## **Public Comments for ICR 202204-0607-004**

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## **Comments Received:**

Patient-Led Research Collaborative (PLRC) applauds the addition of Long COVID/PASC questions to the Household Pulse Survey. We recommend the following changes to the PASC questions to ensure they collect valuable and accurate data:

- PASC1 does not specify if the coronavirus symptoms that are being asked about were in the acute infection stage or later on. Because of that, we recommend that PASC2 and PASC3 be asked of all respondents, since there are reports of people developing Long COVID from an initially asymptomatic case of COVID, and respondents would likely assume PASC1 is asking about the acute infection stage.
- We recommend adding the following symptoms to the symptom list in PASC2 as we have found them to be prevalent among people with Long COVID but not as often identified as Long COVID in the public sphere: menstrual changes, changes to taste/smell, and inability to exercise.
- We recommend removing "Depression, anxiety, or mood changes" from the symptom list in PASC2 as respondents who only have that as newly onset may indicate "Yes," but if the goal is to use this question as a way to indicate Long COVID prevalence, the presence of this one psychiatric symptom would not suffice for a Long COVID case definition.

Additionally, the current employment questions do not capture changes to employment due to Long COVID. Our research found that of people with Long COVID are unable to work or have had to reduce their hours, and Brookings Institute found that Long COVID could account for at least 15% of unfilled jobs. Therefore, we recommend the following change to the EMP4 question:

Split "I am/was sick with coronavirus symptoms or caring for someone who was sick with coronavirus symptoms" into three options:

- "I had coronavirus, either without symptoms or with symptoms, for less than three months."
- "I have had symptoms from a confirmed or suspected coronavirus infection for longer than three months that impact my ability to work."
- "I am/was caring for someone who was sick with coronavirus (short or long-term) symptoms."

Change "I am/was sick (not coronavirus related) or disabled" to "I am/was sick or disabled (not coronavirus related)" as sickness and disability can both be coronavirus related.

Approximately 45% of people with Long COVID have been able to continue working but have had to reduce their hours. It is important to capture their experience. We recommend adding the following question to the EMP section:

If you are currently working for pay or profit but had to reduce your hours worked, by how much have you had to reduce your hours?

Less than 5 hours/week 5-10 hours/week 11-20 hours/week More than 20 hours/week

I have not reduced my hours worked

We recommend replicating EMP4 question but for reducing hours worked:

[If any hours were selected in questions above] What is your main reason for reducing your hours worked? Select only one answer. I reduced my hours because:

Include all EMP4 answers relevant to reducing hours, including selections added above.

Lastly, we recommend the following change to question ED4 to capture changes to people's ability to go to school:

- Add option "Had coronavirus symptoms for over three months that impacted ability to take classes"
- Change "Caring for someone with coronavirus" to "Caring for someone with coronavirus or long-term symptoms from coronavirus"