New prevalence data for ME/CFS from the US: what does it mean for the UK and Scotland?

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It is important to acknowledge that all prevalence estimates for ME are of limited accuracy, due to gaps in understanding of the disease, both scientifically and among healthcare professionals. However, it is necessary to decide on a figure that can be used. The Center for Disease Control (CDC) has recently published results of a survey showing that 1.3% of adults in the US have ME/CFS. This survey provides data following the onset of the COVID-19 pandemic; importantly, this will include any increase in the prevalence of ME due to the pandemic, as well as many with Long Covid due to the overlaps between the two conditions.

The finding of 1.3% is significantly higher than the 0.4% estimate derived from UK Biobank data before the COVID-19 pandemic and used in the NICE guideline on ME/CFS. The US survey did not include children, but combining the US survey data with a recent extract of Scottish GP data gives a prevalence estimate of 0.06% in children. **Applying these new estimates to UK populations gives estimates of 700,000 people with ME in the UK and 58,000 in Scotland.**

The US survey

The CDC's National Centre for Health Statistics recently published estimates of ME prevalence among the US population, broken down by sex, age, and other characteristics, using data from the 2021-2022 National Health Interview Survey (NHIS)[1]. This is an important study because its size and sampling methods are designed specifically to produce nationally representative estimates of morbidities, i.e. illnesses, in the US population.

The prevalence estimates for ME were based on data from 57,133 adults aged 18 and over. A person was considered to have ME/CFS if they responded yes to the following two survey questions: 'Have you ever been told by a doctor or other health professional that you had Chronic Fatigue Syndrome (CFS) or Myalgic Encephalomyelitis (ME)?' and 'Do you still have Chronic Fatigue Syndrome (CFS) or ME?'

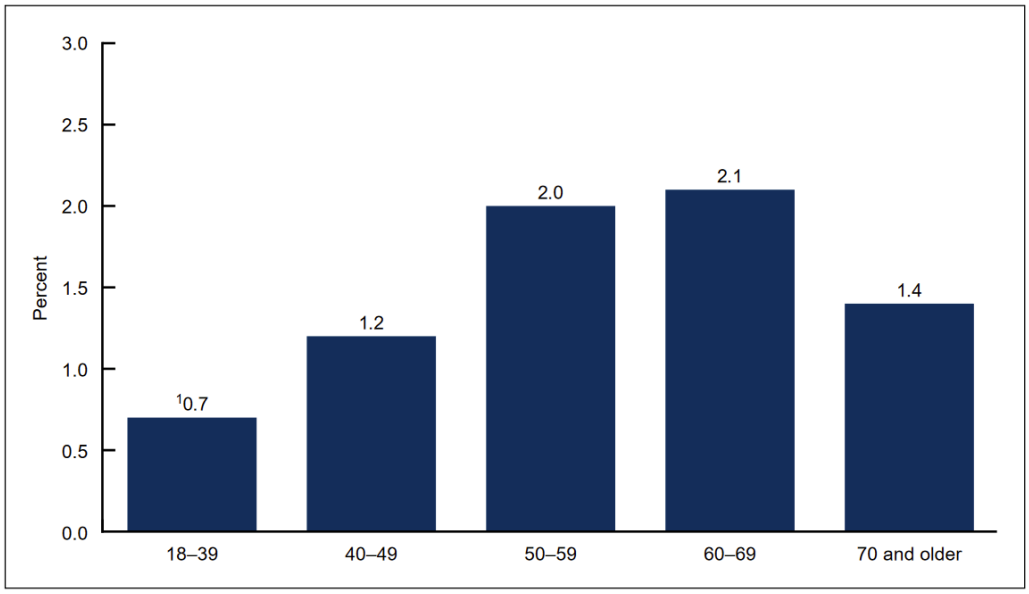
[1] Vahratian A, Lin JS, Bertolli J, Unger ER. Myalgic encephalomyelitis/chronic fatigue syndrome in adults: United States, 2021–2022. NCHS Data Brief, no 488. Hyattsville, MD. National Center for Health Statistics. 2023. DOI: https://dx.doi.org/10.15620/cdc:134504.

Key findings from the US survey

During 2021-2022, 1.3% of adults in the US had ME/CFS. Women (1.7%) were more likely than men (0.9%) to have ME/CFS.

The percentage of adults who had ME/CFS increased with age, from 0.7% among those aged 18-39 to 2.0% and 2.1% among those aged 50-59 and 60-69 respectively, and then declined to 1.4% among those aged 70 and older (see below).

Figure 2. Percentage of adults who had Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, by age: United States, 2021–2022



What does this mean for the UK/Scottish population?

Table 1 shows the CDC rates applied to the UK adult population.

	Age	UK	Scotland
Population	18+	53,188,204	4,454,919
ME prevalence (1.3% of adults)	18+	691,447	57,914

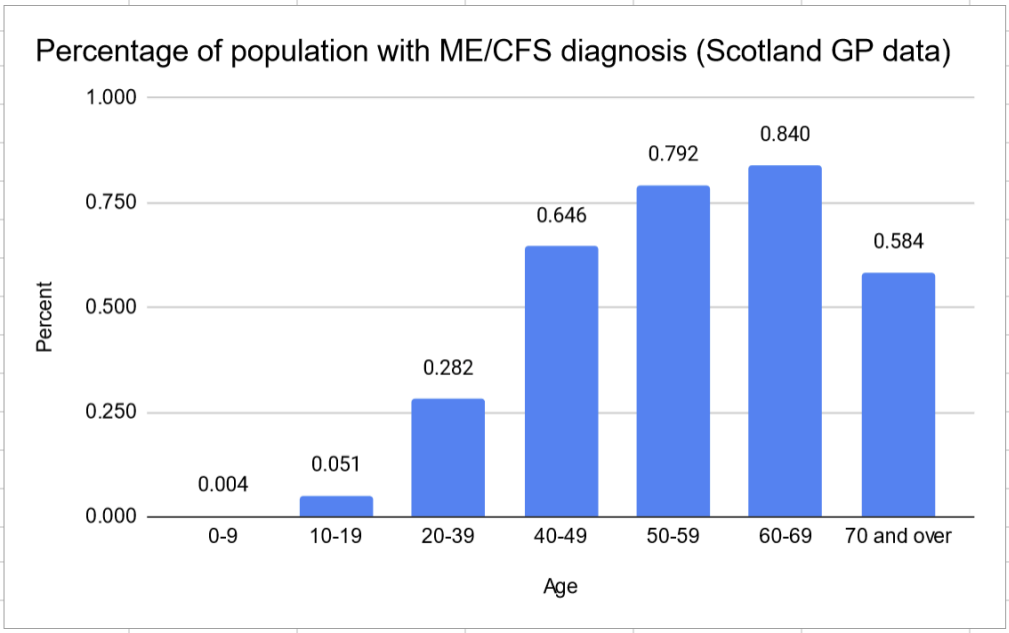
Table 1: CDC rates applied to the UK and Scottish populations (mid-2021 population estimates[2])

2 https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/populationestimatesforukenglandandwalesscotlandandnorthernireland

Prevalence in children

Unfortunately the CDC analysis does not include prevalence in children, but the breakdown by age gives us a clue as it shows much lower rates in the younger adult age groups. This is not surprising as fewer young adults are likely to be 'long haulers'. We know it is not uncommon for people with ME to stay ill for years or even decades, so older age groups will include those who first became ill 10, 20 or 30 years previously as well as those more recently diagnosed.

Another indication of the prevalence in children is the Scottish GP data in the Neurological Conditions report published by the Scottish Government in 2022[3]. This report includes counts of patients registered with a GP who had ever had a recorded diagnosis of ME/CFS or Post Viral Fatigue Syndrome (PVFS) as of April 2022, by sex and 5-year age band. We have no confidence that GPs have been accurately diagnosing and recording ME, and the data is acknowledged to be experimental and incomplete including only 73% of patients registered with a GP (some GP practices did not submit any data and others were excluded due to data quality issues). We do not know how many of the 73% were in each age band, but the age profile of the wider Scottish population allows us to estimate rates by age group for comparison with the NHIS data. The resulting age profile is very similar to the NHIS data for ages 20 and older:



3 https://www.gov.scot/publications/neurological-conditions-estimating-prevalence-scotland-selected-conditions-using-gp-hospital-admissions-datasets/documents/

Comparison between the two sets of data shows consistently lower recorded diagnoses in the Scottish data than the NHIS report. This suggests that Scottish GPs are failing to diagnose people with ME across all adult age groups.

Overall, the Scottish data shows a prevalence rate for adults aged 20 and over of 0.57%. The NHIS prevalence rate of 1.3% is 2.3 times greater than this. Assuming a similar proportion of children are missing from the Scottish data, we can multiply the Scottish prevalence estimates by 2.3 to account for them.

To gain a prevalence estimate for children aged 0-17, we need to consider both age groups 0-9 and 10-19.

For young people aged 10-19, adjusting the Scottish data by a factor of 2.3 gives a prevalence of 0.12% (1 in 850). For the 0-9 age group, the Scottish data recorded only 15 cases. Adjusting by a factor of 2.3 gives a prevalence of less than 0.01% (1 in 12500).

Weighting these two age groups to exclude the 18 and 19 year olds gives a prevalence in children aged 0-17 of 0.057%.

Table 2 shows estimates for ME prevalence in the UK and Scotland using these new prevalence estimates for adults and children. Overall it suggests 700,000 people in the UK and 58,000 in Scotland have ME.

	Age	UK	Scotland
Population	0-17	13,838,088	1,024,981
	18+	53,188,204	4,454,919
	All ages	67,026,292	5,479,900
ME prevalence (1.3% of adults, ~0.06% of children)	0-17	7,823	579
	18+	691,447	57,914
	All ages	**699,270**	**58,493**

Table 2: Adult and child rates applied to the UK and Scottish populations (mid-2021 population estimates)

Strengths and limitations of this analysis

All prevalence estimates for ME are of limited accuracy due to gaps in our understanding of the disease, and more research is urgently needed to address these. However the US survey provides useful extra data especially due to its timing in relation to the COVID-19 pandemic; any increase in the prevalence of ME due to the pandemic will be reflected in the figures. The estimates will include many with Long Covid due to the overlaps between the two conditions.

The estimate from the UK Biobank used in the NICE guideline, published in 2021, is two years older than the US survey. This difference in timing is likely to explain some of the discrepancy between the prevalence estimates due to the impact of the COVID-19 pandemic.

One major factor affecting the quality of prevalence estimates for ME is uncertainty around the diagnosis of the disease. As there is no unique biomarker for ME, diagnosis relies on the observation of a constellation of symptoms. The exact criteria continue to be debated, with various different criteria being adopted by clinicians and researchers at different times and for different purposes. As ME becomes better understood, diagnosis and prevalence estimates will increase in accuracy.

Another factor affecting prevalence estimates is the lack of confidence in many GPs and paediatricians in diagnosing ME, which studies suggest has led to many with ME being undiagnosed[4]. We expect the prevalence estimates for both adults and children to change as GPs and paediatricians become more confident in diagnosing ME.

The figures may include some people who have been diagnosed with medically unexplained fatigue, rather than ME/CFS. Again, until ME is better understood, some confusion between these diagnoses is likely to continue.

The estimate of ME prevalence in UK adults based on the NHIS data assumes a similar demographic among UK and US populations. Given that the NHIS identified differences in prevalence between different demographic and geographic characteristics, there are likely to be further differences between UK and US populations which we have not been able to account for.

The estimate of ME prevalence in children relies heavily on the assumption that ME diagnoses are missing from a similar proportion of children to adults. However diagnosis in children follows a different process to adults so this may well not be correct: notably 1) children are generally assessed and diagnosed by a paediatrician not a GP, and 2) anecdotal evidence suggests that paediatricians are reluctant to diagnose ME.

This data, although experimental, shows the importance of using age-disaggregated data to estimate the prevalence of ME.

[4] Institute of Medicine. Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness. Washington (DC): National Academies Press (US); 2015

Appendix: Data tables

Table 3: Patients with diagnosis of ME/CFS/PVFS in Scottish GP data extract[5]

Age	Females	Males	Total
0-9	7	8	15
10-19	131	104	235
20-39	2,227	939	3,166
40-49	2,425	943	3,368
50-59	3,448	1,427	4,875
60-69	2,930	1,418	4,348
70+	2,328	1,161	3,489
0-19	138	112	250
20+	13,358	5,888	19,246
All ages	13,496	6,000	19,496

Table 4: Patients in Scottish GP data extract by age and sex assuming age distribution is the same as Scottish population (mid-2021 population estimates)

Age	Females	Males	Total
0-9	207470	219539	427009
10-19	223799	233559	457359
20-39	563074	561282	1124356
40-49	266597	255029	521626
50-59	319016	296192	615208
60-69	268130	249764	517895
70+	334792	262716	597507
0-19	431269	453098	884368
20+	1751609	1624983	3376592
All ages	2182878	2078082	4260960

[5] https://www.gov.scot/publications/neurological-conditions-estimating-prevalence-scotland-selected-conditions-using-gp-hospital-admissions-datasets/documents/

Table 5. Prevalence of ME in Scottish GP data extract (%)

Age	Females	Males	Total
0-9	0.003	0.004	0.004
10-19	0.059	0.045	0.051
20-39	0.396	0.167	0.282
40-49	0.910	0.370	0.646
50-59	1.081	0.482	0.792
60-69	1.093	0.568	0.840
70+	0.695	0.442	0.584
0-19	0.032	0.025	0.028
20+	0.763	0.362	0.570
All ages	0.618	0.289	0.458