

# Myalgic Encephalomyelitis and Chronic Fatigue Syndrome (ME and CFS) topic paper

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Suffolk County Council Public Health & Communities  
Knowledge, Intelligence and Evidence team  
[knowledgeandintelligence@suffolk.gov.uk](mailto:knowledgeandintelligence@suffolk.gov.uk)

## Background and request

This topic paper has been produced to examine Myalgic Encephalomyelitis and Chronic Fatigue Syndrome (ME and CFS). The report covers the Suffolk & North East Essex (SNEE) geography. This is a different geographical coverage from Suffolk County Council (SCC), and includes Colchester and Tendring as part of the Integrated Care System (ICS) footprint. Where possible data has been broken down by lower tier local authority (LTLA). Note: East Suffolk LTLA includes the Lowestoft and Waveney area, which is in the Norfolk and Waveney ICS.

## Type of report

This report is a topic paper in the Suffolk Joint Strategic Needs Assessment, rather than a full health needs assessment. A health needs assessment is a systematic approach to understanding the needs of a population that can be used as part of the commissioning process to ensure that the most effective support is provided for those in greatest need. A topic paper, however, is a one-off analysis of specific data on a given subject, usually in response to a specific request for information. It should be utilised as an overview of the topic, rather than a comprehensive examination of the health needs of a population.

## Summary of report

- Myalgic Encephalomyelitis and Chronic Fatigue Syndrome (ME and CFS) are chronic and potentially debilitating conditions associated with long-term fatigue and pain that are generally difficult to diagnose as they lack specific diagnostic tests and are based on certain sets of symptoms.
- In Suffolk and North East Essex, hospital admission rates for ME and CFS between 2018/19 and 2021/22 were statistically significantly higher in Babergh, East Suffolk, Ipswich and Mid Suffolk LTLAs compared to the East of England regional rate.
- Data from NHS Hospital Episode Statistics showed some individuals having high numbers of repeat admissions for ME and CFS across these Suffolk LTLAs, although in East Suffolk in particular, admission rates were very high across all age groups.

## National data and prevalence estimates

National data on conditions such as ME and CFS are generally quite poor. As the causes of these conditions are often unknown, with diagnosis only confirmed by the absence of certain measurable biological markers in the individual and generally limited understanding of conditions by clinicians <sup>1</sup>, there are concerns that these conditions are under-diagnosed <sup>2</sup>. Although work is ongoing to improve recognition, understanding and diagnosis, it is recognised that people with these conditions often experience prejudice and disbelief regarding their symptoms <sup>3</sup>.

## Myalgic Encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS)

There is no universal definition or single diagnostic test for ME and CFS, though the diagnostic criteria include: debilitating fatigue which is worsened by activity, sleep disturbance and/or unrefreshing sleep and cognitive difficulties, where other diagnoses have been ruled out <sup>3</sup>. The severity of these symptoms can vary over time, but in the most severe cases, it can be debilitating to the point where the individual cannot walk or get out of bed.

Prevalence estimates based on research in three regions of England (including East Anglia) identified a minimum prevalence rate of ~0.2%, although the study noted that the number of people reporting chronic fatigue but not meeting the specific criteria for ME and CFS is higher still <sup>2</sup>. Chronic fatigue

diagnoses were much higher in women (70% of diagnoses) and generally in those of middle age (median age 49.3 years; interquartile range 40.7-56.1), although only those aged 18-64 were considered in this study, which may skew data <sup>2</sup>.

Incidence estimates of recorded cases of ME and CFS are approximately 15 cases per 100,000 population per year, which are generally consistent across studies in the UK in the 21<sup>st</sup> century <sup>2,4</sup>.

## Local SNEE data (Hospital Episode Statistics)

Data were obtained from the NHS Hospital Episode Statistics (HES) admitted patient care dataset (2018/19 to 2021/22) to examine the numbers and rates of admissions of SNEE residents to hospital with the following ICD-10 codes at any position in their concatenated diagnoses strings (not just primary diagnosis):

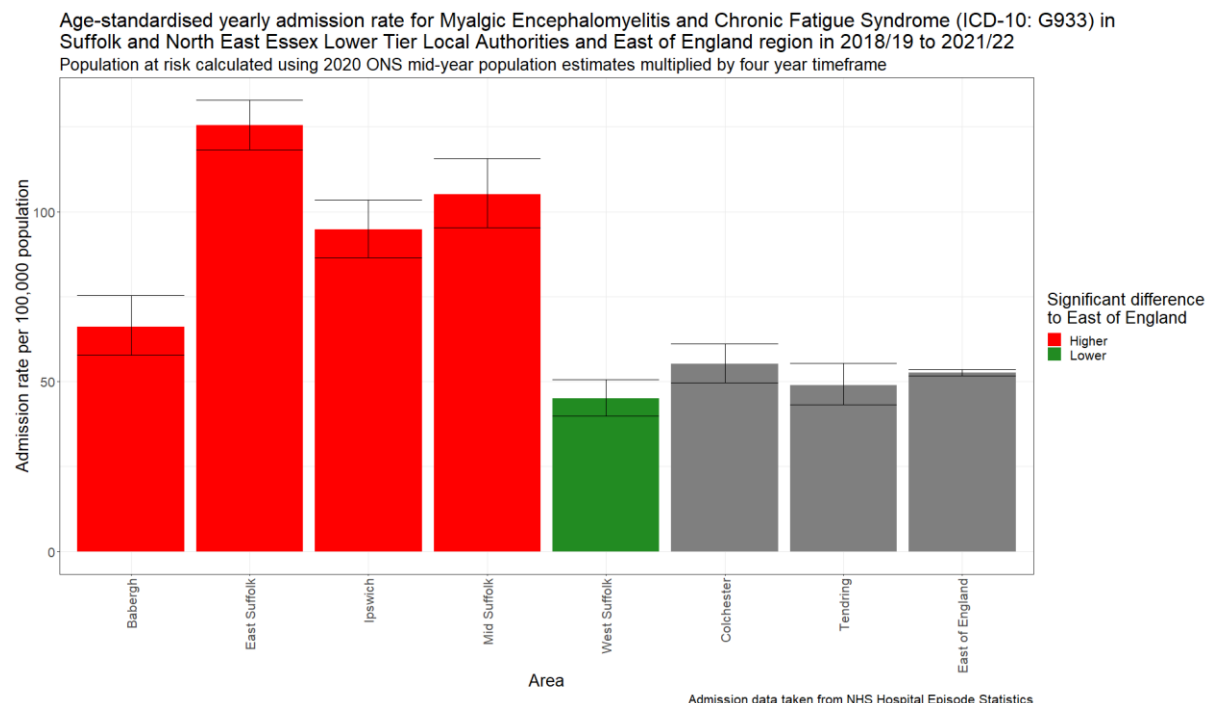
- G933 – Benign myalgic encephalomyelitis (Chronic Fatigue Syndrome)

Data to calculate rates have been taken from the ONS mid-year population estimates (MYE) for 2020 (with these denominators used across all years). Population at risk was calculated using the 2020 MYE multiplied by four to account for the four years of HES data.

For the following analysis, admission rates have been calculated as the number of admissions where the appropriate ICD-10 code appears in the diagnosis codes. This means that individual people can appear multiple times if they have had multiple admissions.

This analysis therefore indicates demand on the system as a result of these conditions, rather than the prevalence across the population.

Figure 1: Age-standardised yearly admission rates for SNEE LAs compared to East of England region

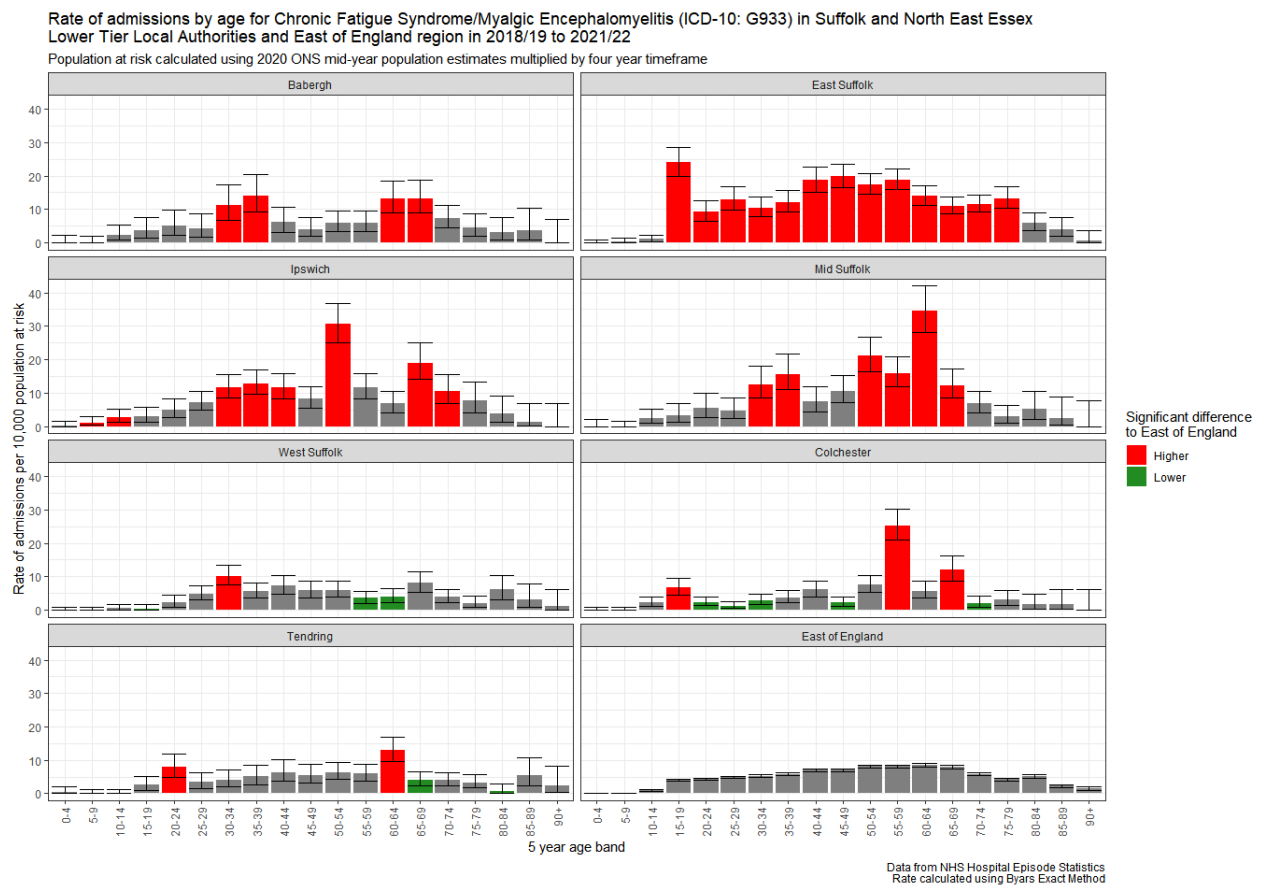


ME and CFS had higher yearly admissions in four Suffolk LTLAs (Babergh, East Suffolk, Ipswich and Mid Suffolk) compared to the East of England (Figure 1). Given that most people living in each of these LTLAs would likely be admitted to Ipswich Hospital, differences in coding of admissions could impact this, however this would require some further investigation in the acute trust. The

significantly higher rates of admissions for East Suffolk in particular appear to be driven by admissions across the age range, with many of these being repeat admissions for certain individuals across various age, indicating that these individuals frequently require acute hospital care (Figure 2).

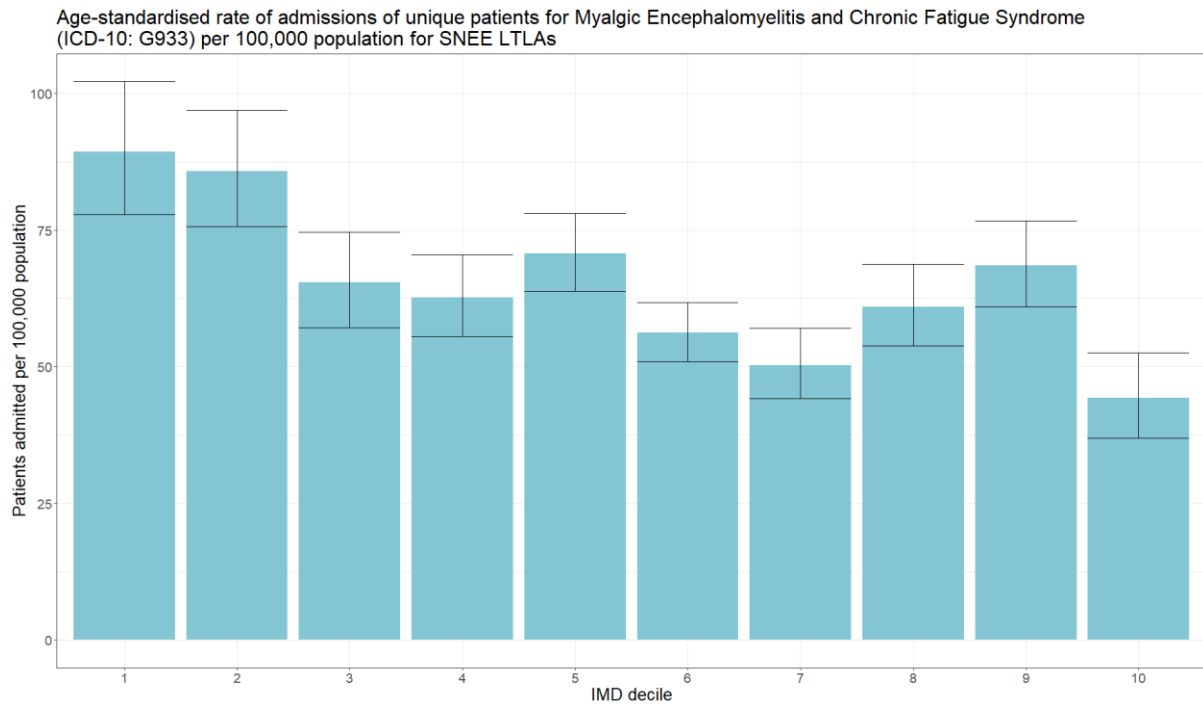
Following national trends <sup>2</sup>, the vast majority of ME and CFS admissions in SNEE LTLAs and the East of England more generally have been in women (64.9% - 83.6%) and generally higher rates in those of middle-age, although admissions do continue at only slightly lower rates into elderly age groups, particularly in East Suffolk and Ipswich (Figure 2).

Figure 2: Rates of ME and CFS admissions by 5-year age-band for SNEE LTLAs and East of England region between 2018/19 and 2021/22



Incidence for ME and CFS has been shown to be statistically significantly higher in people living in more deprived areas <sup>4</sup>. In the SNEE admission data, there is a clear slope index of inequality for deprivation in admissions for these diagnosis codes, with people living in the most deprived areas of Suffolk and North East Essex having statistically significantly higher age-standardised rates of admissions of unique patients for the combination of these conditions (Figure 3).

Figure 3: Age-standardised admission rates per 100,000 population for ME and CFS by Index of Multiple Deprivation decile for Suffolk and North East Essex



## References

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