LYPFT

Leeds and West Yorkshire ME/CFS Service - Response to ICB Information Request

(For onward submission to Kirklees Health and Adults Social Care Scrutiny Panel)

Service Overview

Leeds and York Partnership NHS Foundation Trust (LYPFT) host a specialist ME/CFS service covering Leeds and the wider West Yorkshire area. The service provides assessment, diagnosis, and specialist management in line with current NICE guidance.

Question 1: Actions taken regarding the 2021 NICE Guidelines and July 2025 DHSC Delivery Plan

NICE Guideline (NG206, 2021) Implementation

The service undertook a comprehensive review of its compliance with NICE Guideline NG206 (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Diagnosis and Management), reviewing 119 relevant recommendations. We found that 97% of relevant recommendations are fully met, with the remaining recommendations either partially met or not applicable to the service remit.

Areas of strong compliance included holistic assessment, multidisciplinary working, personalised care planning, energy management, symptom management, support for severe ME/CFS, carer involvement, and provision of specialist advice to primary care. The small number of partially achieved recommendations largely relate to areas outside the service's direct responsibility (particularly primary care reviews and investigations), or practical implementation challenges such as providing resources in multiple languages and accessible formats, where a case-by-case approach has been adopted.

Since the previous review, the action tracker has been updated to reflect service developments, including the re-establishment of the severe ME/CFS pathway, updates to guidance and training resources, and the removal or revision of actions relating to COVID-19. Overall, the review demonstrates a high level of alignment with NICE guidance and a strong commitment to continuous service improvement.

Areas of strong compliance included:

- Multidisciplinary care delivery
- Holistic assessment and personalised management approaches
- Energy management (pacing) as a core intervention
- Avoidance of graded exercise therapy in line with NICE guidance
- Provision of flexible, accessible care (including remote consultations and home visits where appropriate)

Evidence:

- Attached

Primary Care Guidance

The service updated its Primary Care Guide, incorporating:

- NICE diagnostic criteria
- Management approaches focused on energy management (pacing)
- Clear guidance on cautions regarding graded exercise therapy

This guidance is publicly available via our website:

https://www.leedsandyorkpft.nhs.uk/our-services/leeds-and-west-yorkshire-myalgic-encephalomyelitis-me-and-chronic-fatigue-syndrome-cfs-service-primary-care-guide/

Dr McKeever, GPwSI working within the LYPFT ME/CFS service contributed directly to the Department of Health and Social Care ME/CFS Delivery Plan.

DHSC Delivery Plan Response

Following publication of the Department of Health and Social Care ME/CFS Delivery Plan (2025), the Leeds and West Yorkshire ME/CFS Service reviewed the plan against current service provision and development priorities. The review identified substantial alignment between the Delivery Plan priorities and existing service activity. While many of the initiatives described below were established prior to publication of the Delivery Plan, they directly support its aims relating to research, education and awareness, service accessibility, co-production, and support for people living with ME/CFS. Future service development work will continue to be informed by the Delivery Plan

The Leeds and West Yorkshire ME/CFS Service supports the aims of the Department of Health and Social Care's 2025 ME/CFS Delivery Plan through ongoing work across the key themes of research, education and awareness, and improving the lives of people living with ME/CFS.

Research

As part of Leeds and York Partnership NHS Foundation Trust, the service contributes to an organisation that has made a strategic commitment to embedding research within clinical practice. The Trust's Research and Development Strategy aims to place research at the center of organisational activity, recognising its role in improving quality of care, patient outcomes and service development. The Trust's stated objective is to develop and deliver high-quality research for the communities it serves.

The ME/CFS team actively supports the development and dissemination of research within the field. Team members regularly attend national conferences and professional events to remain up to date with emerging evidence, including attendance and presentations at the BACME Annual Conference and attendance at the International Post-Infectious Conditions (IPIC) Conference.

The service has recently been approached regarding potential future research into sleep and ME/CFS and is awaiting further information.

One team member is currently undertaking a research internship exploring the lived experience of people with ME/CFS who are also neurodivergent, whilst another is undertaking a Clinical MSc Programme commencing in September 2026 with the intention of developing future research focused on clinical interventions for people with severe and very severe ME/CFS.

Many members of the team are active members of BACME. Team members also contribute to wider professional research and development through membership of professional networks, including Royal College of Occupational Therapists specialist forums relating to long-term conditions and fatigue.

Attitudes and Education

The service is committed to improving understanding of ME/CFS amongst healthcare professionals, support services, patients, carers and the wider community.

The service GPwSI regularly delivers teaching and training sessions both locally and nationally. This includes education for GPs, acute medical teams, neurologists, infectious disease physicians, rehabilitation medicine clinicians, and other healthcare professionals. Recent teaching has included presentations on hormones, hypermobility and ME/CFS to the Yorkshire Family Planning Primary Care Group. The GPwSI has also facilitated peer learning and support groups for doctors working within ME/CFS services.

In addition, the GPwSI is leading BACME's national tube-feeding project for people with ME/CFS, with publication anticipated later this year.

Members of the MDT have delivered teaching sessions to occupational therapists, physiotherapists, and multidisciplinary teams working with people with ME/CFS and related fatigue conditions. The service is currently developing educational links with Leeds Mental Wellbeing Service and Leeds Teaching Hospitals NHS Trust Neurorehabilitation Services to further improve understanding of ME/CFS across healthcare settings.

The service also contributes to workforce development by providing regular placement opportunities for Occupational Therapy and Nursing students. Work is underway to develop a specialist leadership and innovation placement for MSc Occupational Therapy students.

Education and consultation are also provided to care agencies supporting people with severe and very severe ME/CFS.

Living with ME/CFS

Service development is informed through patient feedback and co-production activities. The service has an established patient forum and is developing a co-design subgroup to support service-level improvement projects.

The service maintains an extensive library of written resources and is collaborating with other ME/CFS services to develop accessible video-based resources and workbooks informed by patient feedback.

The service provides specialist ME/CFS support across West Yorkshire. Most assessments and interventions are delivered remotely, reflecting patient preference. Feedback highlights reduced energy expenditure associated with travel, greater flexibility around work and childcare commitments, and easier management of symptoms during appointments. Home visits are available where required.

The service has an established pathway for people with severe and very severe ME/CFS, providing flexible assessment and intervention approaches, including home visits, adapted assessments and extended intervention timeframes.

Supporting participation in education and employment is a routine component of the therapeutic pathway. Vocational rehabilitation approaches are routinely used, and the team regularly provides supporting information regarding reasonable adjustments.

Summary

The service demonstrates strong alignment with the priorities set out in the 2025 ME/CFS Delivery Plan through its commitment to research engagement, professional education, co-production, accessible information, support for severe and very severe ME/CFS, service accessibility, and support for participation in education and employment.

Delivery Plan Theme	Priority Area	Current Service Activity
Research	Research engagement	Conference attendance and presentations at BACME and other related conferences such IPIC.
	Research activity	OT research internship exploring ME/CFS and neurodivergence; Lead OT commencing MSc with plans for future severe ME/CFS research.
	Research culture	Culture is supported and fostered by the wider trust and their commitment to embed this organisational planning. Team members' active participation in professional forms such as BACME and RCOT. On-going service evaluation and quality improvement projects.
Attitudes & Education	Professional education	Teaching provided to GPs, acute medicine, neurology, rehabilitation, AHPs, and primary care teams.
	Supporting wider services	Advice and education provided to care agencies and partner services supporting people with ME/CFS.
	Workforce development	Regular OT and Nursing student placements; development of a specific leadership and

		innovation OT placement to be made available in the service
	Regional and national contribution	Participation in BACME, regional ME/CFS and long covid networks, forums and national specialist interest groups.
Living with ME/CFS	Co-production	Established patient forum, co-production training, mentorship and development of a co-design group.
	Accessible information	Written resources available by post and email; development of video resources and workbooks in response to patient feedback and co-design priorities.
	Access to services	West Yorkshire-wide specialist service; predominantly remote delivery based on patient preference; home visits available on severely affected pathway.
	Severe and Very Severe ME/CFS	Dedicated pathway offering flexible assessment, home visits, adapted approaches and ongoing pathway evaluation.
	Education and employment	Vocational rehabilitation, education support, advice regarding reasonable adjustments, and supporting letters.

Question 2: Details on any commissioned speciality ME services that meet NICE requirements

LYPFT hosts a commissioned specialist ME/CFS service for Leeds and West Yorkshire.

The service is structured to meet NICE NG206 requirements, including:

- Specialist multidisciplinary assessment
- Individualised management plans
- Support for varying severity levels

Full service details are available here:

https://www.leedsandyorkpft.nhs.uk/our-services/leeds-and-west-yorkshire-myalgic-encephalomyelitis-me-and-chronic-fatigue-syndrome-cfs-service-primary-care-guide/

Question 3: Waiting times for assessments, diagnosis, and specialist support – (from Kirklees)

Service Demand (Context)

The ME/CFS service is managing high and sustained referral volumes across West Yorkshire, which is an important factor when considering access and waiting times.

Between November 2025 and June 2026, the service received approximately 95-100 referrals per month on average, with a peak of 137 referrals in March 2026.

Acceptance rates vary month-to-month following clinical triage.

Kirklees-Specific Demand

Referrals from Kirklees are consistently received each month, ranging from:

- 13 to 29 referrals per month in last 6 months

This demonstrates a steady and ongoing demand for specialist ME/CFS provision from the Kirklees population.

Waiting times for assessments, diagnosis, and specialist support

Current Waiting Times

- The current waiting time for initial assessment is approximately 11 months from receipt of referral. Following assessment service users diagnosed with ME/CFS are typically offered a place in therapy pathway within 4 weeks.

Service Context and Improvement Work

- The service is managing high levels of demand across West Yorkshire, with referral numbers remaining consistently high. This demand has contributed to extended waiting times for initial assessment. The service continues to review its pathways and delivery models to ensure available resources are used as effectively as possible, whilst maintaining compliance with NICE guidance and preserving the quality and individualised nature of the specialist support provided. Whilst service improvements may support efficiencies and improvements in patient flow, waiting times are also influenced by the level of demand for specialist ME/CFS services across the region relative to the capacity available within the service.

Summary

Waiting times apply equally across the region, including Kirklees

While there is a long wait for initial assessment, access to therapeutic interventions following assessment is relatively prompt

Question 4: Engagement with Kirklees & Calderdale ME Campaign Group

This question will be primarily addressed by the ICB.

However, locally:

- Members of the LYPFT ME/CFS service have undertaken engagement activity with the Kirklees & Calderdale ME Campaign Group. This has included communication and involvement in discussions relating to service development and patient experience.
- Leeds and West Yorkshire ME/CFS service has had a service user forum for many years. This provided a space for previous service users to catch up with each other, learn and support developments within the service and offer their feedback and support to the service as able. We have many members who attend from all over West Yorkshire. We have several members of the Kirklees and Calderdale ME Support Group who have attended the service user forum for several years.
- Since coming into role, our Lead occupational therapist, Katie Agnew, has been working with the exiting members to develop the forum, with the aim of extending the space to further support lived experience and inform co-design. When the new format was first introduced – we met with the Kirklees and Calderdale support group leaders in Autum 2025, as they wished to discuss a number of specific issues that we felt was not on the agenda and would not be given the time to explore appropriately in the next forum. This was a valuable opportunity to strengthen relationships, answer their questions, provide updates on the service model, and gain a better understanding of the work they have been undertaking within their local communities. During this meeting, we discussed their concerns that patients from Leeds were being prioritised over those living elsewhere in West Yorkshire. We were able to reassure them that this was not the case and explained our service model, including our predominantly remote delivery approach as well equity on service provision and wait times. Feedback from most patients has indicated a preference for remote appointments, as they can be more easily adapted around fluctuating symptoms and reduce the practical challenges associated with travel, work, education, and caring responsibilities. We also discussed the severely affected pathway, which serves patients across the whole of West Yorkshire and includes home visits where clinically required. In addition, they were eager to understand our approaches to ME/CFS and were explained the dysregulation model that underpins our clinical approach, complementing our therapy-led rehab approach.
- We met again in March 2026, where discussions focused on their ongoing engagement with the Integrated Care Board (ICB). We reviewed the NHS England Delivery Plan and the NICE guidelines and discussed how the service is working to align with both. We also discussed the introduction of a co-design element within the patient forum. It was explained that the initial focus would be on service-level developments and improvement projects. At the same time, we recognised and supported the Kirklees and Calderdale group's broader

discussions with the ICB and welcomed opportunities for them to share relevant updates through the forum. One of the of the Kirklees and Calderdale group attended the first co-design forum in April, where a wide range of ideas and potential service improvements were discussed between new and older members. Unfortunately, these forums were temporarily paused due to organisational decisions within the Trust and have not taken place since April. However, we are hopeful that they will recommence in late summer or early autumn.

- We very much welcome continued engagement with the Kirklees and Calderdale ME Support Group. We are keen for the Leeds and West Yorkshire ME/CFS service user Forum to be recognised primarily as a co-design and service development group for current and former service users. Individuals who wish to become involved in broader advocacy activities will be signposted to local support organisations, including the Kirklees and Calderdale ME Support Group, whose leadership team has been highly supportive in facilitating patient involvement across West Yorkshire.

Question 5: Training provided on ME and proportion of staff who have completed

NHSE E-learning Module

The service is aware of the new NHSE ME/CFS e-learning modules

Implementation approach:

- All new staff joining the service are to complete these modules

- Existing staff (with prior expertise and up-to-date knowledge) are encouraged but not required, as we have established staff who are already ahead in terms of the skills and competencies taught in these modules. As this e-learning is designed for general clinicians working with people with ME, not specialists in ME/CFS. We as a specialist team provide training on it ourselves. Despite this some established staff members have completed the training voluntarily.

Internal Staff Training

The service has:

A structured induction programme for all new staff

Weekly educational sessions embedded within team practice

Staff are expected to:

Maintain up-to-date knowledge through continuing professional development (CPD)

Use protected learning time for this purpose. Our team are supported by the service and the Trust to attend external training courses and events with a feedback loop into the education sessions, so learning is up to date and shared across the team.

Training Provided to Non-Specialists

Delivering education externally is a key component of the service's role, aligning with priorities in the DHSC Delivery Plan.

Examples include:

Training delivered by Dr McKeever our service GPwSI to a range of medical and other clinicians, e.g. recent training to Acute Medical Team (St James's University Hospital), to regional network of Neurologists, Infectious Diseases physicians and Rehabilitation Medicine specialists and GP training schemes (VTS).

We have also provided training to care agencies to help them understand severe ME/CFS and how these impacts on people and how to approach working with this service user group.

Dr McKeever is currently Project Lead for a BACME project investigating tube feeding provision in ME/CFS

Question 6: How people with severe and very severe ME identified and supported (from Kirklees)

Patients with severe or very severe ME/CFS are identified through information provided at referral, screening prior to assessment and initial clinical assessment

The service has a specific pathway for patients with severe presentations, including:

- Modified assessment processes
- Flexible approaches to care delivery, including Session timing, Mode (e.g. virtual, telephone) and reduced sensory/cognitive burden

Enhanced Support

- Involvement of family/carers, where appropriate and with patient consent
- Home visits, where clinically indicated and within catchment
- Access to a dedicated MDT forum for discussion of severe cases

This ensures care is tailored to the complexity and vulnerability of this group.
