Responses to Participants' Questions

The overarching goal of the 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* to questions asked by seminar participants related to the following presentations at the R3 Seminar ***RECOVER in Action: Characterization of PASC Among Adults, Cohort Insights*** held on June 13, 2023:

- **Segment 1: Presentation of Findings**
- **Segment 2: Panel Discussion and Takeaways**
  Upinder Singh, MD
  Tanayott Thaweethai, PhD
  Andrea Foulkes, ScD
  Sairam Parthasarathy, MD

* Responses may have been edited for clarity.

All Presenters: Questions and Responses

Q. What are some of the key takeaways from this analysis?

Responses:

Dr. Singh: I think this work nicely demonstrates that individuals who score 12 or more points meet the criteria and definition for Long COVID. But as Dr. Thaweethai said multiple times, and which is a very important takeaway, people who have a score of less than 12 may still have Long COVID. I'm going to say that again: People who have a score of less than 12 may still have Long COVID. This is why the PASC indeterminate definition was used and not PASC negative. This has been a question that many individuals have and it's something we want to make sure people understand and take away.

Dr. Parthasarathy: One of the other key takeaways is that the *JAMA* paper findings and the PASC score specifically should not be used for clinical use or for designing disability ratings. It's a first step. It's the initial step for coming up with a working definition that needs to be further refined. And it's not time to apply it in the clinical or the disability realms. I think this is an extremely important takeaway that we need to consider.

Dr. Singh: I know that many individuals are wondering about clinical trials and when will treatment options become available. We're really excited to see the emergence of important clinical trials through RECOVER and other mechanisms. But it's very important to recognize that the PASC score, in our expert opinion, should not be used for assessing eligibility for clinical trials. Instead, eligibility should be based on the history of COVID infection. If somebody has proven COVID infection by seropositivity or a history of probable or definite infection followed by symptom or organ dysfunction, then it could be used as a certain focus of the trial but definitely not as a PASC score cutoff.

Dr. Foulkes: I'll add that the 12 identified symptoms are not necessarily the most common, the most troublesome, or the most burdensome symptoms that patients are experiencing. We found these symptoms to be the ones that most set apart and most discriminated in the RECOVER cohort between the infected and uninfected participants at the 6-month or later visit. Consequently, the score serves as an important first step to unravel the mechanistic underpinnings. However, in addition to the 12 symptoms that contributed directly to the score, we also found 25 other symptoms that were more common in people with a history of SARS-CoV-2 infection than people without a history of infection. So, the *JAMA* paper really highlights the diversity of symptoms that individuals are experiencing beyond the 12 identified symptoms.

Dr. Thaweethai: One of the key findings has to do with the different manifestations of Long COVID that we identified, which are a helpful starting point for understanding the different ways people are affected by Long COVID. We're very hopeful that this will help motivate mechanistic studies to understand some of the subclinical changes occurring in people who develop Long COVID so we can understand why it is that people become sick and then identify potential treatments that are specific to different manifestations of Long COVID.

Dr. Singh: I'll add another takeaway, which is that COVID vaccination did seem to be associated with reduced odds for having Long COVID. This finding provides a rationale for added benefits to primary and especially booster vaccination to protect against another variant. So, as you saw in the presentation, vaccination seems to be protective and repeat infections seem to be more harmful. This can help to inform ongoing public health recommendations for people to stay up to date on vaccinations and to avoid further COVID infections.

Dr. Parthasarathy: Another interesting finding is the demonstration of the data that Dr. Thaweethai presented with regard to multiple infections and the more virulent strains in the pre-Omicron era, such as the Delta strain variant, that were associated with a greater risk of individuals having PASC. This suggests that it could be multiple hits on those organs that's causing the organ dysfunction as the anti-pathogenic mechanism. But again, PASC is a syndrome of syndromes and there are other pathogenic mechanisms in play such as viral persistence, autoimmunity and immune dysregulation, and even gut dysbiosis. But what this says is that when the virus hits multiple times, there's more organ injury and the likelihood of PASC as evidence, but also a greater chance of having PASC in people with hospitalizations as opposed to people who are not hospitalized.

I would go even further to say it's part of a combined takeaway that Dr. Singh just talked about in terms of vaccination. It's important that people don't just resort to natural immunity, and this essentially underscores the importance of reducing repeat infections and the fact that vaccines confer protection. And this is why people should get the booster shots. Unfortunately, only 17% of the US population has taken the booster shots, although upward of 70% of the population has taken the primary series. Vaccination is key because our country is still expected to be exposed to another new variant that could emerge, which is rated at a 20% chance over the next 2 years.

Q. How do the findings presented today compare with or expand on some of the prior research that's been done?

Responses:

Dr. Singh: It's obviously been a heroic effort by the investigators, the participants, and the entire scientific community. As has been noted, this is the largest prospective cohort study of PASC. It's very additive to data that have emerged, such as data from electronic health records. In some ways this is the first example, but I think a lot of the power of this work is going to be demonstrated over the next year as we see participants follow up to see how their symptoms progress, change, or don't change; and as we see participants taking part in further studies, imaging tests or blood work, we'll have further analysis emerging from pathobiology studies. So, this study is very important in establishing the cohort and setting this national framework for research, out of which I think more important data will emerge.

Dr. Parthasarathy: I would add that this is a large, adequately powered prospective study. Dr. Foulkes mentioned the fact that this study was specifically designed with patient input, representative input, and other stakeholders designed questions to capture symptoms such as post-exertional malaise (PEM) that are specific to the SARS-CoV-2 infection. This study includes a contemporaneous uninfected cohort so that it can make contemporaneous comparisons during the middle of the pandemic because we know that even in uninfected individuals their health deteriorated during the course of the pandemic. For example, people gain weight, or their blood pressure is not under adequate control. As a consequence, there was even incident diabetes and cardiovascular disease during the pandemic, even in uninfected individuals. One of the key strengths of this study is the prospective observational nature with the contemporaneous uninfected controls.

Additionally, you have the acute Omicron-infected individuals so that you can actually see in this variant the incidence of PASC, which comes up to about 10% after adjustment for weighted comparisons—about 9.8% or something—which is remarkably similar to the CDC household pulse survey for what happened to people who were infected during the Omicron era and had symptoms of PASC or Long COVID. So, there's external validity to the findings of this prospective observational cohort and that's what in fact sets this study apart.

The last thing I want to say is that there's simultaneous settlement of multiple symptoms, every single symptom that we can identify. Yes, there are 44 symptoms, and we could have gone up to 200 symptoms. Some of that may also refer to language in terms of how patients relay their symptomatology. There are other studies, even if they're smaller or prospective studies, but if they don't ascertain or don't measure a particular symptom, are they going to end up having skewed findings? I think a lot of thought went into making sure that we captured all the symptoms and defined a solid data analysis approach. It was essentially a data-driven scoring framework that was developed. The data spoke for itself and drove the scoring and the system, as opposed to us arbitrarily choosing some symptoms and saying, "This one or that one is more important." It's the prospective observational contemporaneous controls, uninfected controls, acute Omicron cohort, and the statistical methods that are the strengths of this study and set it apart.

Q. The National Academies of Sciences, Engineering, and Medicine is hosting a symposium called "Examining the Working Definition for Long COVID." How would you advise symposium participants to use RECOVER's findings?

Response:

Dr. Parthasarathy: I did not acknowledge the more than 200 authors and investigators and the institutions involved in this work and want to thank them for their hard work. Today, we're representing a lot of work and a lot of people behind the scenes, including the National Institutes of Health. There are a lot of minds that went into this and the key thing for them to consider is that this is a framework. This is in no way, shape, or form the final definition; this is a first step, as clearly stated in the *JAMA* paper and as presented by Drs. Foulkes, Thaweethai, and Singh. Further refinements need to occur with regard to the clinical diagnostic tests and imaging tests that are going to be available, along with integration of biomarkers and of further analysis of extreme phenotypes. That's going to give us greater resolution and clarity. I would liken it to a telescope before you go to the Hubble, before you go to the James Webb, so that you get a bit better resolution of the images and of the definition. And by no means is this form meant to be the final definition. The key thing is once you set the framework, you can keep refining it in an iterative manner.

Q. Is RECOVER gathering the dates and number of vaccines and boosters administered over the trial period? Is it accurate to call this a trial period?

Response:

Dr. Foulkes: Yes, we're collecting information on vaccination and boosters over what we think of as the observation period. We're also collecting information on repeat infections. We have a lot of what we think of as time-varying exposures, so multiple vaccinations or boosters, multiple infections, infections with other viruses and other clinical outcomes measured over time. We're collecting that information; and again, this is really a first step

where we wanted to get some results out as swiftly as possible. Given the scope of this large study, there are many more questions that we'll be probing and thinking about. They're very complex questions and require a lot of input on sophisticated methodologies from our epidemiologists and biostatisticians and with critical input from clinicians and from patients with Long COVID. We're beginning to embark on looking into these additional questions that integrate all these different sources of data and the information on vaccination and boosters over time.

Q. How are patients who were COVID-negative at the start of the observation period but have subsequent infections—asymptomatic or not—treated in these or later analyses?

Responses:

Dr. Thaweethai: From a data perspective, individuals who enroll as uninfected but then develop infections crossover into the infected arm of the study and their questionnaires reflect this. So now we're able to study them as infected. In future analyses, these individuals can, in a sense, serve as their own controls. It's a natural crossover design. These are individuals that we can learn a lot from going forward in analyses. So that's part of how these individuals' data would be incorporated into RECOVER aims.

Dr. Singh: The power of a longitudinal observational study is that we can see people who are not infected who then get COVID maybe once or twice and then follow them. You have their symptoms and their general health before they got infected. Now you'll have their symptoms and general health during acute infection and then for several years after. So these individuals will contribute data to different aspects of the analysis, but it's such a powerful way to follow people. I think that really highlights one of the strengths of this study.

Q. How is infection defined here? Were participants required to have a positive PCR or an antigen test? Is it self-reported? Is a physician diagnosis accepted? How is that determined for this study?

Responses:

Dr. Singh: The goal of this study was to be as inclusive as possible and to be as scientifically rigorous as possible. The idea here is to take people who have a range of definitions of positive—for example, if somebody had a positive PCR; a positive antigen test; self-reported infection (that is, it doesn't have to be physician reported); evidence of antibodies before vaccination occurred; and clinical syndrome consistent with COVID—but they were not able to access testing. It was very important to include people who may have been infected early in 2020 before tests were easily available and people who were infected during some of the infection surges where there wasn't enough access to health care or testing.

To be as inclusive as possible, people are allowed to enroll with a variety of different definitions of positive. We do note when they're enrolled whether they had a positive antigen or PCR test, were self-reported, or had a clinical syndrome consistent with COVID. To be scientifically rigorous, we do want to follow these individuals and

understand how they entered the study. It's an important question and I think one of the strengths of this type of study.

Dr. Parthasarathy: There's also a health disparity aspect to what would be mentioned because there are people who come from disadvantaged neighborhoods who don't have access to testing. We needed to be all inclusive to make sure that people who were disadvantaged in such a manner were also included in the study.

Dr. Foulkes: One more layer to add is that for the uninfected participants, we do enrollment testing to see if there's an infection that they didn't know about, but we may not capture all of them. One of the challenges that we face is that we don't have perfect classification, particularly of the uninfected participants. We expect some of the individuals who we think are uninfected may actually have had a history of infection that was not reported; either they didn't know about it or it was not included in the data capture.

Q. Was the infected population stratified by acuity of illness, such as hospitalized as compared with not hospitalized? It would seem like many of the PASC symptoms would be confounded by pulmonary fibrosis or other organ damage?

Responses:

Dr. Thaweethai: I can speak briefly to what was mentioned in the *JAMA* paper about severity of illness, which I didn't have time to cover in the presentation. Among participants who were hospitalized for their first infection, 39% were PASC-positive. Among participants who were not hospitalized during their first infection, 22% were PASC- positive. We were seeing that if you were to just stratify on hospitalization as compared with not hospitalized, looking at infected participants overall the rate was higher. We're collecting information on other aspects of severity of illness, types of treatments received, the level of care looking at Extracorporeal Membrane Oxygenation (ECMO), Intensive Care Unit (ICU) admissions, and other things. But for the purposes of the first paper, we focused on hospitalization.

Dr. Singh: Initial severity of illness did seem to be associated with worse disease. However, people who had mild infection and were never hospitalized, who maybe even had asymptomatic infection and were diagnosed because a family member was positive, can have PASC and can be quite symptomatic with their PASC. COVID is one of those illnesses where you more or less can't predict who's going to get really sick, who's going to get hospitalized, who's going to do worse, and who's going to do better. Unfortunately, these parameters seem to be carrying over to PASC. It's hard to predict based on the initial severity of symptoms who will develop PASC. Collectively, when we look at the almost 10,000 study participant population, we see definite themes. But I don't want people to walk away thinking that people who had mild COVID can't get PASC. That's not true. People who have mild or asymptomatic COVID can get PASC.

Dr. Parthasarathy: That's why scientifically *PASC* is the more accurate term than *Long COVID*. In other words, someone who never had the symptomatic condition called COVID, which is due to the SARS-CoV-2 infection, can go on and develop PASC. In terms of underlying pulmonary fibrosis and other conditions, that's where the additional clinical diagnostic tests, including imaging, become available and it's an ambidirectional study. In other words, we can get the information from medical records and images for which the participants provide access, but we can also obtain information not just through questionnaires but also through electronic health records. We can see whether they had pulmonary fibrosis before or whether it's a new fibrosis diagnosis. A lot of rich data are going to come out of this to answer these questions.

Q. There is a concern in the patient community about the recent article in *JAMA*, which has received a lot of attention. There is concern about having a limited number of PASC symptoms; the paper has 12. Can you speak to the engagement with the patient community and how this work will influence decisions moving forward?

Responses:

Dr. Singh: We've been involved with RECOVER since the very beginning when a group of investigators were selected by the NIH and asked to come together to discuss developing a protocol. We've always had very strong patient, provider, and community engagement representation. I think my answer may not always be as satisfactory, but science is a compilation of thoughts, opinions, and observations that are iterative so that we always get better. For example, our understanding of cancer, lung cancer, or breast cancer is different now than it was 50 years ago or even 20 years ago. Our definition of what it means—for example, should women get hormone replacement therapy—is different now than even 10 years ago. Science moves, science improves, science keeps adding new information. I think this study more than almost any other study, or in fact more than any other study I've been involved in, has taken a global inclusive approach the whole time.

I do think we've been very careful in the paper and in our conversations with media to say we understand there are hundreds of symptoms that people with Long COVID can have. We're simply defining some where there is the most difference between people who appear to have Long COVID and people who may or may not have long COVID; again, PASC indeterminate. Unfortunately, what happens is that it's become a yes or no. And what we're saying is yes or maybe, but the black-and-white philosophy tends to be the soundbite that gets projected and that is absolutely not what we're saying an that's absolutely not what's in the paper. We want patient and provider engagement to continue because, again, people will help us iterate. So that's my perspective, but I don't know what others think.

Dr. Parthasarathy: I'd like to go back to what Dr. Singh said was her main first takeaway, which is that just because someone doesn't have their symptoms represented in the 12 identified symptoms (which Dr. Foulkes underscored are not the most common or most bothersome symptoms), they can still have PASC. One of the limitations is that

there are many patient groups who have done their own collection of symptoms, which they provided early on, but also collected and compiled independently, which amount to about 200 symptoms that we did not incorporate. Some of them are overlapping symptoms and there are also differences in what the participants call these symptoms. We acknowledge that there are other symptoms that need to be looked at, and just because someone's symptom is not one of the 12 distinguishing symptoms, that doesn't mean that they don't have PASC or Long COVID. They should still seek medical attention. And that's why we don't want this definition of PASC to be used for clinical use or disability rating.

Dr. Thaweethai: The symptoms that were part of the symptom survey had to be questions that could be answered by a patient regardless of prior diagnoses that they received from other clinicians they had seen in the past. We were trying to capture the symptoms they were experiencing and make sure that it was in a format that was reasonable for them to complete alongside the other forms that are part of each study visit.

As I talked about in the presentation, we were trying to develop a framework for identifying people who met this symptom-based criteria for PASC and trying to identify which symptoms were the best at differentiating people with infection history from people without infection history. Again, there are many other symptoms that were correlated with the ones that ended up in the scoring framework. The idea being that we would for the most part be able to capture and include individuals who had those other symptoms because they were highly correlated with the ones that were included in the score.

Q. Some symptom clusters, such as loss of smell and taste, thirst, and gastrointestinal problems, add up to a PASC score of 12 but show up as a minimal loss of function on the PROMIS-10 scale. As you look forward to next steps, how do some of the analyses you've done here relate to other metrics, protocols, measures, and models that contain similar symptoms?

Responses:

Dr. Foulkes: We were somewhat heartened to see that there was a correlation between the PASC score and some of these existing metrics of overall quality of life and physical health. That's not to say that people who have a score less than 12 don't also have very severe symptoms. That will be part of the next step to identify these individuals to be sure to include them. We're seeing correlation with existing metrics and continue to integrate these different types of data into the analysis.

I'd also like to address the question about the use of this definition, if not for clinical or diagnostic purposes. I want to emphasize that people with a very high PASC score do appear to have poor quality of life or poor physical health, and this presents a scientific opportunity to better understand what's happening to these very sick people. Using this approach of looking at more extreme phenotypes, which we see in lots of different research settings,

will help us understand mechanistically what's happening with these more extreme phenotypes that we've identified. Hopefully, it will provide insight into the full spectrum of PASC. We have a lot more work to do to find many more people that meet this symptom-based definition. But this definition gives us a way of saying we are reasonably sure that these people have Long COVID. And then, as Dr. Thaweethai presented, we have these different manifestations: some people have loss of smell and taste and others have post-exertional malaise, brain fog, fatigue, etc. By looking at these different manifestations, we can try to understand if there are different pathways and different ways in which people are getting these persistent symptoms. This is critical if we're going to start treating people. If we're going to be able to identify effective treatments, one of the major things we need to do is understand mechanistically what's going on. So again, creating this definition of who has Long COVID will help us feel more certain as to who meets this definition of Long COVID, and we can start to better understand what's under the hood and what's making these people sick, which will allow us to start the critical process of finding effective treatments.

Dr. Parthasarathy: An exemplar for how it would help is that for the people who have a score greater than 12, we are fairly certain they have PASC, and researchers can identify biomarkers associated with these extreme phenotypes and then take these biomarkers and apply them to the unspecified group. Applying these biomarkers to people who did not have a score of 12 can allow us to find out who's more likely to have PASC and have been left out of that mix because they had a score of less than 12. That's just one example, besides understanding the mechanisms of disease as Dr. Foulkes spoke about, to help ensure that no one gets left behind. The key thing is not to leave anyone behind and to identify everybody and do it in a scientifically rigorous manner.

Q. Now that we have a PASC score, what are the next steps? Are there opportunities for access to some of the preliminary data sets?

Responses:

Dr. Parthasarathy: As we said, this is just the first step. We talked about the clinical tests, the imaging, and the diagnostic tests that will further refine this definition. Then you have participants that are still in the study that didn't get caught by this net of the 6-month requirement. There are more participants involved. And then there are the biological samples that have been obtained from them. There are these diagnostic tests, which are called tier 2 or tier 3, depending on the level of invasiveness and how intrusive they are to someone in terms of undergoing the testing as part of the study.

All of that is going to allow us to further and better define PASC, but also longitudinally follow these people to see some of the consequences that we don't know of yet. For example, are they more likely to develop diabetes? There are some reports from smaller studies indicating a greater likelihood of developing diabetes or cardiovascular disease. Is that true? And then, as Dr. Thaweethai mentioned, there are study participants who move from one category to another category and serve as their own controls. And it gives data clarity and a better

understanding so that then we can figure out what are the underlying mechanisms based on these biomarkers and not just identify people but also identify which one of those 4 or 5 disease processes that we talked about earlier are playing a role here. And then we can use precision medicine to treat them. If it's gut dysbiosis as compared with vascular injury as compared with organ injury as compared with autoimmunity or immune dysfunction dysregulation, then we can use specific treatments for the appropriate patients.

There also are rich opportunities for identifying PASC; most importantly, social determinants of health because we're seeing what's happening to people losing their jobs and not being able to work and how that is affecting their lives. That's something that the National Academy of Sciences needs to pay attention to because we need to swiftly address them and not just observe. And we need to bring other resources in to address them; for example, changes in their life situation such as joblessness and things of that nature that need to be addressed because these are all important factors and there's a group that's working on it. There are multiple groups working on that. These are all the next steps and the foundations have been laid.

Dr. Foulkes: The data used in the initial study are currently available for investigators within RECOVER and there are plans underway to make the data more widely available to the public. We anticipate that in the coming months the data will be available more broadly and we really do encourage groups to use the data and hope that collectively we're going to be able to continue to improve on the definition of Long COVID; and more importantly, the mechanisms of disease and how we can find pathways to recovery.

Dr. Singh: COVID and Long COVID have seen the attraction of multiple different scientific realms. Dr. Parthasarathy is a sleep physician and I'm an infectious disease physician, for example. Also, within RECOVER we're seeing people with expertise in pulmonary and lung disease or people with expertise in neurology. It really does have the attention of a very broad and deep group of scientists. I think we're going to obviously learn a lot about Long COVID. I'm also really excited to see what else we're going to learn about illnesses that mimic Long COVID, ME/CFS, or others. And to me, the way I always describe things to my kids is one experiment leads to one answer, but often leads to more questions and more things to investigate. A well-designed experiment, which I think this study is, opens a lot more doors than it closes.

I'd encourage people to think about how this research is opening all these doors for different questions that we can help answer. It hasn't closed the door on anything. It hasn't said you don't have Long COVID. Rather, what it's doing is to iteratively lay the framework for us to answer so many more questions. I think if we talk in a year, there'll be a lot more information that will emerge including things that I suspect will surprise all of us. I think that's the cool stuff about science is that you have a preconceived notion and sometimes you're right and sometimes you're not. And I think we want to go into all of this with an open mind.

Dr. Thaweethai: I think to answer just very simply from a very specific research perspective, we have a score. Now, that makes it so much easier to do other types of studies. Rather than administering a survey that consists of

dozens and dozens of questions where you're looking at whether some exposure is associated with each individual symptom or each specific comorbidity, now there's a unified framework for thinking about whether something is associated with Long COVID. We're hopeful that others will use this research tool that we've conceived to answer all the new questions that will arise for future research.

Dr. Singh: I know we thanked all the participants and the physicians and the people at the different sites, but I think it's so important to recognize that the 4 of us are privileged to present this work. However, this is the work of hundreds, probably thousands of people, including research coordinators and nurses and social workers at the different sites including community engagement. And it just wouldn't happen without participants continuing to come in and give of their time, their blood, and other samples. We're so grateful and the success of ongoing work will depend on all the stakeholders continuing to be engaged. It's been a lot of work, a lot of hard work, but just so gratifying to see. I hope that the community and patients and everybody recognizes that really this is a collective success for all of us.

Q. Did the study include those who were infected in the very first wave in February and March 2020?

Response:

Dr. Thaweethai: Yes, it did.

Q. Is there a recognized protocol for objective tests to determine the existence/impact of cognitive deficits resulting from Long COVID? Or are most diagnostic protocols highly dependent on patient self-reporting?

Response:

Dr. Thaweethai: Yes, the NIH toolbox is one of the many objective tests for cognitive and behavioral function that is being performed as part of RECOVER. The results from these tests were not included in the analysis presented during this seminar because the focus was on self-reported symptoms.

Q. Is POTS tracked for Long COVID?

Response:

Dr. Thaweethai: In RECOVER, POTS (postural orthostatic tachycardia syndrome) is diagnosed by a combination of self-reported symptoms and objective clinical tests, such as heart rate and blood pressure monitoring. The analysis presented during this seminar focused only on self-reported symptoms. So, while POTS is measured in RECOVER, it was not evaluated in the present analysis.

Q. Why was the comparison group noninfected population controls, rather than noninfected healthy controls? If you remove people with chronic health conditions from the noninfected controls, the comparison numbers would probably look quite different, and thus the definition you arrive at may look quite different. Likewise, why was there no consideration of worsening of existing symptoms in creating this definition?

Response:

Dr. Thaweethai: Noninfected population controls are inclusive of individuals with both many and few comorbidities to mirror the composition of infected individuals in the study. Ensuring that the two groups are comparable in terms of comorbidities allows us to determine which symptoms define Long COVID, rather than the symptoms that are attributable to comorbidities alone.

Q. Is the data you are basing this on only from the survey answers, or is it from the test results also?

Response:

Dr. Thaweethai: It is based on self-reported symptoms.

Q. How are patients who present with symptoms equal or greater than 12 with no history of acute COVID being evaluated? Could they have had COVID-19 without knowing it or is there some way to correlate the symptoms to another syndrome or illness?

Response:

Dr. Thaweethai: It is possible that these individuals may have had COVID-19 without knowing. The rate of uninfected participants who meet the PASC score threshold is described in the manuscript.

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