



May 30, 2023

Sheleen Dumas
Department PRA Clearance Officer
Office of the Chief Information Officer
U.S. Department of Commerce
Washington, D.C. 20230

Re: Agency Information Collection Activities; Submission to the Office of Management and Budget (OMB) for Review and Approval; Comment Request; Household Pulse Survey (OMB No. 0607-1013)

Sheleen Dumas,

Introduction

Thank you for the opportunity to comment on the upcoming revisions to the U.S. Census Bureau Household Pulse Survey (the "Pulse Survey"), proposed to be implemented in Phase 3.9 on or about May 31, 2023. I am writing to you on behalf of Pandemic Patients, which is a 501(c)(3) non-profit patient advocacy organization that works to relieve the harm caused by COVID-19 and Post-COVID Conditions. The U.S. Census Bureau has proposed several revisions to the Pulse Survey questionnaire for Phase 3.9. Some of these revisions are specific to COVID-19, including adding questions about the use of antivirals to treat COVID-19 and how households obtain COVID-19 tests. As a patient advocacy organization for people who have been affected by COVID-19, we respectfully offer our recommendations to the U.S. Census Bureau to improve the agency's efforts to fully understand American household experiences during the coronavirus pandemic. Further, we emphasize that the public's information needs have evolved over the course of the pandemic to require additional data collection regarding the long-term symptoms of COVID-19 ("long COVID" or "PASC").

1. The Household Pulse Survey Should be Continued

The U.S. Census Bureau's Household Pulse Survey is an important data collection tool that has provided invaluable real-time information to the public about the impact of the coronavirus pandemic on American households. As advocates for people who have been affected by COVID-19, we have relied on the Pulse Survey's findings when discussing COVID-19 with policymakers. Our need for this data has only increased alongside a rise in the number of Americans who continue to experience long-term symptoms of COVID-19 following an acute infection. We believe the Pulse Survey must continue to be administered regularly and we believe the value of the data greatly outweighs its cost.

2. Additional Information on the Coronavirus Pandemic's Impact on Children Should be Collected

The Pulse Survey has collected important information regarding children's education, nutrition, mental health, and vaccination against COVID-19. However, the questionnaire does not collect any data on children regarding COVID-19 infections or long COVID symptoms. We believe the Pulse Survey should collect this information.

3. Additional Information on COVID-19 Infections Should be Collected

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. We support the agency’s decision to expand the data collected by changing this question. However, this question could be further modified to provide more robust information. 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”) whereby a respondent could identify the number of infections they experienced in each calendar year.

4. Additional Information on COVID-19 Antiviral Treatments Should be Collected

Revision 3.9 of the Pulse Survey questionnaire proposes to add the question “TREAT1,” which asks respondents whether they took Paxlovid or Lagevrio for their most recent COVID-19 infection. We believe this is important data to collect because these medications are the only available treatment options for COVID-19. Data regarding the utilization of these treatments represents the U.S. healthcare system’s effectiveness for delivering timely treatments to patients that can reduce the likelihood of severe illness and death following a COVID-19 infection. This data is also important because it will provide additional information about whether these medications can reduce the risk of developing long COVID following a COVID-19 infection. However, the question “TREAT1” by itself will not collect critical information about the use of these medications, including the incidence of symptom rebounds and treatment access barriers for patients.

To improve the data collected by this question, we propose adding two follow-up questions that respondents are prompted to answer if they answer “Yes” to the question “TREAT1.” First, respondents should be asked, after they received a full five-day course of treatment, whether they experienced a reemergence of their COVID-19 symptoms after testing negative for COVID-19.¹ Second, respondents should be asked whether they have had any problems accessing Paxlovid and Lagevrio. The answers to this question should account for the following possibilities: they could not get a prescription, they could not get it covered by insurance (including utilization management protocols like prior authorization), they could not afford it, they had contraindicated medications, or they had a contraindicated health condition. Respondents should also be allowed to describe other situations that are not listed. By asking this question, the U.S. Census Bureau can help identify COVID-19 treatment access barriers that may become more common following the end of the Public Health Emergency.

5. Additional Information on Long COVID Should be Collected

As mentioned above, revision 3.9 of the Pulse Survey questionnaire includes four questions specific to long COVID. We wish to call attention to certain elements of these questions the U.S. Census Bureau should be aware of. Further, we recommend including follow-up questions to improve the depth of data collected by these questions.

a. Question “PASC1”

This question asks respondents to describe their coronavirus symptoms when they were at their worst. However, the question makes no distinction between an acute COVID-19 infection and long COVID. We recommend limiting this question to acute COVID-19 infections and defining the time period associated

¹ https://emergency.cdc.gov/han/2022/pdf/CDC_HAN_467.pdf.

with the acute phase of the infection in the question. Additionally, the responses to this question are subjective and difficult to characterize because they ask the respondent to categorize their symptoms as “mild,” “moderate,” or “severe.” These categories are not defined.

COVID-19 survivors might categorize their illness differently depending on whether they were hospitalized. Due to hospital capacity issues at various times during the pandemic, a COVID-19 survivor may not have been able to access critical care when they otherwise should have been hospitalized. Further, one survivor might feel that their symptoms were moderate, while another survivor might feel that those same symptoms were severe. We urge the U.S. Census Bureau to be mindful of these details.

We request the agency add a follow-up question for respondents who reported having “mild,” “moderate,” or “severe” symptoms, asking them to indicate whether they were hospitalized during the acute phase of their infection. The answers should account for the following possibilities: they were not hospitalized because they did not think they needed to be, they were not hospitalized though they think they should have been, they were not hospitalized because they were unable to gain admission to the hospital, or they were hospitalized. We believe it would also be helpful for the agency to gather data on factors that could contribute to a person declining to seek care at a hospital, including: the fear of exposure to COVID-19 or other pathogens in a hospital setting, low confidence in treatment, access to hospital facilities, treatment cost, etc. This data can help public health authorities identify capacity shortfalls that can impede access to access to critical care services. Additionally, this data can help characterize the public’s attitude towards the effectiveness of hospital services for the treatment of COVID-19. Further, as several hospital systems across the country have chosen to abandon masking policies for their health care workforce, we believe it is important to collect data on the public’s perception of hospital safety in the absence of these precautions.

b. Question “PASC2”

This question asks respondents whether they have experienced any symptoms lasting three months or longer that they did not have prior to having COVID-19. This question is accompanied by a list of symptoms that are commonly associated with long COVID. We suggest including additional symptoms to this list, including allergies and allergic reactions, diabetes, high or low blood pressure, headache, migraine, exercise intolerance, worsening of symptoms after physical or mental exertion, rashes and other skin conditions, and sexual dysfunction.

We also suggest adding a follow-up question for respondents who answer “Yes” to the question “PASC2,” which asks them to describe their long-term symptoms when they were at their worst. The answers to this question should use the same language found in the answers to the question “PASC1” (“mild,” “moderate,” and “severe”). While this language is subjective, we believe this data will help policymakers understand how frequently patients experience asymptomatic or mild COVID-19 infections that result in more severe long-term symptoms.

The question “PASC2” collects valuable data on the prevalence of long COVID in the United States. However, the question does not collect data on two important populations: 1) people who experience these same long-term symptoms after receiving a COVID-19 vaccine, and 2) children who experience long COVID. We believe the U.S. Census Bureau should ask additional questions like “PASC2” targeted towards these populations to collect this data.

This question also does not collect data on people who experience serious health events following their COVID-19 infection, including a heart attack, stroke, aneurysm, blood clot, and organ failure, among

others. Respondents with these health outcomes may not answer “Yes” to the question “PASC2” because they might not think of them as “long-term symptoms,” even though they have severe long-term health consequences. Researchers have clearly established that COVID-19 infection places patients at high-risk of experiencing these serious health events in the months and years following the initial infection.² We recommend the U.S. Census Bureau add one or more questions to the Pulse Survey to collect this data so policymakers can better understand the long-term health consequences of COVID-19.

The National Academies of Sciences, Engineering, and Medicine (NASEM) has convened a committee to reexamine the U.S. Government’s interim working definition of long COVID.³ The current definition of long COVID used by NASEM differs from the language used in the question “PASC2,” and it may diverge more significantly following the conclusion of the committee’s work. We respectfully request additional information from the U.S. Census Bureau on whether the agency anticipates incorporating the NASEM definition into the Pulse Survey.

c. Question “PASC3”

This question asks respondents whether they are currently experiencing long-term symptoms following a COVID-19 infection. We suggest including two follow-up questions to provide additional data points that will provide more information about the disease course and health burden of long COVID. If a respondent indicates they are currently experiencing long-term symptoms, they should first be asked about the duration of their symptoms. We recommend the following options: between three and six months, between seven and twelve months, between one and two years, between two and three years, and three years or longer. Second, respondents should be asked about how their long-term symptoms have changed over time. We recommend the following options: symptoms have improved, symptoms have worsened, some symptoms have improved while others have worsened, and symptoms have stayed the same.

d. Question “PASC4”

This question asks respondents whether their long-term symptoms have impacted their ability to carry out day-to-day activities compared to before they have COVID-19. The answers to this question include “Yes, a lot,” “Yes, a little,” and “Not at all.” The distinction between “a lot” and “a little” is ambiguous and subjective. Additionally, “a lot” is not very descriptive. We recommend adding another answer option to characterize how severely incapacitated some long COVID patients may be because of their long-term symptoms. For example, a fourth option could say “Yes, extremely.”

This question reveals important information about respondents’ functional capacity, but it does not capture information about how long COVID has disrupted the American workforce. We suggest including a follow-up question that asks whether the respondents’ long-term symptoms have impacted their ability to work. The answers to this question should account for the following possibilities: they have taken disability or medical leave, their work performance has declined, they voluntarily left their job, they involuntarily left their job, they reduced their hours, they requested disability accommodations from their employer, they have restructured their job responsibilities, they have been demoted or lost seniority, or they have had to change professions entirely. Respondents should also be able to select “Other,” and provide additional information.

² <https://www.nature.com/articles/s41591-022-01689-3>.

³ <https://www.nationalacademies.org/our-work/examining-the-working-definition-for-long-covid>.

6. Additional Information on COVID-19 Tests Should be Collected

Revision 3.9 of the Pulse Survey questionnaire proposes to add several questions about access to at-home COVID-19 tests. We believe this is important information because Americans no longer have guaranteed access to these tests following the end of the Public Health Emergency. In addition to experiencing access challenges for at-home COVID-19 tests, Americans may also face new barriers to laboratory testing, depending on their health insurance coverage. We recommend the U.S. Census Bureau revise its questions regarding COVID-19 tests to collect additional data on access to laboratory testing with the goal of identifying financial access barriers. This data will help policymakers assess whether Americans have adequate access to the tools they need to test for COVID-19 when they get sick.

7. Additional Information on Mental Health Should be Collected

The Household Pulse Survey asks several questions about respondents' mental health, including difficulty concentrating, anxiety, worrying, anhedonia, depression, and feelings of hopelessness. Many of these mental health symptoms are associated with long COVID, as COVID-19 patients are at heightened risk of developing a variety of psychiatric disorders following their initial infection.⁴ Collecting data on these mental health symptoms can help policymakers better understand long-term impacts of COVID-19 that might otherwise be poorly understood. To get a clearer picture of the cognitive and psychiatric impacts of long COVID, we recommend the U.S. Census Bureau include additional questions about mental health. Specifically, we recommend asking respondents about whether they have experienced suicidal ideation, post-traumatic stress disorder (PTSD), sleep disturbances and disorders, memory loss, difficulty multi-tasking, changes to their mood or personality, and impaired judgment. Policymakers would also benefit from data about the prevalence of other symptoms among COVID-19 survivors, including movement disorders (spasms, tremors, loss of muscle coordination) and vestibular dysfunction (dizziness, vertigo, nausea, vomiting, motion intolerance, unsteady gait, nystagmus).

8. Additional Information on Employment Should be Collected

The Pulse Survey asks whether respondents have performed any work in the past seven days with the question "EMP2." For respondents who have not performed any work, the Pulse Survey asks respondents to articulate why with the question "EMP4." Among the reasons for a person not to have worked is "I am/was sick or caring for someone who is/was sick with coronavirus symptoms or concerned about getting or spreading coronavirus (including long-term effects of coronavirus)." We support the U.S. Census Bureau's efforts to collect this important data because it helps characterize how the coronavirus pandemic has impacted workers' ability to maintain their employment. However, this data could be categorized more effectively. For respondents who select this answer, we recommend including a follow-up question that asks them to select the specific reasons that apply to them, including: the respondent is/was sick with COVID-19, the respondent is/was caring for someone who was sick with COVID-19, the respondent was concerned about being exposed to COVID-19 in the workplace, and the respondent is/was experiencing long-term COVID-19 symptoms that impact their ability to work.

9. Additional Information on Access to Healthcare Should be Collected

Many healthcare practices, hospitals, and health systems have rescinded mask mandates for their workforce following the end of the Public Health Emergency. In response to this change, some patients

⁴ <https://store.samhsa.gov/sites/default/files/pep23-01-00-001.pdf>.

may forego treatment because they fear becoming exposed to COVID-19 while visiting a healthcare provider or seeking emergency care. This concern is heightened among long COVID patients because a reinfection could result in further accrual of disabling symptoms. Further, preliminary research suggests that a COVID-19 infection results in damage to the immune system, which may impair patients' response to subsequent infections.⁵ We believe the U.S. Census Bureau should include one or more questions on the Pulse Survey to collect information on Americans' attitudes towards the risk of exposure to COVID-19 in healthcare facilities.

Conclusion

Thank you for providing us with the opportunity to provide our feedback on the latest iteration of the Household Pulse Survey. Please contact me at a.wylam@pandemicpatients.org if I can provide any additional information or if you wish to discuss our recommendations further.

Sincerely,

A handwritten signature in black ink, consisting of the letters 'A' and 'W' in a cursive, stylized font.

Andrew Wylam, Esq.
President
Pandemic Patients

⁵ <https://www.nature.com/articles/s41590-021-01113-x>.