Kirklees Health and Adult Social Care Scrutiny Committee

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS): Local Provision, Implementation of National Guidance and Service Assurance

Report of: NHS West Yorkshire Integrated Care Board and system partners
Date: July 2026
Purpose: For information, assurance and scrutiny

1. Purpose of the Report

This report responds to questions raised by the Kirklees Health and Adult Social Care Scrutiny Committee concerning:

- implementation of the 2021 NICE guideline for ME/CFS and the July 2025 Department of Health and Social Care national plan;
- commissioned specialist ME/CFS provision;
- waiting times for assessment, diagnosis and specialist support;
- the number of Kirklees residents diagnosed with ME/CFS and Long COVID, or awaiting assessment;
- engagement with the Kirklees & Calderdale ME Campaign group;
- workforce training; and
- identification and support of people with severe and very severe ME/CFS.

This report provides an overview of the current arrangements for people living with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) in Kirklees. It draws together information provided by NHS West Yorkshire Integrated Care Board (ICB), Kirklees place-based commissioning and primary care, local NHS provider organisations, the Leeds and West Yorkshire specialist ME/CFS service and wider public health provision.

ME/CFS is a complex, chronic and potentially disabling condition. Its severity varies considerably. Some people can maintain aspects of daily life with appropriate support, while others with severe or very severe ME/CFS may be substantially housebound or bedbound and require highly individualised and flexible care.

2. Executive Summary

ME/CFS is a complex, chronic and potentially disabling condition. People may experience a wide spectrum of severity, from those able to maintain some daily activities with appropriate support to people with severe or very severe ME/CFS who may be substantially housebound or bedbound.

Kirklees does not have a separately commissioned specialist ME/CFS service located within the district. Kirklees residents have access to the regional Leeds and West Yorkshire specialist ME/CFS service, commissioned for the West Yorkshire population.

Following national guidance updates, information was circulated to primary care and GP practices in Kirklees. This included updated NICE guidance, referral information, required investigations and diagnostic tests, annual review guidance, patient education and support materials, and information about reasonable and practical adjustments.

Kirklees ICB also promoted three NHS England and Royal College of General Practitioners-approved ME/CFS e-learning modules. However, comprehensive data on the proportion of staff completing this training are not currently held.

Data supplied by the place-based ICB data team in January 2026 identified 1,837 Kirklees residents with a recorded diagnosis or clinical read code for Myalgic Encephalomyelitis or Chronic Fatigue Syndrome. There is not currently a comprehensive validated figure for residents diagnosed with Long COVID, people with both conditions, or those awaiting ME/CFS assessment.

Kirklees-specific waiting-time information is not currently available at place level because referrals are made directly to the specialist service. Current waiting-list and waiting-time data should therefore be obtained from the specialist provider.

Engagement has taken place between West Yorkshire representatives, the specialist ME/CFS service and the Kirklees & Calderdale ME Campaign group, with a series of meetings identified between February 2025 and March 2026.

The information gathered demonstrates existing provision and activity but also identifies opportunities to strengthen system-wide assurance, particularly in relation to waiting-time data, workforce training uptake, implementation monitoring, and coordinated support for people with severe and very severe ME/CFS.

3. Response to the Committee's Questions

3.1 Actions taken in response to the 2021 NICE guideline and July 2025 national plan

NHS West Yorkshire ICB commissions services with the expectation that care is delivered in accordance with relevant national guidance, including NICE Guideline NG206, published in October 2021.

Following relevant national updates, the NHS West Yorkshire ICB Medical Director circulated information to acute and mental health trusts. At Kirklees place level, an update and notification was circulated to all primary care and GP practices through established communication routes.

The information provided to primary care included:

- updated NICE guidance for clinicians;
- links to the Leeds and West Yorkshire specialist ME/CFS service;
- referral information, including an updated referral form and details of investigations and diagnostic tests required to support referral;
- annual review guidance for patients with ME/CFS, including management information;
- updated patient education and support information that can be downloaded and shared;
- links to other professional resources and support organisations; and
- information on reasonable and practical adjustments that primary care services can make for people with ME/CFS.

Kirklees ICB also continues to circulate pathway and referral updates received from the specialist service, with referral guidance most recently updated in May 2026.

At Calderdale and Huddersfield NHS Foundation Trust (CHFT), the 2021 NICE guidance was previously reviewed and, given the passage of time and changes in medical personnel, a further review is being undertaken within the Integrated Medical Specialties directorate. The Department of Health and Social Care plan was reviewed by the Trust's Executive Board in July 2025, and CHFT reports that it considers itself well placed in relation to delivery and is progressing relevant work.

Mid Yorkshire Teaching NHS Trust (MYTT) has advised that its Rheumatology and Neurology services do not receive referrals for the diagnosis or management of ME/CFS and do not implement specialist ME/CFS treatment plans. It has therefore not undertaken specific implementation activity relating to specialist service recommendations, with suspected ME/CFS generally managed through primary care and referral to the regional specialist service where appropriate.

The available evidence demonstrates dissemination of guidance and referral information and some organisational review activity.

3.2 Commissioned specialist provision

There is no separately commissioned specialist ME/CFS service located within Kirklees.

Kirklees residents have access to the Leeds and West Yorkshire specialist ME/CFS service commissioned for the West Yorkshire population.

The specialist service provides assessment, clinical advice, personalised management planning, symptom and energy management support and multidisciplinary input where appropriate, for eligible residents across the West Yorkshire ICB area, including Kirklees. It accepts referrals for people across the spectrum of ME/CFS severity.

Primary care clinicians can refer patients directly to the specialist service in accordance with the referral pathway. Kirklees ICB circulates pathway and referral guidance updates to GP practices.

CHFT has also confirmed that where patients require specialist ME/CFS care, its pathway is to refer onwards to the regional specialist service. The Trust notes that ME/CFS can present across multiple specialties and is not owned by one individual hospital specialty.

The commissioned specialist pathway is expected to operate in accordance with NICE NG206

3.3 Waiting times

Kirklees place-based ICB does not directly hold waiting-time information for specialist ME/CFS assessment and support. GP practices and clinicians refer directly to the regional specialist service, and relevant referral and waiting-list information is therefore held by individual practices and/or the specialist service provider.

MYTT similarly does not hold comprehensive information on waiting times because it does not provide or manage the specialist ME/CFS service.

CHFT has advised that it cannot quantify ME/CFS-specific referral information before diagnosis from its available data. Where specialist ME/CFS input is required, patients can be referred to the regional specialist service.

Consequently, the information currently available does not provide Kirklees-specific figures for:

- time from presentation to diagnosis;
- time from referral to specialist assessment;
- the number of people currently waiting;
- median or longest waits; or

3.4 Number of residents diagnosed or awaiting assessment

Data supplied by the place-based ICB data team in January 2026 identified **1,837 people registered in Kirklees with a diagnosis or clinical read code for Myalgic Encephalomyelitis or Chronic Fatigue Syndrome**.

For comparison, the corresponding figures provided were:

- Calderdale: 1,075;
- Kirklees: 1,837;
- Wakefield: 1,517; and
- total across these three areas: 4,429.

The Kirklees figure represents people identified through recorded diagnosis/read-code data and provides a more specific local measure than the earlier prevalence estimate of approximately 940–1,880 residents.

However, this does not necessarily represent every person living with ME/CFS. Differences in coding, people who remain undiagnosed and individuals currently undergoing assessment may affect the total.

The information currently available does not provide a validated figure for:

- Kirklees residents diagnosed with Long COVID;
- people diagnosed with both Long COVID and ME/CFS; or
- people awaiting ME/CFS assessment or diagnosis.

MYTT has confirmed that any ME/CFS figures derived solely from its hospital activity would represent only a subset of the wider population and could therefore be misleading.

CHFT reported 957 inpatient episodes since April 2023 involving patients who had an ME diagnosis recorded, although only three had ME as the primary diagnosis. These are episodes of care rather than a count of unique Kirklees residents and should not be interpreted as prevalence data. CHFT also identified 95 Kirklees patients with an ME diagnosis who had been seen in a Neurology outpatient setting over the period covered by its data.

3.5 Engagement with the Kirklees & Calderdale ME Campaign group

Engagement has taken place between West Yorkshire representatives, the specialist ME/CFS service and representatives of the Kirklees & Calderdale ME Campaign group.

Meetings or discussions were identified on:

- 3 February 2025;
- 14 April 2025;
- 9 June 2025;
- 14 July 2025;
- 13 October 2025;
- 8 December 2025;
- 12 January 2026; and
- 16 March 2026.

An ME/CFS plan was also recorded as completed on 9 June 2025.

Kirklees place-based ICB representatives have not directly held separate engagement sessions with the campaign group. However, through updates at the West Yorkshire Mental Health, Learning Disability and Autism commissioning forum, Kirklees representatives were aware of engagement involving West Yorkshire programme representatives and the specialist service provider.

In communications to GP practices, Kirklees ICB also advised that the Kirklees and Calderdale patient group had offered support and advice to practices undertaking in-house educational activity and provided contact details for this purpose.

CHFT has advised that there are currently no scheduled meetings with the campaign group but that it is open to increasing awareness of ME/CFS within the Trust, including through internal communications and promotion of relevant community awareness activity.

The specialist service also operates a bi-monthly patient forum through which people who have received care from the service can contribute to discussions about service development and future improvement.

3.6 Workforce training

Kirklees ICB promoted three NHS England and Royal College of General Practitioners-approved e-learning modules:

1. Introduction to ME/CFS;
2. Guidance for community-based healthcare practitioners; and
3. Managing severe ME/CFS.

Practices were advised that completion could contribute towards continuing professional development requirements.

Primary care also received updated NICE guidance, referral information, annual review guidance, patient information and advice concerning reasonable and practical adjustments.

In addition, primary care received updated NICE guidance, specialist referral information, annual review guidance, patient information and advice concerning reasonable and practical adjustments for people with ME/CFS.

However, Kirklees ICB does not hold comprehensive completion data and cannot currently provide the proportion of relevant staff who have completed ME/CFS-specific training.

MYTT does not currently provide bespoke ME/CFS training and does not hold completion data for ME/CFS-specific education.

3.7 Severe and very severe ME/CFS

People with severe and very severe ME/CFS may be housebound or bedbound and can experience substantial limitations affecting mobility, communication, self-care and access to healthcare.

The regional specialist service accepts referrals for people across all levels of ME/CFS severity and offers both outpatient and community assessments and if required an inpatient service.

Potential support across the wider system includes specialist advice, remote consultations, coordination with primary care, community support, reasonable adjustments, personalised symptom and energy management and other health and

care support according to individual need. Support across the wider system may include:

- specialist assessment and advice;
- remote or telephone consultations where appropriate;
- coordination with primary care;
- community-based support;
- home visits where clinically appropriate and available;
- reasonable and practical adjustments to accessing primary care;
- personalised symptom and energy management;
- occupational therapy, physiotherapy or other community support where clinically appropriate; and
- support for associated physical or mental health needs.

Kirklees public health provision that may provide wider support includes the Wellness Service, social prescribing and Community Champions.

South West Yorkshire Partnership NHS Foundation Trust supports people in relation to mental health needs and co-morbidities but does not operate an internal ME/CFS diagnostic pathway. It has identified the potential benefit of closer working between physical and mental health pathways to provide more coordinated and holistic care.

MYTT does not operate a dedicated ME/CFS pathway or maintain a register of people with severe or very severe ME/CFS. Its Rheumatology and Neurology services do not routinely diagnose or manage the condition, with suspected cases generally managed in primary care and referred to specialist services where appropriate.

CHFT similarly recognises the regional specialist service as the specialist hub for Kirklees patients requiring dedicated ME/CFS expertise.

4. Recommendations

The Committee is asked to:

1. **Note** the current specialist ME/CFS arrangements available to Kirklees residents.
2. **Note** the January 2026 data identifying 1,837 Kirklees residents with a recorded ME/CFS diagnosis or clinical read code.
3. **Note** the actions undertaken to disseminate national guidance, referral information and professional training resources.
4. **Encourage** closer collaboration across primary care, acute, community, mental health, adult social care and specialist services to reduce gaps between organisational pathways.

5. Conclusion

Kirklees residents have access to a regional specialist ME/CFS service, supported by primary care and wider health, community and public health services. There has been significant dissemination of updated guidance and referral information to

primary care, access to nationally approved professional training, and ongoing engagement between the specialist service, West Yorkshire representatives and the Kirklees & Calderdale ME Campaign group.

The January 2026 primary-care data identifying 1,837 Kirklees residents with an ME/CFS diagnosis or read code provides an important indication of the scale of local need.

A key theme emerging from the information provided is that ME/CFS care crosses organisational and professional boundaries. Continued collaboration between commissioners, primary care, acute and community providers, mental health services, adult social care, the specialist ME/CFS service and people with lived experience will therefore be important in ensuring that Kirklees residents receive accessible, coordinated and person-centred care.