

**MAY 2022**

**PUBLIC COMMENT IN RESPONSE TO FEDERAL REGISTER:**

[Patient-Led Research Collaborative](#) (PLRC) is a group of Long COVID patient-researchers who conducted the [first](#) and [most comprehensive](#) research on Long COVID. To date, there has been a dearth of quality studies in the US that estimate the prevalence of Long COVID and its impact on people's employment.

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:

- 1) 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.
- 2) 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.
- 3) 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  $\frac{2}{3}$  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”

Thank you again for your addition of the PASC questions to this phase of the Household Pulse Survey.

### **SUGGESTED QUESTIONS FOR REFERENCE:**

**PASC1: (Universe: VAC8\_B = 1 tested positive for COVID-19 or believed had COVID-19)  
How would you describe your coronavirus symptoms when they were at their worst?**

- o I had no symptoms (1)
- o I had mild symptoms (2)
- o I had moderate symptoms(3)
- o I had severe symptoms (4)

**PASC2: (Universe: PASC1=2:4 reported having any symptoms) Did you have any symptoms lasting 3 months or longer that you did not have prior to having coronavirus or COVID-19?**

*Long term symptoms may include: Tiredness or fatigue, difficulty thinking, concentrating, forgetfulness, or memory problems (sometimes referred to as "brain fog", difficulty breathing or shortness of breath, Joint or muscle pain, Fast-beating or pounding heart (also known as heart palpitations), Chest pain, Dizziness on standing, Depression, anxiety, or mood changes.*

- Yes
- No

**PASC3: (Universe: PASC1=2:4 reported having any symptoms)**

**Do you have symptoms now?**

- Yes
- No

**EMP4 What is your main reason for not working for pay or profit? *Select only one answer.***

**I did not work because:**

- I did not want to be employed at this time
- I am/was sick with coronavirus symptoms or caring for someone who was sick with coronavirus symptoms
- I am/was caring for children not in school or daycare
- I am/was caring for an elderly person
- I was concerned about getting or spreading the coronavirus
- I am/was sick (not coronavirus related) or disabled
- I am retired
- I am/was laid off or furloughed due to coronavirus pandemic
- My employer closed temporarily due to the coronavirus pandemic
- My employer went out of business due to the coronavirus pandemic
- I do/did not have transportation to work
- Other reason, please specify \_\_\_\_\_

ED4 Why did household members' classes this term change? *Select all that apply.*

- Had coronavirus or concerns about getting coronavirus
  - Caring for someone with coronavirus
  - Caring for others whose care arrangements are disrupted (e.g., loss of day care or adult care programs)
  - Institution changed content or format of classes (e.g., from in-person to online)
  - Changes to financial aid
  - Changes to campus life
  - Uncertainty about how classes/program might change
  - Not able to pay for classes/educational expenses because of changes to income from the pandemic
  - Some other reason related to the pandemic, please specify
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