



October 12, 2026

Jeffrey M. Zirger  
Information Collection Review Office  
Centers for Disease Control and Prevention  
1600 Clifton Road NE, MS H21-8  
Atlanta, Georgia 30329

**Re: Docket No. CDC-2026-1387, National Health Interview Survey (OMB Control No. 0920-0214), Proposed Data Collection Submitted for Public Comment and Recommendations**

Dear Mr. Zirger:

Solve M.E. appreciates the opportunity to comment on the proposed revision of the National Health Interview Survey (NHIS) and the planned 2028 redesign. Solve M.E. is a national nonprofit serving people living with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), Long COVID and other post-infection chronic illnesses. We value the NHIS as "the single most important source of statistics to track progress toward HHS health objectives." We understand NCHS's need to shorten the questionnaire and contain costs, and we support the goal of a self-administered design that more people can complete.

NCHS has asked for comments on "the importance of specific content additions or removals" and on "the potential effect of these changes on data quality, usability, and trend measurement." Our comment addresses both. It also identifies, as NCHS encourages, the minimum question sets needed.

**1. The NHIS is the nation's source of ME/CFS and Long COVID prevalence data.**

Section 306 of the Public Health Service Act directs NCHS to collect statistics on "the extent and nature of illness and disability" in the United States. For ME/CFS and Long COVID, the NHIS fulfills that mandate.

- **ME/CFS.** CDC's National Center for Emerging and Zoonotic Infectious Diseases (NCEZID) has sponsored chronic fatigue syndrome content in 2021–2024 and 2026. The notice states this content "will remain in 2027." These data produced CDC's national estimate that 1.3% of U.S. adults had ME/CFS in 2021–2022. The prevalence was higher among women (1.7%) than men (0.9%) and among adults below the federal poverty level (2.0%). A 2026 analysis of 2021–2023 NHIS data found that adults who reported no longer having ME/CFS remained significantly impaired compared with adults never diagnosed.
- **Long COVID.** The NHIS measured Long COVID from 2022 through 2025, including sponsored content in 2023–2025. In 2022, 6.9% of adults had ever had Long COVID and 3.4% had it at the time of interview. Using NHIS data from 2022 to 2024, researchers found that the share of affected adults who had recovered rose from 51.2% to 59.7%. They also found that 8.3% of U.S. adults reported ever having Long COVID in 2024.

**2. The draft 2028 adult questionnaire contains no measure of ME/CFS, Long COVID or fatigue.**

The draft chronic conditions section asks about a range of conditions, including "arthritis, rheumatoid arthritis, gout, lupus, or fibromyalgia" (item B10b). It does not include ME/CFS or Long COVID. The draft also contains no questions about fatigue, tiredness or energy. Fatigue content is rotating off the adult core in 2027, and the redesign ends the rotating schedule under which such content periodically returned. As drafted, 2027 would be the last year of the ME/CFS series, and the Long COVID series, last fielded in 2025, would not resume.

**3. The remaining disability measures will not identify most people with these illnesses.**

We support keeping the Washington Group Short Set. However, its six items ask about seeing, hearing, walking, cognition, self-care and communication. ME/CFS and Long COVID often limit a person mainly through reduced

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energy, worsening of symptoms after exertion (post-exertional malaise) and symptoms that fluctuate from day to day. None of the six items measures these. Without a condition-specific question or a fatigue measure, many adults whose lives are substantially limited by these illnesses would not be identifiable in the 2028 data.

#### **4. Removing these measures would break established trend lines.**

NCHS has built a multi-year ME/CFS series (2021–2024, 2026–2027) and a Long COVID series (2022–2025). These series show how prevalence, recovery and disparities change over time. Ending them in 2028 would leave no way to know whether these illnesses are growing, shrinking or shifting across populations. That information is essential to research, clinical guidance and public health planning.

#### **5. Recommendations and minimum question sets**

The notice states that the redesign "allows for the addition of content on topics of current and emerging interest" and that "space will still be reserved for federal agencies to fund sponsored content." We ask NCHS to use that flexibility as follows.

1. **Add ME/CFS to the chronic conditions section.** The minimum set is the two items NCHS has already fielded: "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?" These could be added to the existing B10 list at minimal burden.
2. **Retain a Long COVID measure.** The minimum set is the established screening item, "Did you have any symptoms lasting 3 months or longer that you did not have prior to having COVID-19?", plus the follow-up on current symptoms that NCHS uses to estimate current Long COVID.
3. **Retain at least one fatigue measure,** using an item NCHS has previously fielded, so that energy-limiting conditions are visible in the data.
4. **Retain the disability-related items proposed for removal,** consistent with NCHS's mandate to measure "the extent and nature of illness and disability."
5. **Make clear how sponsored content will continue,** including the existing NCEZID chronic fatigue syndrome content, so the series can continue into 2028.
6. **Publish a crosswalk of the 2027 items not carried into the 2028 draft,** and provide an opportunity for comment when the revised 2028 questionnaires go to OMB in 2027.

We also encourage NCHS to make the self-administered online and paper versions accessible to people with energy-limiting illnesses. This includes the ability to save progress and return later, and continued use of knowledgeable proxy respondents when an adult is unable to respond. These features would improve participation by some of the people most affected by these conditions.

Thank you for considering our comments. We would welcome the opportunity to share expertise from the ME/CFS and Long COVID community as NCHS finalizes the 2028 questionnaires.

Sincerely,

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