

# Responses to Participants' Questions

This document provides responses to questions raised by webinar participants related to the following presentations:

- **Presentation 1: *Characterizing Long COVID in an International Cohort: 7 Months of Symptoms and Their Impact***  
Hannah Davis, JD, Co-founder, Patient-Led Research Collaborative
- **Presentation 2: *Pediatric Clinical Spectrum of PASC***  
Sindhu Mohandas, MD, Assistant Professor of Pediatrics, Infectious Diseases, Children's Hospital Los Angeles, University of Southern California
- **Presentation 3: *Post-Acute Sequelae of COVID-19 – What We Know in the Adult Population***  
Igho Ofotokun, MD, MSc, Professor of Medicine, Emory University

## Presentation 1: Questions and Responses

**Q1. Given the persistent nature of neuropsychiatric symptoms, I am wondering why screening for psychosis is not included in RECOVER. Also, I am seeing reports of association with childhood stress and long-haul COVID and I have similar questions about excluding screening for early stress (the psychiatric planning committee included two questions on early stress).**

**Response:** Neurological symptoms are common, but psychosis is not common. Our study (Davis et al., 2021) asked about neurological symptoms and found the prevalence was low. However, it makes sense for providers to ask about psychosis in patients showing signs following a COVID infection.

Childhood stress has been researched exhaustively in other viral-onset conditions. Current findings show that depression is a better indicator of childhood trauma than post-viral illness, and people with post-viral illness without depression (which is a majority) don't have higher rates of childhood trauma (Clark et al., 2017).

**Q2. Is there a statistic on the percentage of people with COVID-19 that get long-term (more than 3 months) Long COVID?**

**Response:** Most studies now use the 3-month/12-week threshold to determine Long COVID prevalence because we know a lot of people recover before then. Most studies suggest the 12-week prevalence is between 10% and 30%. The REACT study, conducted by Imperial College London, recently suggested that at least 15% of people have 3 or more symptoms at 12 weeks.

**Q3. Please comment on the prevalence information for symptoms given the lack of controls in many studies [as] the prevalence attributable to COVID may be much less for some of these symptoms.**

**Response:** Symptom prevalence in adult studies that include control groups ranges from 10% to 30%. However, control groups in Long COVID studies are not perfect because 75% of COVID cases are undocumented, and two-thirds of mild cases lose their antibodies after a few months (especially among females). This results in COVID-infected people accidentally being included in the control group.

**Q4. What category of symptoms would Dysautonomia/POTS fit into? It is a nervous system issue, so neurological?**

**Response:** Dysautonomia/POTS are effects caused by the disruption of the autonomic nervous system. So yes, it is a neurological issue.

## Presentation 2: Questions and Responses

**Q5. Are we seeing patients with headaches resolve symptoms past 3 months? Do you have recommendations for doctors who might be helpful in treatment? Many are connected with local neurologists (like us), but are there others that are dealing with these post-COVID neurologic symptoms in children that may be helpful?**

**Response:** Post viral symptoms in children are being seen at far greater rates in children after COVID and the scale of the pandemic has further magnified the problem. I agree that education, not just for parents and children but also for MDs, is very important to help recognize the true extent of the problem and provide support to the patients and families.

Local neurologists are the best resource at the current time. I am also hopeful that we can put together a network of specialists—including neurologists who have more experience in management of post-COVID symptomatology—and have this as a resource on the RECOVER website.

**Q6. Is there any documentation for pediatric Long COVID?**

**Response:** Long COVID as a diagnosis now has an ICD-10 code (U09.9) that can be used to document children with Long COVID.

**Q7. Are there long-term cardiac complications from recurrent dysautonomia from post-viral illness?**

**Response:** I have not heard of long-term cardiac complications caused by POTS, but I don't think we know enough on this topic. Long-term follow-up of patients with Long COVID will help answer this question more definitively.

## Presentation 3: Questions and Responses

**Q8: Is there an increase or decrease in prevalence of Long COVID by variant of concern?**

**Response:** I don't think we know for certain. Data from the earlier waves/strains suggest some relationship between disease severity during the acute phase of COVID-19 and subsequent development of PASC. Because the later variants, Omicron, and the sub lineage BA.2, are associated with much milder illnesses, one can speculate that they may be associated with lower rates of PASC. Hopefully, the RECOVER study will help us tease this out.

**Q9. For the data showing that individuals with severe PASC (life-threatening illness or death) are more likely to have been in the ICU or hospitalized during acute infection, is this likely due to the advanced age and comorbidities typically associated with this population?**

**Response:** The short answer is that this could be the case. Our knowledge of the predisposing risk for PASC is still emerging and it is very likely there are clinical-demographic factors—including advanced age, comorbidities etc.—that predispose those recovering from COVID-19 to PASC.

## Webinar Slides

To request a copy of the R3 Webinar slides, please email RECOVER\_ACC@rti.org.

## To Learn More

- Information about RECOVER research: <https://recovercovid.org/research>
- Locate and volunteer for studies: <https://studies.recovercovid.org>
- Frequently Asked Questions about RECOVER and PASC: <https://recovercovid.org/faqs>
- RECOVER What is Long COVID page: <https://recovercovid.org/long-covid>
- CDC information: Information for the general public and for healthcare providers about post-Covid conditions: <https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/>

## References

- Clark JE, Davidson SL, Maclachlan L, Newton JL, Watson S. Rethinking childhood adversity in chronic fatigue syndrome. *Fatigue*. 2018;6(1):20-29. <https://www.tandfonline.com/doi/full/10.1080/21641846.2018.1384095>
- Davis HE, Assaf GS, McCorkell L, Wei H, Low RJ, Re'em Y, Redfield S, Austin JP, Akrami A. Characterizing long COVID in an international cohort: 7 months of symptoms and their impact. *EClinicalMedicine*. 2021;38:101019. doi: [10.1016/j.eclinm.2021.101019](https://doi.org/10.1016/j.eclinm.2021.101019)