

## Robin Gelburd on findings of study on patients with long COVID-19

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### Featured topic and speakers

A discussion with Robin Gelburd, JD, president of FAIR Health in New York, about the organization's recent study on patients with long-haul COVID-19 in what is currently the largest study to date looking at long-term symptoms post-COVID-19 infection.

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#### Speaker

- Robin Gelburd, JD, president of FAIR Health

### Transcript

**Unger:** Hello, this is the American Medical Association's COVID-19 update. Today we're talking with Robin Gelburd, president of FAIR Health in New York about the organization's recent study on patients with long-haul COVID. I'm Todd Unger, AMA's Chief Experience Officer in Chicago.

**Unger:** Robin, thanks so much for joining us. Ever since I read about this study a couple of months ago, I really, really was interested in speaking with you and hearing more about the results. Why don't just for starters, quick background on FAIR Health for the folks out there?

**Gelburd:** Sure. So, FAIR Health is an independent national not-for-profit. We were created over a decade ago to really bring fairness, integrity and transparency to health insurance information. We do that in a variety of ways for both research, government, academic uses in curricula and medical school education and so forth.

**Unger:** We're going to get into that in terms of how you conducted the study, but just as background, in June of this year FAIR Health published a very, very detailed study of long-haul COVID patients in what was the largest study to date of long-term symptoms. Robin, if you could just start by giving some parameters around the study. I mean, this was not a small study, but I think it's very interesting for people to understand how many folks we're looking at and where the data came from.

**Gelburd:** Sure. So for this study, we looked at our longitudinal data collection of private health care claims, which I should mention also includes Medicare Advantage. What we did was the study period was from February 2020 to February 2021, and we identified all of those patients who had a COVID diagnosis. We found that 2.3 million individuals fit those parameters, and then of those individuals, we looked at their comorbidities and identified certain comorbidities, such as cancer, cystic fibrosis, COPD, and other conditions, and excluded those patients because their results might have confounded the ultimate findings.

Of that once those were excluded, we had 1.96 million individuals left, and from there that's when we started looking at post-COVID conditions that presented themselves as new conditions 30 days out from their index date or from the first time that they had been diagnosed with COVID.

**Unger:** Just in terms of demographics, can you give us a look there? I mean, this was across many ages, including children. Any other kind of specific demographic parameters we want to just put out there?

**Gelburd:** I think why this captured the attention of so many was because of the breadth of the cohort. It did cross all ages. We looked at differences between males and females and found some interesting findings with respect to the types of conditions that presented in those two different gender groups as well as how ages impacted what types of conditions were presented 30 days out.

**Unger:** So I think what really struck me when I read about the study, I thought it was a shocker in terms of what you found about really how many people were experiencing long-haul COVID symptoms. Why don't you give an overview of key findings here?

**Gelburd:** Sure. So I should note that when we had that close to 2 million person cohort, we divided them into three different groups. We divided them into those that had been hospitalized, which meant they were either in the ICU or an inpatient. We then separated out those who were symptomatic, but not hospitalized, and those who were asymptomatic.

It was interesting. In terms of the numbers of people in general overall from that close to 2 million cohort, close to 455,000 people had presented with a new condition 30 days out. Of those who were hospitalized, it was at least about half had presented. In terms of those who were symptomatic, about 27%, but most surprising were 19% of those who were asymptomatic were among those who presented with a new symptom.

**Unger:** I mean, that's incredible. I have to ask you, were you surprised by this?

**Gelburd:** We were surprised by that. I think the team really found that notable, and I think what that allows us to do in communicating that finding is to alert other stakeholders because they can take that information and create actionable responses to it in different ways. So for example, a physician who may be treating a patient who had COVID and then presents with a new symptom would know that they may want to explore more deeply what that relationship may be.

It also may impact in terms of vaccine utilization. For example, some people may not think that they are really at risk for a serious response once they get the virus and may just be asymptomatic as many people are, not knowing that even if you are asymptomatic you might have some persistent symptoms afterwards. So, that might open the door for a conversation between the physician and their patient about stressing the importance of vaccination.

**Unger:** I think we should talk more about that, because what really stood out to me here was the number of people, even those that had asymptomatic experience with COVID-19 are then finding themselves in a situation where they're experiencing long-haul COVID systems. The percent of those folks, that that was a huge surprise. I think to your point about vaccinations, people need to take that into account that their risk is not just getting COVID, it's that you can experience these kinds of symptoms for months after "recovery." Why don't you talk a little bit about the kind of common symptoms that you're seeing with this group?

**Gelburd:** Sure. So what we saw across the board among all ages, pain presented as the most common post-COVID condition that we saw. That would be diagnoses like neurologia, myalgia, neuritis. We also saw breathing difficulties, which both pain and breathing difficulties have been cited on the CDC website as post-COVID conditions. We also saw hyperlipidemia and hypertension among those presenting as post-COVID symptoms. Why that's significant, these are patients who never before presented with traces of hyperlipidemia or hypertension. So again, it just warrants further investigation.

I should emphasize that our study was an observational study and just tried to introduce certain correlations between people who have been diagnosed with COVID and then presented with symptoms, and then they can take that further. We're basically handing the baton off to the medical and research community.

But even besides hyperlipidemia and hypertension, we saw malaise and fatigue, a whole other variety of symptoms. Whether it's thyroid issues, intestinal issues, migraines and other headaches, tick disorders and a number of mental health responses.

**Unger:** So in essence, even those presenting with asymptomatic cases of COVID-19, this can really have an impact on you. Can you talk just more specifically about the asymptomatic patients and how many of them are experiencing these long COVID symptoms?

**Gelburd:** Well, in that cohort that we had, it was approximately 206,000 individuals who had been asymptomatic that presented with one or more of these post-COVID symptoms, what had been at least identified in the literature as those related to post-COVID sequela. What that might do is in an interaction between, for example, in a clinical setting, someone may not have known that they had COVID, and if the patient presents with any one of these symptoms, it might then trigger more detailed history of the patients, where they may have traveled.

If they haven't been vaccinated, it may warrant a COVID test to see if they have antibodies, which may suggest they might have had COVID. Then that could then unleash a whole number of other questions or potential tests that might engage both the patient and the professional.

**Unger:** It's interesting to kind of look at the numbers. You had mentioned, overall I think it was 23%, but if you kind of start to segment that out, you've got nearly half of patients that were hospitalized, they're having these ongoing problems, 27% of people who had mild or moderate symptoms, but the big shocker here is the percent of people who had asymptomatic cases. Can you talk more about that?

**Gelburd:** Yes, so again, with the asymptomatic, I think it really translates into a whole variety of possible interventions. So, it might just introduce more questions on the intake questionnaire between the physician and the patient asking whether they have been exposed to anyone, whether they had ever been previously tested, or if they've been vaccinated. It may suggest that if you haven't been vaccinated, to actually prescribe the test, even if they are asymptomatic, but have these new conditions to see, as stated, if those antibodies are in that individual's ... if they appear in the test results.

I think what's fascinating too is that there are studies underway now that are suggesting vaccinations might possibly ameliorate these post-COVID sequela. So by making the physician community aware of asymptomatic patients presenting with these post-COVID conditions, they should really track these studies because it may result in further communications to their patient about why they should be vaccinated. Because not only would it prevent possible other conditions, it may ameliorate those conditions that they already do have.

**Unger:** So that's really important, I think, just the number, to go back to the study, is about 19% of people who said they were asymptomatic with their initial infections later experience these kind of long-haul symptoms. What you're saying is, so when someone presents with a physician, it's just so important to, first of all, take that step of identifying whether or not someone had COVID, because some of these symptoms might be an outcome of that. Is that basically right?

**Gelburd:** Yes, but I should mention, we are looking at claims data to really tell this story. We can only know what we know. In other words, once an individual interacts with the health care system and it results in a claim, it comes to FAIR Health and we can see what that narrative is showing. There may be instances where someone has symptoms but is controlling them at home and not seeking professional care, so they would not be tracked.

So, that is even another reason why a detailed sort of intake survey of their patient is important to be able to ask them, have you had symptoms after you were diagnosed for which you did not seek professional care? But then it would allow that physician to connect the dots of some new conditions that are presenting with that COVID diagnosis. So in other words, that patient may then ultimately fall in the bucket of the symptomatic group but they're not in our repository as such, because they have not engaged a health care professional, which resulted in a claim.

So again, it just broadens the conversation, it enriches the conversation between the patient and the physician to explore not only what they sought help for but asking if they know the person had COVID. Did you experience any of these symptoms that you were basically just treating yourself for at home? For example, have you experienced headaches that are unusual for you? And tease out other pieces of information that might be quite relevant to their treatment.

**Unger:** So in other words, they might be underestimated in terms of the impact. Is that ...

**Gelburd:** Correct. Well, right. It might be underestimated in the aggregated terms of impact, and what may be considered asymptomatic may really fall in the symptomatic bucket, but people did self-help, they engaged in treatments at home with over-the-counter types of medications and so forth, so we don't have a window into that group. But we do know from what we see, given the breadth of the data, it really suggests there is a large cohort of asymptomatic patients that are manifesting new conditions that may ultimately be linked back to COVID. We can't say for sure there's a causative link, but there's certainly a correlative link.

**Unger:** Are there any other things that you hope that physicians take away from this study?

**Gelburd:** I think that one of the things that we saw is how anxiety crosses all age groups as a post-COVID condition. So there, again, should be special attention to unusual mental health manifestations that might then really be linked back to the virus itself and, again, to help inform what type of pathway they send their patient on. Sadly, too, we saw, in terms of the younger cohort, we've seen tick

disorders manifest themselves, particularly in boys.

For the most part, as I mentioned, we looked at gender differences, women tend to outdistance men generally in most of the categories, but there were a few where males outdistanced women, and that was in kidney failure, cardiac inflammation, so forth. But tick disorders in children, in boys in particular, was something that, again, reared its head in our findings.

**Unger:** Gosh, this just is so incredibly important as a messaging point to folks about the need to get vaccinated. Last question for you. We recently heard from the Biden administration that long COVID should be considered a disability under civil rights laws. How do you see data? What came from this study to help inform policy and ensure that patients are able to get the care they need in the long-term?

**Gelburd:** Well, thank you for that question. We look at our repository, which now has over 34 billion private health care claims, as really a living laboratory that allows us to inform the public and create potential actionable items from it that impacts policy. Our prior COVID study specifically looked at those conditions that give rise to more adverse responses if you have COVID.

That was when vaccine prioritization protocols were being established and we identified developmental disabilities and intellectual disabilities as among those, and many jurisdictions caused those populations to percolate to the top. With this study, I think what it suggests is, one, the Biden administration may want to dedicate funding at the NIH level or other agencies to really look more deeply at these correlations between these post-COVID sequela and COVID. It may also impact reimbursement policies, benefit design, also public health educational campaigns.

As expressed earlier, this may really help move the dial on getting people to get vaccinated if they understand that while the virus itself may not lead to hospitalization or severe illness, you may have these other symptoms that persist and impact your quality of life.

**Unger:** Robin, thank you so much for this information and your perspective. It is so important to understand that that outcome is there and more reason to get vaccinated. Appreciate you being here. That's it for today's COVID-19 update, we'll be back with another segment soon. In the meantime, for more resources on COVID-19, visit [ama-assn.org/covid-19](https://www.ama-assn.org/covid-19). Thanks for joining us today, please take care.

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## **988 Suicide & Crisis Lifeline**

With an increased number of people reporting worsening mental health in recent years, it is imperative that people are aware of the 988 Suicide & Crisis Lifeline (formerly known as the National Suicide Prevention Lifeline) telephone program.

People experiencing a suicidal, substance use, and/or mental health crisis, or any other kind of emotional distress can call, chat or text 988, and speak to trained crisis counselors. The national hotline is available 24 hours a day, 7 days a week.

The previous National Suicide Prevention Lifeline phone number (1-800-273-8255) will continue to be operational and route calls to 988 indefinitely.