Myalgic Encephalomyelitis and Chronic Fatigue Syndrome (ME & CFS)

Suffolk / Suffolk and North East Essex

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Background

This paper explores Myalgic Encephalomyelitis and Chronic Fatigue Syndrome (ME and CFS) within the Suffolk & North East Essex (SNEE) area. This area differs from that covered by Suffolk County Council (SCC), also including Colchester and Tendring within the Integrated Care System (ICS) footprint. Where available, data is presented by lower tier local authority (LTLA). It is important to note that the East Suffolk LTLA includes the Lowestoft and Waveney area, which falls under the Norfolk and Waveney ICS.

Type of report

This report serves as a profile paper within the Suffolk Joint Strategic Needs Assessment (JSNA), rather than a comprehensive health needs assessment. A health needs assessment systematically evaluates the needs of a population to inform the commissioning process, ensuring the most effective support for those in greatest need. In contrast, a profile is an analysis of specific data on a particular subject, typically produced in response to a specific information request. It provides an overview of a topic rather than a detailed examination of the population's health needs.

Summary of report

- Myalgic encephalomyelitis, also called chronic fatigue syndrome or ME/CFS, is a long-term condition that can affect different parts of the body. The most common symptom is extreme tiredness. The cause of ME/CFS is unknown[1]
- Hospital admission rates for ME and CFS in Suffolk and North East Essex between 2020/21 and 2023/24 were higher in four Suffolk LTLAs (Babergh, East Suffolk, Ipswich and Mid Suffolk) and one North East Essex LTLA (Tendring), compared to the East of England rate
- NHS Hospital Episode Statistics data revealed that East Suffolk had particularly high admission rates for ME and CFS across all age groups, with many repeat admissions for certain individuals across various age groups, indicating these individuals frequently require acute hospital care

National data and prevalence estimates

The reporting on the number of people living with ME/CFS in the UK is poor. Estimates on prevalence are based on epidemiological research along with clinician's opinions, researchers and people who have the condition[2]. There is currently no cure for ME/CFS, and most treatments help to manage the condition and relieve symptoms involving energy management, cognitive behavioural therapy (CBT) and medicine to control symptoms such as pain and sleeping problems. People with ME/CFS will need to adapt their daily routine and pattern of activities on a long-term basis. There may be periods when and individual's symptoms get better or worse.

Extreme tiredness and other physical symptoms can make it hard to carry out everyday activities for those living with ME/CFS, which can also affect mental and emotional health and have a negative effect on self-esteem.

A report to the Chief Medical Officer in 2002 estimated 0.2-0.4% of the population could have ME/CFS[3]. In May 2024, the ME Association published an article exploring prevalence updates[4]. Whilst this article noted more recent research estimated the prevalence of people with ME/CFS in the UK may be around 390,000 (0.6%)[5], the article had not been peer reviewed at the time of this profile's update and thus findings should be interpreted with caution. The ME Association also assert that there has been a rise in the number of people developing post-Covid or Long Covid ME/CFS during the past 4 years (people whose symptoms match the criteria for ME/CFS). However, the prevalence data remains very speculative. Many people with ME/CFS remain undiagnosed or could have been misdiagnosed.

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

There is no specific test for ME/CFS, so it is diagnosed based on symptoms and ruling out other conditions that could be causing symptoms. The 4 main symptoms of ME/CFS are:

- feeling extremely tired all the time (fatigue), which can make daily activities like taking a shower, or going to work or school, difficult
- sleep problems, including insomnia, sleeping too much, feeling like you have not slept properly and feeling exhausted or stiff when you wake up
- problems with thinking, concentration and memory (brain fog)
- symptoms getting worse after physical or mental activity, and possibly taking weeks to get better (also called post-exertional malaise, or PEM)

Some people with ME/CFS may also have pain in different parts of the body or flu-like symptoms, such as high temperature, headache and aching joints or muscles[1].

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. 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[6].

Local SNEE data (Hospital Episode Statistics)

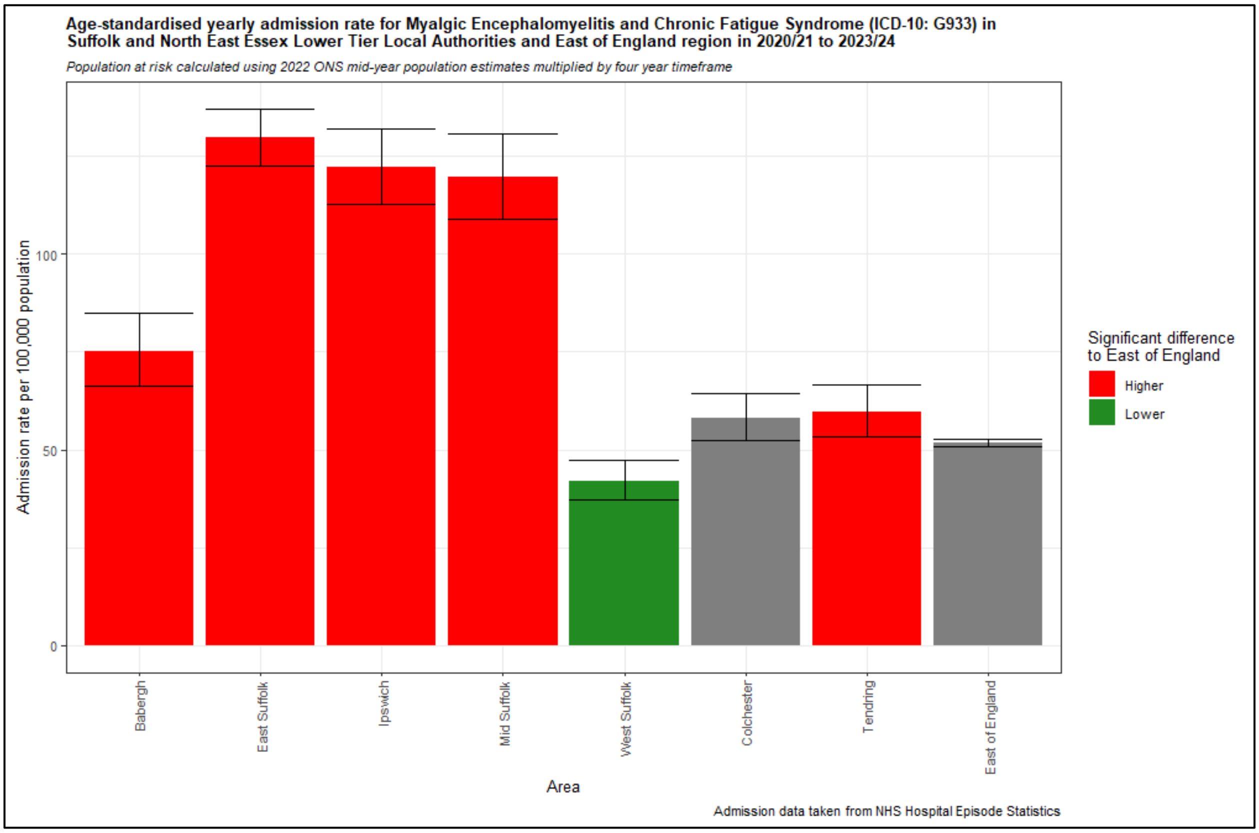
To investigate the number and rate of hospital admissions for SNEE residents, data was collected from the NHS Hospital Episode Statistics (HES) admitted patient care dataset from 2020/21 to 2023/24. The analysis focused on admissions where the following ICD-10 code appeared in any position within the diagnosis string (not just the primary diagnosis):

- G933 – Benign myalgic encephalomyelitis (Chronic Fatigue Syndrome)

The rates were calculated using the ONS mid-year population estimates (MYE) for 2022 as the denominator for all years. The population at risk was determined by multiplying the 2022 MYE by four, corresponding to the four years of HES data.

Admission rates were based on the number of admissions where the relevant ICD-10 code was recorded in the diagnosis codes, meaning individuals could be counted multiple times if they were admitted multiple times. This analysis reflects the demand on the healthcare system due to these conditions, rather than their prevalence in the population.

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

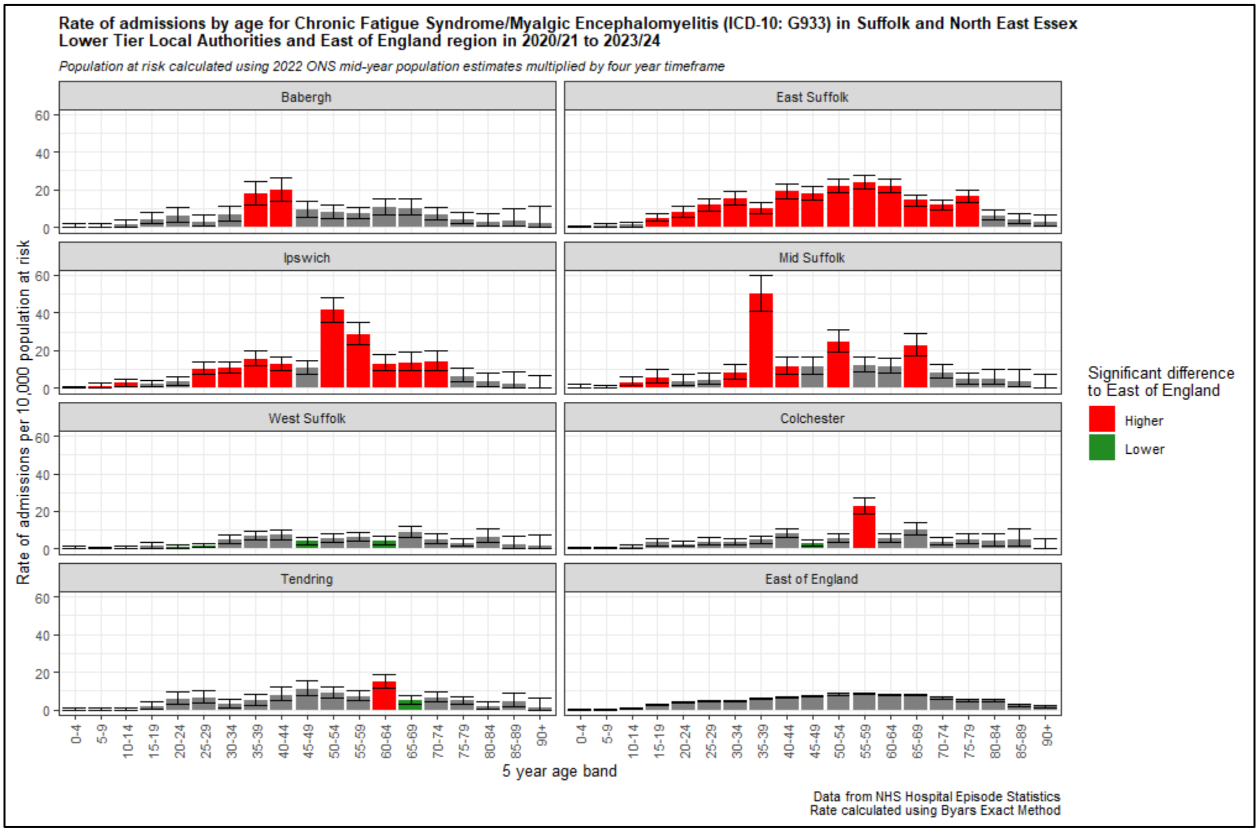


ME and CFS had higher yearly admissions in four Suffolk LTLAs (Babergh, East Suffolk, Ipswich and Mid Suffolk) and one North East Essex LTLA (Tendring), compared to the East of England. While most people living in each of these LTLAs would be likely to be admitted to Ipswich Hospital, differences in coding of admissions could impact this, but would require further investigation.

There are also statistically significantly higher rates of repeat admissions for ME/CFS across Babergh, East Suffolk, Ipswich and Mid Suffolk compared to the East of England average. West Suffolk conversely has a statistically significantly lower repeat admission rate for ME/CFS compared to the East of England average.

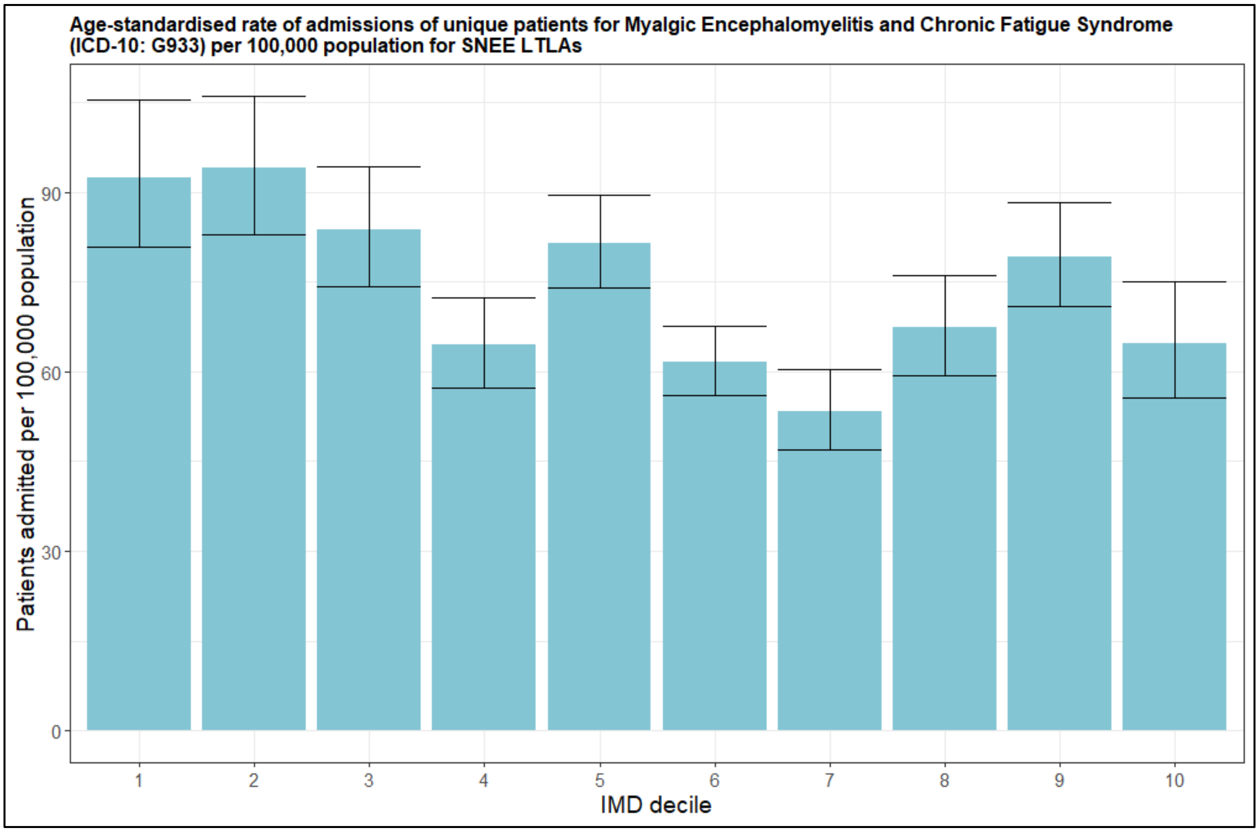
Following national trends[6], most of ME and CFS admissions have generally higher rates in those of middle-age, although admissions do continue at only slightly lower rates into elderly age groups, particularly in East Suffolk and Ipswich.

Figure 2. Rates of ME and CFS admissions by 5-year age-band for SNEE LTLAs and East of England region between 2020/21 and 2023/24



Incidence for ME and CFS has been shown to be statistically significantly higher in people living in more deprived areas[7]. In the SNEE admission data, there is a 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. 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

1. NHS. Myalgic encephalomyelitis or chronic fatigue syndrome (ME/CFS) - NHS. Published May 28, 2024. Accessed July 2, 2024. https://www.nhs.uk/conditions/chronic-fatigue-syndrome-cfs/

2. The ME Association. How many people have ME/CFS in the UK? Published May 2024. Accessed July 2, 2024. https://meassociation.org.uk/2024/05/how-many-people-have-me-cfs-in-the-uk/

3. CFS/ME Working Group. *Report to the Chief Medical Officer of an Independent Working Group*.; 2002. Accessed July 2, 2024. https://meassociation.org.uk/wp-content/uploads/CMO-REPORT-2002.pdf

4. Shepherd C. How many people have ME/CFS in the UK? https://meassociation.org.uk/2024/05/how-many-people-have-me-cfs-in-the-uk/.

5. Samms GL, Ponting CP. Unequal access to diagnosis of myalgic encephalomyelitis in England. *medRxiv*. Published online January 1, 2024:2024.01.31.24302070. doi:10.1101/2024.01.31.24302070

6. Nacul LC, Lacerda EM, Pheby D, et al. Prevalence of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) in three regions of England: A repeated cross-sectional study in primary care. *BMC Med*. 2011;9(1):1-12. doi:10.1186/1741-7015-9-91/TABLES/7

7. Collin SM, Bakken IJ, Nazareth I, Crawley E, White PD. Trends in the incidence of chronic fatigue syndrome and fibromyalgia in the UK, 2001-2013: a Clinical Practice Research Datalink study. *J R Soc Med*. 2017;110(6):231-244. doi:10.1177/0141076817702530