

Responses to Participants' Questions

The overarching goal of the RECOVER Research Review (R3) Seminars is to catalyze a shared understanding of the research being conducted by the scientific stakeholder community within the RECOVER Consortium. The R3 Seminars and the Q&As typically feature highly scientific material intended for researchers and clinicians. For other audiences interested in these topics, a link to the National Library of Medicine's MedlinePlus medical dictionary is provided at the end of the Q&As as a resource to help in understanding the scientific terminology.

This document provides responses (edited for clarity) to questions raised by seminar participants related to the following presentations at the R3 Seminar *Characterizing Long COVID During Early Childhood* held on July 8, 2025 (videos for this and previous seminars are available from the [Seminar Series page](#) on the RECOVER website):

- ***Characterizing Long COVID Symptoms During Early Childhood***
Rachel Gross, MD, MS
Tanayott Thaweethai, PhD
- ***Family Perspectives***
Krista Coombs, RECOVER Patient Representative
Megan Carmilani, RECOVER Patient Representative
- **Discussant: Amy Salisbury, PhD, RN, FAAN**

All Presenters: Questions and Responses

Q: What is RECOVER-Pediatrics doing now and what are the plans going forward for longitudinal studies with children?

Responses:

Dr. Gross: There are so many things happening in RECOVER-Pediatrics. As I mentioned with the broader aims, we're looking at so many of these different factors at the same time so that we can learn as much as we can. The research we presented today is fundamental in being able to understand which children are experiencing different symptoms at different ages and building on this. We are following a large group of the children in RECOVER for up to 4 years, and hopefully longer, to be able to understand how symptoms are changing over time. So that's one of the first things that we're looking at: Do children have symptoms that persist for a long time? Some children's symptoms are improving, but they may be coming back and coming and going, and so studying the change of symptoms over time can also give us a lot of information. Then we're looking at factors that are related to having different types of Long COVID symptoms or also having different trajectories of symptoms over time. We are examining what clinical factors and social factors might be contributing to this to help us understand the

underlying mechanisms. So we're starting to look at changes in the immune system, and how that might relate to what we're seeing. We're looking at vaccination, we're looking at other social factors and biological factors. So are there genetics, other exposures that might be related to this, so we can identify the underlying mechanisms?

Dr. Thaweethai: I would just add that the results that we presented today were really focused on a single visit that a large number of children and their caregivers completed that used only symptom data. But in RECOVER, there's so much data that's collected in the longitudinal phase, as Dr. Gross mentioned. We continue to ask about the symptoms that are being experienced, but can integrate clinical assessments, including labs, and other things that measure learning ability, more behavioral-related assessments that can help paint a higher dimensional image of what's going on with children as they age rather than just what symptoms they are reporting through their caregiver. There are many ongoing projects related to neurocognitive outcomes, dysautonomia-related outcomes, and more, a deeper dive into sleep-related outcomes that are actively being worked on, and then we hope to be able to share at future R3 seminars going forward.

Q: What resources and support are available for families and caregivers now?

Responses:

Ms. Carmilani: Long COVID Families is a nonprofit that I'm associated with. Our mission centers around accelerating research. So we share a lot of information about the research, access to education, and access to medical care. We do have a page dedicated to 504 plans (accommodations for students with disabilities), Individualized Education Programs (IEPs), things like that. I have former experience being on an IEP team, so we have a lot of information about that. Then we have information about accessing medical care. We don't have a group right now that's active; we're developing it. So we're adding a discussion forum kind of way for families to connect. That's on an app that's independent from social media that's coming. Hopefully, we'll have that up within the next 2 months or so, but if you sign up for our newsletter, you'll get that information. Then we are hosting Pediatric Long COVID Awareness week beginning July 21st. There's information on our website about that, as well with several toolkits and ways for families to get involved, or other organizations can get involved. And if you are within the public health field, there's a toolkit for you as well. As Ms. Coombs said earlier, children really need the community at large to get involved.

Ms. Coombs: Thank you, Ms. Carmilani, and I'm excited about the week coming up and advocacy for pediatric Long COVID. So for me, I can't say enough about word-of-mouth referrals and finding people within your same state or a bordering state. Finding caregivers with kids around the same age might direct you the best right now, too, such as finding a medical professional that might be worth seeing that's within an area that you can get to possibly, and support navigating all the education needs while being sick as a kid. There are so many of us here to help families that I just wanted to kind of put that out there. I think we're your best resource right now. Please find us and keep

asking questions. Let's keep working on this together until the rest of the world catches up. There are also organizations and people with other conditions and diseases who have been helpful and welcoming, who have guided our family to get better support and suggested ways to talk about our new symptoms.

Q: What's the most important thing for schools to understand?

Response:

Ms. Carmilani: So the most important thing for schools to understand is that Long COVID is an umbrella term. There isn't just one presentation of symptoms and experience. It could present in a number of different ways. I often hear from schools about, "Well, we're not medical providers; we don't diagnose." The reason they're saying that is because most children with Long COVID do not have a diagnosis. And my response always to schools is that we're not looking for you to diagnose it. We're just looking for you to identify what symptoms are impairing a child's ability to learn and then to address and accommodate those symptoms. So what I would say to schools is, if you see a child that's disengaged, if you see a child that's irritable, if you see a child that may seem like they're dysregulated, and they're lashing out in class, things at this point we need to stop and ask, could it be Long COVID? Because a child's not going to say, "You know, I have a migraine. Therefore, when you ask me to do something, I snapped at you." Kids don't really have that ability. I mean, I was a very irritable kid because I was in a lot of pain. I had infection-associated conditions; I was irritable a lot. I didn't make the connection between the fact that I was in pain and that I was talking back to my parents. I wasn't making that connection. We need the adults to kind of get curious about why children might be behaving this way if they're falling asleep in class, for example. Let's not just assume they're bad kids.

Q: What are the types of data that you have that can help identify children's abilities to taste and smell?

Response:

Dr. Gross: This is such an important question. And for me, what it begins to highlight as our next step is to understand why we're seeing the symptoms that we see across the different ages. When I look at the symptoms we see in infants and toddlers, and people mentioned this in the chat, as poor appetite or trouble sleeping, or things that caregivers can observe as something that they see in their baby. The question is, why are we seeing these symptoms? Because babies don't have the verbal ability to share with us that maybe it's because their smell and taste are changing, and that's why they don't want to eat. Or maybe it's more related to how their stomach is feeling. We don't know why; we just know that these are the symptoms being expressed that caregivers can see, and they're more likely to be Long COVID. Our next steps are to understand these are the types of symptoms being observed. What are the underlying things? It leads us to ask that question about smell and taste in younger kids.

We are working to see how we can add more specific tests to actually objectively test smell and maybe taste in young children. As we've learned these things about the young children, it is interesting that the adolescents do report a high level of loss in smell and taste, as do the adults. But our young school-age children are not reporting this as much. It doesn't mean that it's not there. It may be that the kids with vomiting and stomach pain maybe also have a change in taste. We don't know yet, but that's part of the work to understand.

Q: How do asymptomatic infections complicate looking at taste and smell symptoms?

Response:

Dr. Thaweethai: Yes, one result we didn't have time to share is that we did look at uninfected children aged 3 to 5 years who had antibody data and were confirmed negative versus those who had missing antibody data. We found that the results were quite similar in terms of the rates of reaching the Long COVID research index threshold for being Long COVID-probable in both groups. We don't think that our results were very sensitive or impacted greatly by potential misclassification here on the presence or absence of having antibody data because our results were robust, even if we looked at children for whom we could not confirm that they had never been infected. Asymptomatic infection is something that's very tricky to study, but we know it's still possible for a child to develop Long COVID, even if they were asymptomatic during the initial phase of infection. This is something observed in adults and children, and we are mindful that analyses should not assume that it's only children who were very sick during the acute phase who end up developing Long COVID symptoms. Symptoms are only one way that Long COVID can manifest. In some cases, it's the most common way, but that's not necessarily always going to be the case, which is why so many future analyses that are going to come out of RECOVER are looking at clinical assessments that don't require symptoms—which are, of course, subject to recall bias—but looking at more objective clinical measures in the population that we follow to better understand the relationship between Long COVID and potentially asymptomatic presentations of Long COVID.

Q: The next question is about reinfection. We've got a couple of questions about kids who are going to school in person. What effects of reinfection are you seeing in the data? What are you hearing from families about reinfections?

Response:

Dr. Gross: Yes, this is very important to the community and to the development of Long COVID. We do collect information when families enroll about how many COVID infections they believe their child had when they enrolled, as well as collecting that information every 6 to 12 months at each of the visits. We will do our best to look at reinfection over time. We have not started that yet, but that is something we are definitely looking at.

Ms. Carmilani: Yes, we definitely see the impact of reinfections within the community. What we were seeing initially when children would develop Long COVID was that a certain percentage—and I don't know the exact number because it's just community observation—would eventually improve or even report being recovered within about 1½ to 2 years. However, upon reinfection, there would be a major setback, and it was like recovery never happened. So it's almost as if because of reinfections, it wiped out the hope of recovery for many in our community.

Because children are in schools, there's not a lot of control over exposure to infection. Even if a child wears a mask every day perfectly, they still have to eat. A lot of families feel a real source of despair; they feel like they don't have any control. There are many places that are hostile to anyone trying to take precautions about infection. Some school districts will not allow you to have virtual learning. So, in many cases, the only way a family can protect themselves from reinfection is to homeschool their kid, which takes a level of financial privilege that many do not have.

Ms. Coombs: What feels a little left out is that reinfection can also cause Long COVID. Someone might be okay enough, or maybe they had a little bit of a longer infection, and then the reinfection could really take them down. This picture is just really complicated, and it's changing all the time. There's no baseline for cumulative effects of infections, and what we've learned with adults is that it can create a lot more problems.

Ms. Carmilani: Our numbers are still growing as far as children with Long COVID. We saw the first major wave of children after Omicron; typically, we will start hearing from families about 3 to 6 months after the infection because it takes families a little bit to realize that it's Long COVID and that the child isn't recovering. We saw the first wave of families contacting us in the spring following Omicron. Almost every child has had at least one infection, so it's almost all reinfections at this point. After every wave, we still see an influx of kids.

Q: Does the Long COVID research index need to be validated in other research centers with other cohorts of children prior to being widely used in research?

Response:

Dr. Thaweethai: Validation of the index in other pediatric populations against a clinical diagnosis of Long COVID would certainly help the research community better understand and evaluate the performance of the research index. We are very supportive of such validation studies and think they are critical for advancing our knowledge of Long COVID and can inform how Long COVID can be identified clinically. However, we have demonstrated that higher values of the index are correlated with worse measures of quality of life from the Patient-Reported Outcomes Measurement Information System (PROMIS), as well as other measures of overall health, and have demonstrated a level of internal validity of the index. We believe this can be useful for research purposes.

Q: Are there any plans to follow these children long-term to assess how/whether these conditions may influence risk of developing other conditions later in life, such as neurodegenerative diseases, diabetes, mental health disorders, etc.?

Response:

Dr. Thaweethai: Yes, RECOVER is a longitudinal study that follows children for the development of other comorbidities, such as the ones described here.

Q: What outreach has there been to the mental health community?

Response:

Ms. Coombs: As advocates, we talk about mental health, and how not being able to participate in life activities during childhood and adolescence affects mental health. Schools, workplaces, and pediatric medical professionals need to help children and caregivers, because without their support, it is making everything more complicated and more isolating. The burden is on families to figure everything out without outside support, and this affects mental health.

Outreach, support, and resources for families are available from various organizations. Here are some examples:

- [National Academies of Sciences, Engineering, and Medicine \(NASEM\) definition of Long COVID.](#)
- [Video recording of Long COVID Families webinar.](#)
- [Resources from the Brain Inflammation Collaborative.](#)
- [Resources from Dysautonomia International.](#)
- Long COVID Alliance, [Community-Developed Resource Guide for Infection-Associated Chronic Conditions.](#)
- [Centers for Disease Control and Prevention \(CDC\) resources](#), updated July 2025.
- [Resources from #ME Action.](#)

There are also various online support groups available.

Q: We were urged to avoid revaccination after Long COVID developed. Any change in the conventional wisdom?

Response:

Ms. Coombs: Follow your doctor's advice and CDC recommendations. There isn't specific guidance developed for people with Long COVID. The newer CDC guidance says to wait 3 months between having a COVID infection and

being vaccinated, which is clearer than it has been. The closest guidance for some with Long COVID is from the immunocompromised resources:

- CDC guidance, [Vaccines for Moderately to Severely Immunocompromised People](#).
- Bateman Home Center, [COVID-19 Information and Resources](#).
- CDC, [Long COVID Clinical Guidance](#).

Q: Did you collect data on vaccination status as part of this study?

Response:

Dr. Thaweethai: All participants in the pediatric observational study were asked about their COVID-19 vaccine history.

Webinar Slides

To request a copy of the R3 Seminar slides, please email RECOVER_ACC@rti.org.

To Learn More

- [Information about RECOVER research and to volunteer for studies](#).
- [Frequently asked questions about RECOVER and Long COVID](#).
- [CDC Long COVID Basics](#): Information for the general public and for healthcare providers about post-COVID conditions.
- For medical/scientific terminology: [MedlinePlus's Health Topics](#).