wait six months to see a specialist after visiting their GP, with 30% waiting over 12 months

Fig 2 NHS specialist service feedback analytics

Feedback from residents with ME/CFS revealed that many GPs, ME/CFS services, and specialist services, especially those based on psychological approaches, were still recommending GET to people. Patients shared their lived experiences and frustrations through patient groups, feedback portals, surveys, and especially ME Reach, which highlighted the importance of continued engagement.

We also found that most of the services in place were based in one central area rather than across the whole region.

52% of people were not diagnosed by their GP before being referred to a specialist ME/CFS service.

Service provision for severe and very severe ME was almost non-existent.

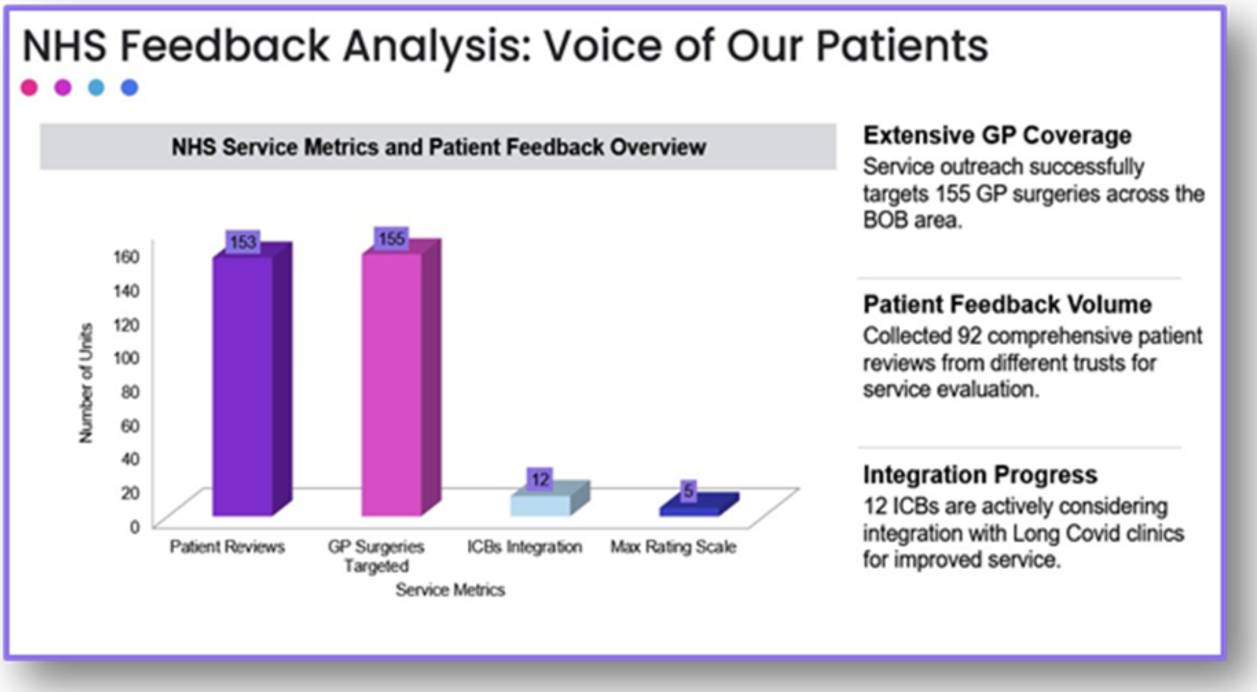
Lack of funding with services reduced by 50% during 2025

Many areas have little or no knowledge of ME/CFS/LC.

Only 4% of people were satisfied with their treatment plan from specialist services. 48% were very dissatisfied and 15 % dissatisfied.

ME/CFS services vary in naming and are categorised under different specialties, such as pain management and mental health.

Incorrect coding often leads to many patients not being recorded as having ME/CFS, complicating accurate statistical tracking.



NHS Feedback Analysis: Voice of Our Patients

Extensive GP Coverage
Service outreach successfully targets 155 GP surgeries across the BOB area.

Patient Feedback Volume
Collected 92 comprehensive patient reviews from different trusts for service evaluation.

Integration Progress
12 ICBs are actively considering integration with Long Covid clinics for improved service.

Fig 3 Snapshot of GP contact, patient voices and number of ICB integration of Long Covid services with ME/CFS.

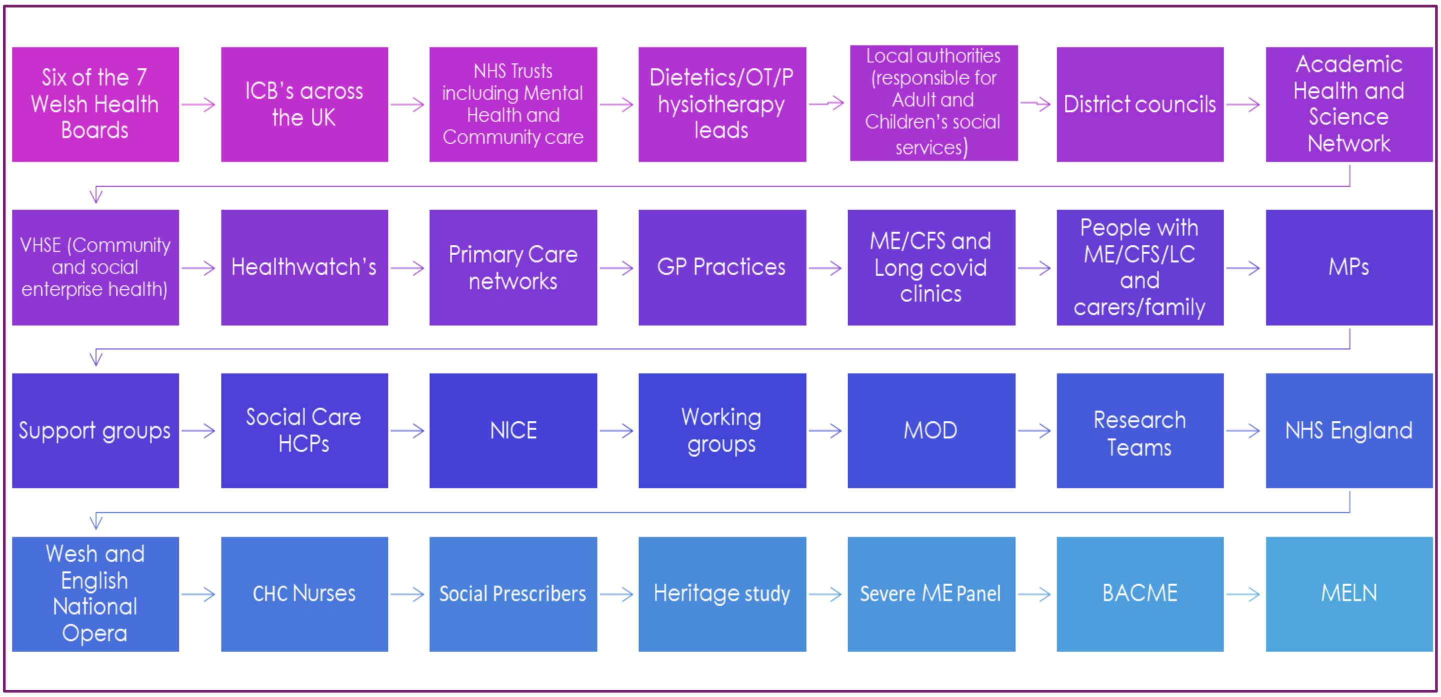


Fig 4: Services the team have collaborated with during the pilot.

During the 12-month pilot program, we collaborated with various services, NHS trusts, and support groups, leading to significant advancements for individuals with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). Our partnerships with key service leaders and organizations across the UK strengthened our credibility and impact.

We worked with the Greater Manchester NHS Trust service model group to establish innovative services. Upon their request, we conducted a review of the South and Northeast Essex (SNEE) service specification to facilitate the development of integrated pathways for the ME/CFS/LC patient population.

Similarly, we were asked for assistance by Kent and Medway in developing a combined service specification for both post-covid conditions and ME/CFS, demonstrating a commitment to positive change in healthcare.

Annual highlights

Persuading ME/CFS services to follow NICE guidelines 2021

Changes to the admission criteria at Essex Community ME/CFS

Engagement with services and people with ME/CFS

Training CHC nurses about ME/CFS and care and support needed in the community setting

Notable actions included advocating for changes in the Essex Community ME/CFS Service, where a patient gained support after the BMI criterion was removed, and updating the referral form at Cambridgeshire & Peterborough NHS Trust to better align with NICE guidelines. We built strong relationships with service leads and kept informed about challenges and barriers to their services and was asked to contribute to the Welsh Manifesto on provision for Severe ME.

"Thank you for your reply. Such an impressive draft for a manifesto. I'd just like to thank you and your colleges for all the wonderful work you are doing to support and improve the lives for all those with ME." response from someone who asked for help with Welsh Manifesto on the need for improved provision for Severe ME"

We focused on raising awareness of the NICE Guidelines and working with service leads across England to improve specialist services for ME/CFS and Long Covid. Our outreach efforts included engaging local representatives, support groups, patients, and caregivers to ensure all voices were heard.

A ME/CFS/LC petition was circulated to everyone in the ICB area to complete (goal 10,000 signatures and these were used in the final report and shared with the service to influence change. We then presented the results to the ICB service leads and commissioner.

Another key issue identified was that ME/CFS diagnoses were not formally recorded in social care assessments, complicating accurate tracking of individuals needing care. Following announcements about NHSE's closure and cost-cutting measures for Integrated Care Boards (ICBs), we assessed potential impacts on service provision and strengthened educational training for healthcare providers to ensure they had the necessary skills.

Actions and Impact

We received support requests from various services outside the pilot area we were working with. Over the past 12 months, these requests have increased significantly, especially following NHS England's announcement to cut funding by 50% and Integrated Care Boards (ICBs) opting to merge ME/CFS services with those for Long Covid.

The inquiries received encompassed a diverse range of requests, highlighting various needs within the community. We responded to 100% of patient queries and concerns through **ME Reach**, our '**Reach out for help**' advocacy service.

Among these were:

A complaint was raised to the team following the recommendation of Graded Exercise Therapy at the **Oxford University Hospitals Trust**. Following a letter and calls from the team with the patient's consultant, Oxford University Hospitals have removed GET from their treatment plan and from the website and leaflets. The Oxford NHS Trust website was updated removing GET from the programme

A referral form from **Cambridge and Peterborough NHS Trust** did not list ME/CFS as a long-term condition but as medically unexplained symptoms. There was also no option to tick cognitive, sensory and nutrition as symptoms. Following recommendations to the trust the form has now been updated to comply with NICE guidelines.

Oxford health Community ME/CFS service had outdated leaflet and information on their website. Following a lot of back and forth they have now agreed to update the website information, remove the outdated leaflet and update the NICE guidelines link to show 2021 version.

Essex Community ME/CFS Service excluded someone from their service due to her high BMI. H4ME declared there was no medical reason to refuse a patient with high BMI and met with the service lead and consultant. They apologised and removed BMI exclusion criteria from their website and referral form.

Cheshire and Merseyside NHS Trust – productive engagement with this Trust in the early stages of integrated service discussions led a place on the Expert Panel review. We were the only ME/CFS representative. We also offered introductions to other commissioners who may be able to help.

Lincolnshire County Council provided outdated information recommending GET and referencing the PACE Trial. We requested the county Council update their website and provided them with guidance ensuring an evidence-based understanding of ME/CFS.

Cheshire and Merseyside NHS (ICB) are closing nine Long COVID clinics. We contacted them and introduced the ME Association and HASC project and highlighted how we have assisted other services with specifications to merge with ME/CFS. We also offered introductions to other commissioners who may be able to help.

Buckinghamshire Fatigue Service held outdated recommended reading list. Issue highlighted by a pwME who was awaiting an appointment with the service. Contacted the service with recommendations for more updated reading list. They replied that they would review the list. Have had feedback from pwME that they were asked about their thoughts on the reading list at their appointment as they are reviewing it. Will follow up.

We engaged with **12 ICBs** and **5 Welsh Health boards** undergoing a significant period of change due to the loss of long COVID funding. This has prompted the consideration of integrated ME/CFS and LC services. Each ICB are at a different stage, but for some, service specifications are being drafted, and we have been asked to review these. By embedding healthcare expertise within our framework, we can engage more effectively and help shape services from the ground up and develop compliant integrated specialist services

We also examined how other ME/CFS and Long Covid services effectively addressed health inequalities. Although it was not part of our project objectives, we met all but 1 of the health boards in Wales. Early in the project, we quickly realised the extent of the need for support and assistance, which led to our geographical reach expanding from one county to the entire UK.

The H4ME team attended key integrated service meetings, alongside the commissioner and service leads, advocating for pwME and actively promoting the adoption of NICE guidance and disclosing evidence of bad practice	Patient surveys were published for residents to take part in, and these were used in the report and shared with the service to influence change
Working Group - set up to understand the lived experience and needs of local people with ME/CFS, carers and their families. The group have been incredibly grateful of our work, and we will present feedback from the BOB ICB meeting at the end of October – nicely tying up the end of the pilot.	To support service development, we provided feedback from working groups, survey results, and relevant contact details. We also shared service specifications and contact information to facilitate collaborative efforts and the exchange of best practices among the ICBs in shaping their service provisions.

Additional leaflets designed for the Health and Social Care service to support charity events, roadshows and wellness groups across communities. These were designed to help people understand the relevance of the Healthcare Team and pilot project with links to information on the website for further reading and reference.

Dedicated to improving healthcare for people with ME/CFS and Long Covid

The Health and Social Care team are engaging with services in Buckinghamshire, Oxfordshire and West Berkshire to urgently bring attention to the challenges faced by those with ME/CFS and Long Covid.

Our goal is to ensure that individuals with ME/CFS have access to essential health and social care services regardless of where they live.

We are diligently reviewing current services and actively collaborating with the NHS, local authorities, Members of Parliament, councillors, residents, and Healthwatch to influence our community's healthcare provision.

We aim to increase the number of clinics dedicated to ME and Long COVID, ensuring these conditions receive the same level of attention and resources as other chronic illnesses in healthcare provision.

We will ensure that the care and management of people with ME/CFS and Long Covid is evidence-based and adheres to the NICE guideline recommendations.

Support our work

Please share your experience of ME/CFS and Long Covid services within Bucks, Oxon and West Berks with the Health and Social Care Team via health@meassociation.org.uk

Health and Social Care Project

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Our goal is to ensure that individuals with ME/CFS have access to essential health and social care services regardless of where they live.

We are

- Reviewing current ME/CFS/LC services
- Collaborating with NHS, Healthcare staff Healthwatch, MPS, Councillors, Social Care and GPs
- Ensuring services adhere to NICE guidelines 2021
- Working with services to increase ME/CFS/LC clinics in each area

Please share your experience of ME/CFS and Long Covid services within Bucks, Oxon and West Berks with the Health and Social Care Team via health@meassociation.org.uk

Education and Training

Our goal over the next 3 years is to ensure all HCPs complete training modules (NHS)online and further training.

All services have full awareness of NICE Guidelines and implement them.

To support our efforts, we will initiate or strengthen educational training programs for healthcare providers, ensuring they possess the most relevant knowledge and skills.

Work with GPs and Primary care providers to improve knowledge and skills.

We successfully hosted a webinar training event for CHC nurses on the complexities of Severe ME. After receiving positive feedback, we were invited to present another event for a different group of CHC nurses.

Working group

Patient severity ranged between moderate to severe, and many members of the working group were housebound. Attendees described similar experiences of dismissal of their symptoms by healthcare professionals and a lack of NHS support, which resulted in some members disengaging with NHS services.

Through a series of working group meetings, key areas of concern and opportunity were identified. This included the need for more coordinated services and the importance of specialist roles within a multi-disciplinary care team.

Discussions highlighted the vital role of ME/CFS specialist nurses, the need for domiciliary care, and barriers to accessing health services and financial support. The group put forward the recommendation of establishing a specialist hub which could provide ongoing follow-up care and annual reviews in line with the latest NICE guidance. There was a strong emphasis on making services more inclusive, particularly for the most severely impacted patients.

The working group compiled an ideal service. ***based on lived experience feedback***

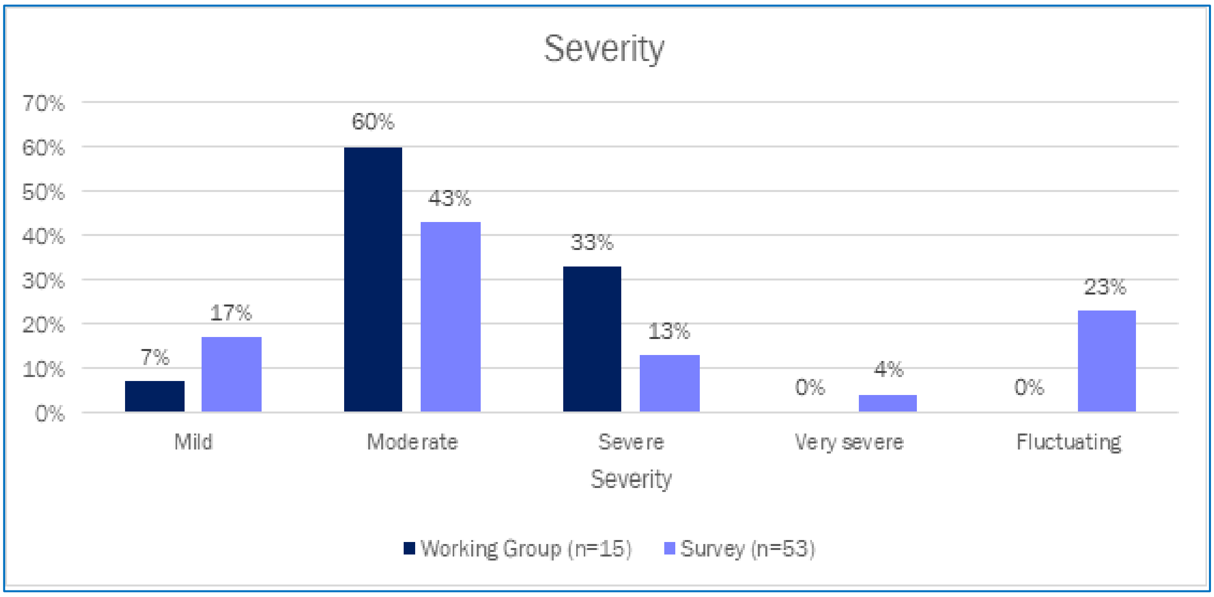


Fig 5 Severity of people with ME/CFS who are part of the working group.

Respect and belief
Patients are listened to, validated, and recognised as experts in their own condition.

Equity
Fair access regardless of severity, geography, age or socioeconomic background.

Patient-led care
Support is tailored to individual needs; not a one-size-fits-all model.

Safety
Services align with NG206, avoiding harmful approaches such as GET and inappropiate promotion of CBT as curative.

Co-production
Services designed and evaluated in partnership with people with lived experience.

Holistic, joined-up support
Medical, social, and practical needs addressed cohesively

Continuity
Ongoing review, not one-off appointments or discharge after assessment.

Fig 6 An analysis of working group member views on an ideal patient pathway

7 key principles that should underpin service design and delivery

The consensus favours a structured, holistic ME/CFS and LC Hub model offering the following:

Early diagnosis and first-line support

- GP recognition of ME/CFS and PEM, with clear diagnostic pathways.
- Appropriate investigations to rule out alternative causes.
- Immediate pacing and symptom-management advice.
- Early signposting to benefits advice, peer support and reliable resources.

Medically led multidisciplinary team

Working group members service with access to:

- Occupational therapy and physiotherapy trained in safe energy management
- Dietetics/nutrition
- Psychologists for emotional support if required (not curative therapy)
- Specialist nurses as named contacts, akin to Parkinson's or MS services

Social and practical support

- Help with PIP, UC, ESA and Blue Badge applications.
- Help accessing welfare support and reasonable adjustments in work and education when required.
- Carer support and access to peer groups.
- Help accessing social care where required.

Management approach

- Strict adherence to NG206 and rejection of psychogenic approaches i.e. no use of GET or curative CBT.
- Patient empowerment through education on pacing, self-care, and symptom management.
- Support for pain, insomnia, POTS, Mast Cell Activation Syndrome (MCAS), GI issues and other co-morbidities with onward referrals where appropriate.

Learning and research

- Ongoing professional education for clinicians.
- Patient-friendly updates on research.
- Services that adapt as evidence evolves.

Continuity of care

- Annual or 6-monthly comprehensive reviews (blood tests, symptom monitoring, support planning).
- Named point of contact for queries, advocacy letters, and onward referrals.

A patient hospitalised with ME/CFS

6. Inclusion of Severely Affected People

- Home visits or fully remote provision for patients too unwell to travel.
- Recognition of distinct needs and greater vulnerability.

Sustainability and funding

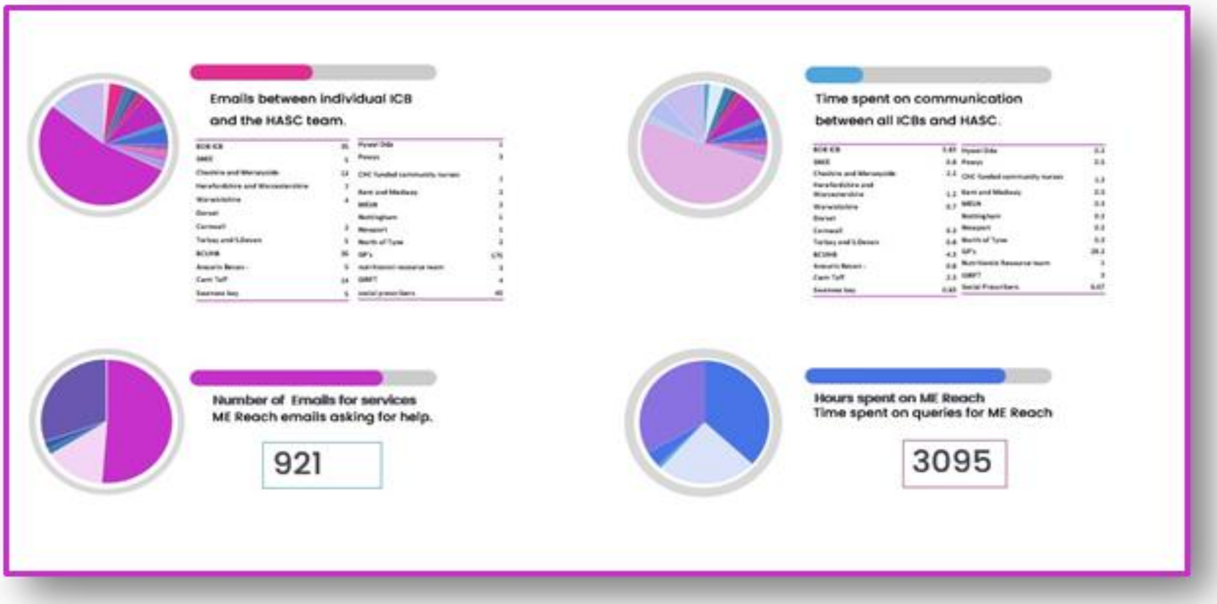


Fig 7 Time spent on emails and communication from the team which consists of 1 full time and 2, twenty-hour part time staff.

The amount of time dedicated to managing emails and communication via ME Reach, along with contacting other relevant services, is crucial for gathering the necessary information to address these queries. This process involves a team structure consisting of one full-time staff member, and two part-time staff members, each contributing 20 hours per week. Their collaboration ensures that all inquiries are handled efficiently and that accurate information is provided in a timely manner.

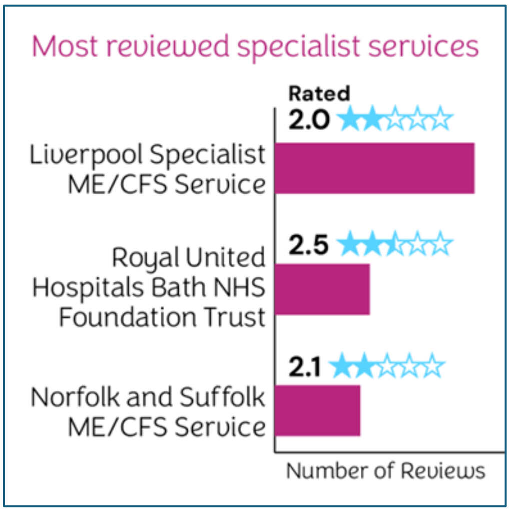
Fundraising

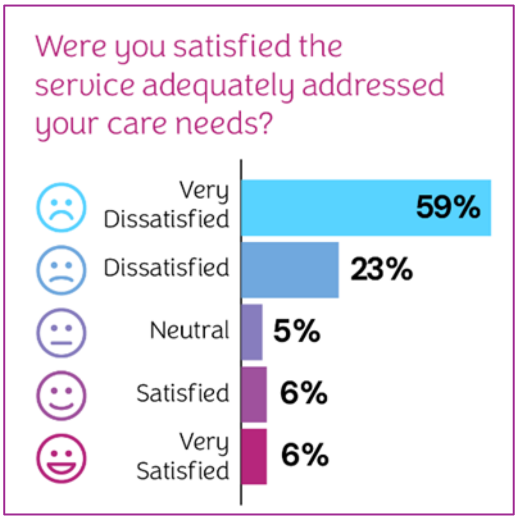
We are working closely with the MEA's fundraising team to pursue new funding streams and partnerships to ensure the long-term sustainability of healthcare within the MEA.

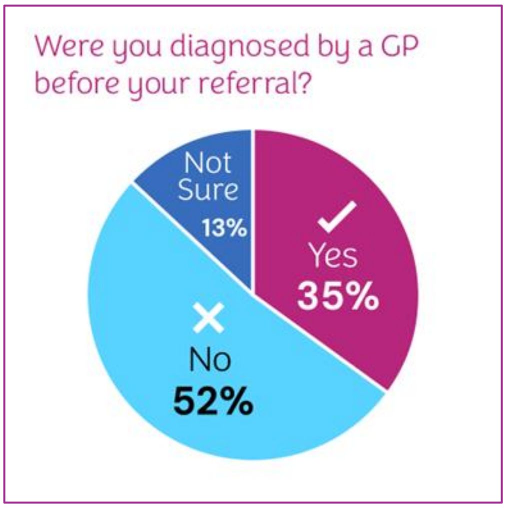
We hope to attract more supporters and help to generate more income as we are seen to be actively working with the NHS and social care providers. Working in conjunction with the fundraising team we will work to sustain the project long term and embed it with the charity full-time.

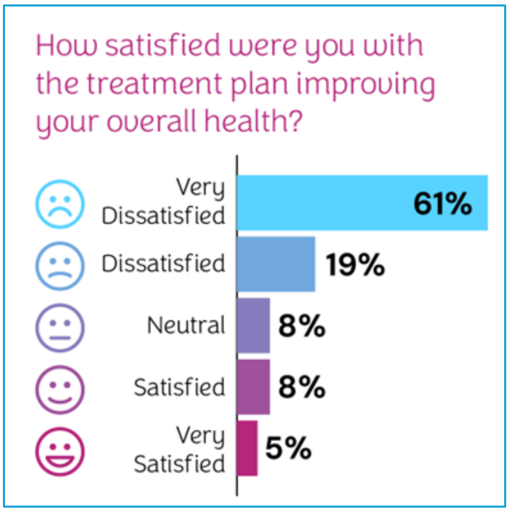
We aim to establish fundraising systems aimed at securing the financial resources needed to support ongoing healthcare initiatives and programs.

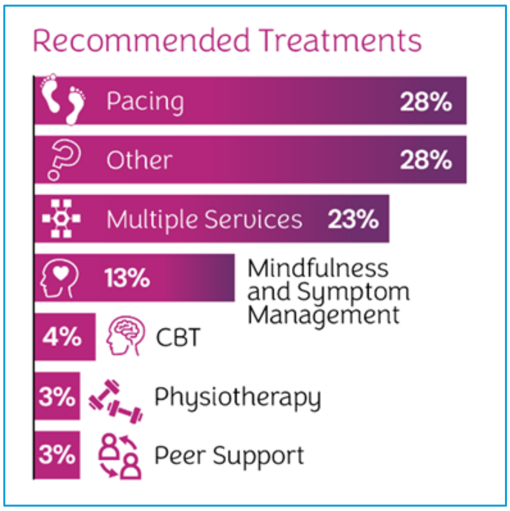
NHS Specialist services feedback reviews











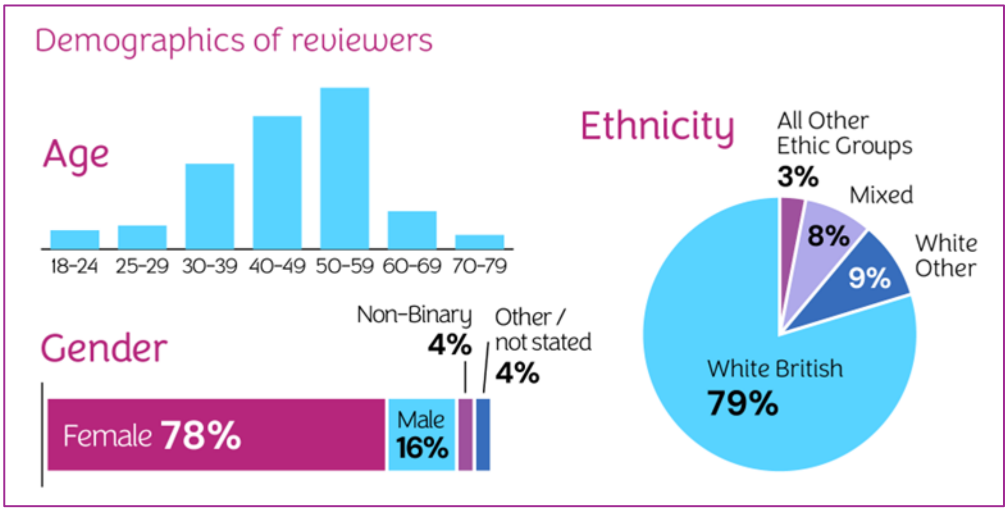


Fig 8-13 results of public feedback about NHS specialist services.

Feedback from people with ME/CFS reviewing the service they attended

Years(on) waiting lists to be seen

Admittedly diagnosed during covid, but never even spoke to consultant. Very good monthly zoom appointments with OT for pacing.

It's a very "one size fits all" approach. There are only 4 sessions of group therapy and 4 individual sessions and that's it. It is not supportive enough.

Struggle to be rereferred after major relapses. Twice in 11yrs. The doctor gave me incorrect information about ME/CFS worsening with age, with no offer of ongoing support. Feel badly let down.

8 months and still waiting for appointment.

Was diagnosed January 2020 (pre-lockdown) from one phone call. Never met a single person. Care wasn't specialised at all. Very generic. I felt like another number

There was no opportunity to speak to a doctor, just a nurse who recommended mindful colouring followed by a zoom meeting, then CBT that was cut short. So, no help at all.

Got the worst advice I've ever had from their "specialist GP" who told me to throw away my heart rate monitor and exercise! Led to a further serious crash that I have never recovered from.

The staff are very caring and understanding, but they cannot help me because so am severe, they just referred me back to the community who are at a loss as they have no idea how to help

They may not cure, but the treatments they offer make our illness bearable.

This service left me very disappointed. They told me that as I have severe ME/CFS they could not offer me any help. How can it be that the more severe your illness is, the less help is available?

The Dr doesn't listen and gives only basic info. I asked for clarification, was told to google it. The physio exercises felt generic, not personalised. The occupational therapist is excellent.

The staff were lovely but had nothing useful to offer beyond a diagnosis. Their approach is purely biopsychosocial, and they will not accept new referrals unless the patient agrees to accept this.

A physiotherapist in clinic discussing an individual plan of care with a ME/CFS patient.

The clinic was staffed by a mental health nurse and a physiotherapist. So, I was concerned it would be CBT and graded exercise. All they offered was a weekly 2 hour zoom call with other patients.

Poor service, not meeting NICE guidelines, no Consultant. Physio nearly killed me, they had no idea what ME was, stating ME was chronic fatigue & was not recognised by WHO as a neurological condition"

Initially when I was first diagnosed, I received reasonable help under the guidelines laid out in 2015. I felt like I was being looked after but then once the service sessions have finished and reviews completed, I am completely left alone. No-one contacts me to see how I am or offer any further help as the years have gone by. I am now 10 years with my CFS/ME and need continued support.

No understanding of PEM. Exercise encouraged and I was told to stop using aids like a perching stool and shower seat. CBT recommended. When I said I thought I needed medical intervention to improve the therapist said my attitude was wrong and discharged me. I have very poor cognitive function, my husband looks after my finances, he was accused of Coercive Control!? Extremely distressing.

Reviews taken at random from NHS review of specialist services portal on MEA website

Excellent service start to finish. I opted for face-to-face individual sessions but there were other options as well, depending on needs and preferences. Incredibly compassionate team, with a great deal of helpful, practical advice that I continue to use day-to-day.

Next steps

Service plans

The HASC team has effectively enhanced the sharing and adoption of service models among ICBs through targeted networking, e-introductions, and knowledge exchange events. This effort supports the delivery plan's goal of **promoting consistent and equitable care nationwide** while reducing local duplication of efforts.

Roadmap

To increase our impact, we aim to scale up our activities. While we've mainly interacted with service leads and commissioners, we plan to proactively reach out to services undergoing reviews for support.

Education:

A focus in year 2 will be on educating primary care services.

We will strive to ensure that at least 50% of staff members at each surgery complete the designated online training modules. Ideally, each surgery will designate a specialist in ME/CFS, which should help staff feel recognised and supported in their efforts to improve patient care.

Collaborative efforts with primary care providers and GPs will be essential.

One action we are planning to implement is to build on existing contributions, raise awareness, engage patients, and encourage participation in service development.

Our dedicated team will provide essential support when individuals face challenges related to ME/CFS.

Once patient appointments and care at specialised service centres are completed, care returns to their GP. Our action plan aims to reassure the audience that patients will receive ongoing, consistent care and will not need to manage their health independently.

- **Enhance outcomes and quality of life for both patients and caregivers.**
- **Decrease long-term NHS expenditures through early intervention and preventive care.**
- **Align regional services with guidelines from the National Institute for Health and Care Excellence (NICE) and emerging national best practices.**

The MEA Healthcare Team

We extend our sincere thanks to all individuals who participated in our pilot project. Your contributions and support have been invaluable, and the comprehensive information collected from both professionals and the public reflects your valuable contributions. You will find some of this information included in the report.

For those who observe the holiday season, we wish you a Merry Christmas and a Happy New Year. We look forward to engaging with many more of you as we move into our 2nd year, working together to improve ME/CFS/LC services.

The Healthcare team.

Healthcare 4 ME

Email: health@meassociation.org.uk