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I have had #ME/CFS for the last 19 years--my entire adult life!!!--and can no longer reliably walk bc of the disease. I am only 37yo and can rarely leave my home. I am further dependent on home care to have any semblance of a life. I am the #MillionsMissing.

This is the same extremely debilitating multisystem neuroinflammatory, metabolic disease that over half of long COVID patients actually have--but hardly ANY are getting diagnosed or getting anything resembling proper medical or social care.

I am therefore horrifically concerned about the continued spread of COVID and the huge burden of Long COVID. I fully support the recommendations on revisions to the Census Bureau Household Pulse Survey that were submitted by the Pandemic Patients organization.

First and foremost, please continue the Household Pulse Survey's questions about COVID and Long COVID. The need for this data has risen along with the number of Americans who experience prolonged after-effects of an acute infection with COVID. As Pandemic Patients noted, the value of the data greatly outweighs the cost of the survey.

Collect More Information on the Pandemic's Impact on Children

The questionnaire should collect data on children regarding COVID-19 infections or long COVID symptoms.

Collect Additional Information on COVID-19 Infections

Question "VAC8_C" asks respondents to describe how long ago they experienced a COVID-19 infection. Revision 3.9 of the Pulse Survey questionnaire amends this question to allow respondents to select multiple options to indicate multiple infections across different time periods. I support the agency's decision to expand the data collected by changing this question. And this question could be further modified for more detail. For example, respondents could be prompted to enter a number in each category instead of checking a box. Thus, a respondent could indicate they experienced multiple infections "more than four weeks ago, but within the last year." Alternatively, the question could group responses by year ("2019," "2020," "2021," "2022," "2023") to identify the number of infections they experienced in each calendar year.

Collect Additional Information on COVID-19 Antiviral Treatments Should be Collected

I support the detailed recommendations of the Pandemic Patients organization on this. Two additional points:

- * It would be useful to ask if people infected with COVID experienced a rebound even if they did NOT take antiviral medications.
- * Regarding people who had difficulty getting access to antivirals, it would be useful to ask if that was because the medication was unavailable at some pharmacies.

Collect Added Information on Long COVID

I support the detailed recommendations of Pandemic Patients for including follow-up questions to improve the depth of data collected by these questions.

I also support the Pandemic Patients' groups recommendations for collecting

- * info on financial access to COVID-19 tests
- * additional Info on mental health concerns of patients after COVID infection
- * info on access to health care
- * info on (un)employment, and whether employment is hindered by current acute COVID, Long COVID symptoms, need to care for someone with COVID or Long COVID, or concerns about lack of COVID protections in workplaces.

Thank you very much for including vital COVID and Long COVID concerns in this survey, and for your valuable efforts to expand on the questions that have been previously used.