

Effective October 1, 2022, the ICD-10-CM, the disease tracking system used in the US, has been updated to provide a unique code, G93.32, for “myalgic encephalomyelitis,” “chronic fatigue syndrome,” and “myalgic encephalomyelitis/chronic fatigue syndrome” as a result of a request by 7 ME/CFS organizations. (1,2) This new code will ensure that the US is able to track diagnosed cases of ME/CFS in newly created electronic health records. Previously, the US had coded ME/CFS the same as the symptom of unspecified chronic fatigue. This made it impossible to separately track ME/CFS cases. This update also specifies that “post COVID-19 condition, unspecified” (U09.9) should be coded when present. This enables the tracking of a COVID association.

On its own, this coding change will not rectify the known problem of people with ME/CFS being misdiagnosed or not diagnosed at all. To ensure tracking of all cases, it’s essential that all people with ME/CFS are properly diagnosed. This is particularly important now, given the evidence of ME/CFS developing after COVID.

This coding change will also not fix historical electronic health records (EHR) created between October 2015, when ICD-10-CM was first implemented, and October 2022. The ME/CFS cases in those records will still be generally coded as the symptom of non-specific chronic fatigue.

What can providers do?

Electronic medical records (EMR) systems should have incorporated the revised version of the ICD-10-CM as of October 1, 2022. Once this has happened, the EMR system will automatically assign the code of G93.32 when the provider types in any of the terms “chronic fatigue syndrome,” “myalgic encephalomyelitis,” and “myalgic encephalomyelitis/chronic fatigue syndrome.” Nothing more is necessary.

Instead of the name, some providers may have been typing in R53.82, the old code for CFS, or G93.3, the old code for ME. These providers will just need to type in the new code, G93.32.

Of course, the first step to accurately tracking ME/CFS is accurately diagnosing it. Providers can help by including ME/CFS in their differential diagnosis of patients presenting with prolonged functional impairment, exertional intolerance, fatigue, cognitive and orthostatic issues and other symptoms, including those with prolonged illness post COVID. Updated clinical guidance on how to do this is available from Bateman et al (3) and CDC (4).

What can patients do to ensure their records are properly coded?

Check with your provider(s) to ensure they are aware of and using the new ME/CFS code. And if you think you have ME/CFS but have not been diagnosed, ask your provider to evaluate you using updated clinical guidance.

What do researchers need to consider?

Researchers using electronic health records to study ME/CFS or Long COVID need to consider both the coding and the underdiagnosis problems in interpreting their findings about ME/CFS. The absence of ME/CFS in these records could simply be the manifestation of either of these problems and the findings will not accurately reflect the nature of ME/CFS or its prevalence post COVID.

References:

1. Summary of ME/CFS ICD-10-CM code changes: https://bit.ly/MECFS_ICDCode
2. Background of request by 7 ME/CFS organizations: https://bit.ly/MECFS_ICD_Background
3. Bateman et al. Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Essentials of Diagnosis and Management. Mayo Clinic Proceedings. Nov 2021. [https://www.mayoclinicproceedings.org/article/S0025-6196\(21\)00513-9/](https://www.mayoclinicproceedings.org/article/S0025-6196(21)00513-9/) Additional information on diagnosis and management can be found on the ME/CFS Clinician Coalition website <https://mecfsciniciancoalition.org/>
4. Centers for Disease Control and Prevention ME/CFS website <https://www.cdc.gov/me-cfs/>