

FDA Public Meeting: Long COVID Survey

The FDA will be hosting a [public meeting](#) on April 25, 2023, titled "Public Meeting on Patient-Focused Drug Development for Long COVID."

The goal of the public meeting will be to provide FDA with the opportunity to hear directly from patients and patient representatives about:

- 1) their experiences with long COVID, including how long COVID affects their daily life;
- 2) the symptoms that matter most to them, their current approaches to treating long COVID; and
- 3) what they consider when determining whether or not to participate in a clinical trial.

[Pandemic Patients](#) will be submitting a written comment to the FDA that answers these questions on behalf of our community.

If you have long COVID, or you care for a loved one with long COVID, please answer the questions below to ensure that our written comment accurately reflects your experiences.

Many of these questions are optional. If a question does not apply to your situation, you may skip that question.

Please share a link to this survey among the people in your network to increase the number of responses we can incorporate into our submission to the FDA.

Thank you for your participation in our efforts and helping us elevate the voices of the patient community.

Interested in receiving updates from us? Use [this link](#) to subscribe to our mailing list.

* Indicates required question

Demographic Information

Please respond to the following questions to help us understand the populations we serve.

1. Gender *

Mark only one oval.

- Male
- Female
- Prefer not to say
- Other: _____

2. Age *

Mark only one oval.

- Under 18
- 18-29
- 30-39
- 40-49
- 50-59
- 60-69
- 70+
- Prefer not to say

3. Ethnicity (Select All) *

Check all that apply.

- American Indian or Alaska Native
- Asian
- Black or African American
- Hispanic or Latino
- Native Hawaiian or Pacific Islander
- White / Caucasian
- Prefer not to say
- Other: _____

4. Education Level *

Mark only one oval.

- Master's Degree or Above
- Bachelor's Degree
- High School
- Prefer not to say
- Other: _____

Daily Impacts of Long COVID Symptoms

5. Which symptoms of long COVID have the most significant impact on your life? *

Mark only one oval per row.

	I don't have this symptom	Little or no impact	Some impact	Significant impact	Extreme impact
Cardiovascular symptoms (chest pain, palpitations, arrhythmia, pounding heartbeat, heart attack, blood clots, stroke, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pulmonary symptoms (difficulty breathing, difficulty catching your breath, persistent cough, pulmonary fibrosis, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cognitive symptoms ("brain fog," issues with memory, confusion, difficulty thinking, concentrating, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Executive dysfunction (difficulty managing your thoughts, emotions, actions,	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

difficulty
planning, etc.)

Mental health
(depression,
anxiety,
suicidal
ideation, etc.)

6. Which symptoms of long COVID have the most significant impact on your life? *

Mark only one oval per row.

	I don't have this symptom	Little or no impact	Some impact	Significant impact	Extreme impact
Fatigue	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Exercise intolerance (post- exertional malaise)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dysautonomia (postural orthostatic tachycardia syndrome (POTS))	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
High or low blood pressure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Persistent fever	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

7. Which symptoms of long COVID have the most significant impact on your life? *

Mark only one oval per row.

	I don't have this symptom	Little or no impact	Some impact	Significant impact	Extreme impact
Joint or muscle pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pain in the extremities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Headache	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tinnitus (ears ringing)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Balance (difficulty walking, vertigo, dizziness, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

8. Which symptoms of long COVID have the most significant impact on your life? *

Mark only one oval per row.

	I don't have this symptom	Little or no impact	Some impact	Significant impact	Extreme impact
Sleep disorders (insomnia, sleep apnea, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Vision changes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Digestive issues	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nausea	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fainting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

9. Which symptoms of long COVID have the most significant impact on your life? *

Mark only one oval per row.

	I don't have this symptom	Little or no impact	Some impact	Significant impact	Extreme impact
Dermatological symptoms (skin rashes, discoloration, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulty communicating	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Changes in taste or smell	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Changes to menstrual cycles	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Seizures	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

10. Are there any symptoms not listed above that have a significant impact on your life? If so, describe each symptom and the impact it has on your life.

(optional)

11. Would you say your long COVID today is well-managed? *

Mark only one oval.

- Yes
- No
- I Don't Know
- Other: _____

12. How has your long COVID changed from original diagnosis to now? *

Mark only one oval.

- Symptoms Worsened
- Symptoms Unchanged
- Symptoms Improved

Daily Impacts of Long COVID Symptoms (continued)

These questions are optional.

13. Are there specific activities that are important to you that you cannot do at all or as fully as you would like because of your long COVID?

(optional)

14. Is there a particular impact of long COVID (such as need to work a reduced work schedule, inability to complete daily tasks, anxiety, or depression) that worries you? If so, what worries you most?

(optional)

Long COVID Treatment Approaches

These questions are optional.

15. Please describe how your treatment regimen has changed over time.

(optional)

16. What factors influenced your decision when selecting a course of management for your long COVID? Examples include cost, health care coverage, side effects, treatment availability, etc.

(optional)

17. Assuming there is no complete cure for long COVID, what specific things would you look for in an ideal treatment for long COVID?

(optional)

18. Is there a particular symptom of long COVID that you would prioritize for treatment? Please describe the symptom you would most like to have treatment options for.

(optional)

19. What would you consider a successful treatment outcome for long COVID?

(optional)

Clinical Trials for Long COVID

These questions are optional. If you have not participated or wished to participate in a clinical trial for Long COVID, you may skip these questions.

20. Have you considered participating or have you participated in a clinical trial for long COVID? If so, please describe your experience.

(optional)

21. What factors (if any) of the clinical trial enabled you to participate?

(optional)

22. What factors (if any) of the clinical trial made it more difficult for you to participate?

(optional)

23. How does the clinical trial intervention (side effects of the medical intervention, how the intervention is administered etc.) weigh into your decision to participate in a clinical trial?

(optional)

24. How does the logistics of the clinical trial (duration of the trial, whether the trial is fully remote or requires clinic visits, the number of in-person clinic visits required, distance from home to clinic site, or whether you might receive a placebo or not) weigh into your decision to participate in a clinical trial?

(optional)

25. What outcomes for long COVID are most important to measure in a trial setting?

(Examples may include reduction in pain, brain fog, fatigue, or other aspects; or improvement in your ability to perform daily activities such as reading, sleeping, or exercising)

(optional)

This content is neither created nor endorsed by Google.

Google Forms