



Testing of Questions on Long COVID

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October 24, 2022

Cognitive Interview testing of Long COVID questions

- In-person, semi-structured interviews
- Conducted in Los Angeles in October 2022
- n=50
- Interviews covered a range of topics including COVID
- 60 minutes

COVID related questions

- Have you ever had or likely had Coronavirus or COVID-19?
- Have you ever been tested for Coronavirus or COVID-19?
- Has a test found that {you/SP} had coronavirus or COVID-19?
- How would you describe your coronavirus symptoms when they were at their worst? Would you say no symptoms, mild symptoms, moderate symptoms, or severe symptoms

Long COVID related questions

- **NHIS: Did you have any symptoms lasting 3 months or longer that you did not have prior to having coronavirus or COVID-19?**
 - Does this reduce your ability to carry-out day-to-day activities compared with the time before you had COVID-19?
- **NHANES: Did {you/SP} experience any new, recurring, or ongoing symptoms four weeks or later after being infected with COVID-19 or suspecting to have been infected with COVID-19? These symptoms can sometimes appear after recovering from the initial infection. Please look at this sheet for some examples of commonly reported post-COVID symptoms.**
 - Among all of the post-COVID symptoms that you experienced, which ones bothered you the most? List up to three different symptoms. You can refer again to this sheet for some examples of commonly reported post-COVID symptoms. What are the {first/second/third} symptoms that bothered you the most?
 - Do you still experience any of these symptoms now?
 - How long {did/have} these symptoms {last/lasted}? 1 month to less than 2 months 2 months to less than 3 months 3 months to less than 6 months 6 months to less than 9 months 9 months to less than 12 months 12 months or more?
- **ONS: Would you describe yourself as having “long COVID,” that is, you are still experiencing symptoms more than 3 months after you first had COVID-19, that are not explained by something else?**

Have you ever had or likely had Coronavirus or COVID-19?

- **Yes (17)**
 - **Including those who didn't have a test or tested negative but assumed they had it due to symptoms**
 - *"I was sick in December. I assume that was covid."*
 - **Including those with no symptoms but positive tests**
 - *"Yep. Had it twice. I was asymptomatic both times."*
- **No (30)**
 - **Including those who don't believe it's real and one who tested positive but believes it was a faulty test**
 - *"I was young and naive. I think it was to stop me from progressing. I should have known things I didn't know. Certain people in that system wanted to stop my progress. Call me paranoid but that's what I think. I was never actually sick."*
- **DK/Refused (3)**
 - **Including those who didn't have symptoms but wondered if they had asymptomatic COVID**
 - *"I don't know if I had it. I don't know. If I did, it would have been asymptomatic."*
 - **Including those who don't believe in COVID**
 - *"Covid is a hoax to take down America... and to "topple the American economy."*

NHIS: Did you have any symptoms lasting 3 months or longer that you did not have prior to having coronavirus or COVID-19?

- **NO (8)**
 - Including one whose taste took 3 months to return but was back to 75% after one month
 - Including respondents who had symptoms 1-2 months
 - *“It felt like it lasted forever but it wasn’t 3 months. More like 6 weeks. Maybe a little longer.”*

NHANES: Did {you/SP} experience any new, recurring, or ongoing symptoms four weeks or later after being infected with COVID-19 or suspecting to have been infected with COVID-19? These symptoms can sometimes appear after recovering from the initial infection. Please look at this sheet for some examples of commonly reported post-COVID symptoms.

- **Yes (2)**

- *“Yeah, I’ve had. I’ve had lingering symptoms. Like I couldn’t taste or smell right for a while. And sometimes it’s still not all the way back... mainly just the taste, but the smell.” “Yeah, I’ve had. I’ve had lingering symptoms. Like I couldn’t taste or smell right for a while. And sometimes it’s still not all the way back... mainly just the taste, but the smell.”*

- **No (4)**

- *“Once I was clean, I was clean.”* This respondent’s symptoms lasted for several weeks and then he had a full recovery.

NHANES: Among all of the post-COVID symptoms that you experienced, which ones bothered you the most? List up to three different symptoms. You can refer again to this sheet for some examples of commonly reported post-COVID symptoms. What are the {first/second/third} symptoms that bothered you the most?

- **Respondent was thinking of ALL COVID symptoms not just post-COVID**
 - Answered *“Severe body aches.”* When prompted, remembered, *“Just not being able to taste and smell was also like really annoying.”*

NHANES: Do you still experience any of these symptoms now?

- **No (1)**
- **DK (1)**
 - *“Probably, I have no clue. I don’t know if my taste is back entirely because the memory of what my taste used to be like is not the same. I don’t have an active comparison- you know what I mean?”*

ONS: Would you describe yourself as having “long COVID,” that is, you are still experiencing symptoms more than 3 months after you first had COVID-19, that are not explained by something else?

- **No (6)**
 - **Several had not heard of the phrase “Long COVID”**
 - **Others thought mostly of taste and smell**
 - *Asked which symptoms Respondent was thinking of “Just the standard ones, like people say they lost their sense of taste and smell. That’s the only one I could think of.”*

Respondents understand questions in the context of their lives

- Living circumstances
- Whether they've felt sick or not
- What they've witnessed
- Other life concerns
- Beliefs

- **NOT ON THE BASIS OF OBJECTIVE TRUTH OR REALITY**

More testing to be done

- Virtual interviews planned for Fall/Winter
- Question for BSC
 - What would you like us to focus on in the upcoming rounds of testing?

For more information, contact CDC
1-800-CDC-INFO (232-4636)
TTY: 1-888-232-6348 www.cdc.gov

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

