Understanding Long COVID: The Unseen Public Health Crisis

Harvard T.H. Chan School of Public Health
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https://youtu.be/5sjiXbvK-Ow

Long COVID now affects millions around the globe – yet we still barely understand this emerging condition. Its devastating and lasting symptoms prevent people from working, socializing, and carrying on their day-to-day lives, for some, the effects are completely debilitating. And like so many chronic-disease sufferers before them, COVID long-haulers face ambivalence and even outright distrust from the very health systems responsible for their care.

We need to raise awareness and better understand this disease in order to head off the next public health crisis. Join us for a riveting discussion that will bring together clinicians, researchers, policy experts, and long COVID patients to better grasp the significant impact of this new syndrome and what we must all do about it – now.

Introduction
Michelle Williams, Sc. D, Dean of the Faculty, Harvard T.H. Chan School of Public Health (@HarvardChanDean)

Moderator
Fiona Lowenstein, Journalist and Speaker; Founder Body Politic (@fi_lowenstein)
Panelists
Hannah Davis, Co-Founder, Patient-Led Research Collaborative (@ahandvanish)
Wes Ely, Co-Director, Critical Illness, Brain Dysfunction and Survivorship Center, Vanderbilt University (@WesElyMD)
Gary Gibbons, Director, National Heart, Lung, and Blood Institute, NIH, one of the co-chairs of the RECOVER initiative (Researching COVID to Enhance Recovery)
Kavita Patel, Nonresident Fellow, Brookings Institution (@kavitapmd)
Steven Phillips, Vice President, Science and Strategy, COVID Collaborative, MD, MPH
Chimére Smith, Long COVID Patient Advocate (@chiluvs1)

Message from Dean Michelle Williams -- mentions the piece she and Dr. Steven Phillips wrote about Long Covid in August.[1]
Goal to better understand this condition and to put patients at the center of this conversation.

2:33 **Fiona Lowenstein**
Thank you so much Dean Williams. It is truly an honor to be here today and to have this opportunity to speak about this incredibly important topic. I, myself, have experienced Long COVID as a patient and I can tell you first-hand that this is a disease that can be at times both incredibly devastating and also feels very confusing to experience. For those of you watching today, we would love to hear from you and take your questions. You can submit those questions via Facebook at Facebook.com/Harvardpublichealth.

I am so grateful to be here and to have this opportunity to moderate what is both an incredibly important and timely discussion and I want to welcome every one in the audience who is watching today.

With that we are going to begin by hearing some first hand accounts of Long COVID from the patients who are experiencing this disease to better understand both the scope and seriousness of today's topic. Let's take a look.

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[1] Phillips, S and Michelle Williams, "Long Covid represents a looming catastrophe' Confronting our Next National Health Disaster—Long Haul Covid. The New England Journal of Medicine, August 12, 2021 https://www.nejm.org/doi/full/10.1056/NEJMp2109285

3:31 **Patient experiences: The Pain of Long COVID** (prerecorded video)
Morgan Stephens (white female) -- As a 31 year old woman I wasn't unable to take care of myself, wasn't able to function
Jessica Lovett (white woman) -- I wasn't able to move my body, my limbs felt like lead
Cynthia Adinig (black female) -- My jaw was tight and I could barely chew, I could barely swallow more than one bite and my heart was racing again and I felt dizzy, lightheaded
JD Davids (white male) – I was in pain a neuropathic burning pain in my feet, in my hands, aching pain in my back, in my neck and a headache
Karyn Bishof (white female) – Now I spent 85 to 90% of my time confined to my bed
Cynthia Ading: I noticed that there was blood in my vomit and at that time I felt both terrified and ashamed
Jessica Lovett – I was a first time Mom and I had a two-year old son. I wanted to play with him. I wanted to be able to pick him up but I couldn't even stand up.
Karyn Bishof – I have been unable to work since April 2020. I was terminated from my job.
Lauren Nichols – I also have battled with suicidality as a result of long COVID, being disbelieved, having my pain attributed a psychological source, when they stem from physical source first and foremost.
Cynthia Adinig- They threatened to have me arrested for asking to be tested while in pain and while my oxygen was dropping
JD David – We have the right to dignified lives with rest, with care, with support,
Lauren Nichols -- We are in dire need of help and research

4:59 **Fiona Lowenstein**
Wow, that's a lot to tackle.

It is very moving to me just having experienced so much of this myself and I think what strikes me most is the intense isolation that these folks are feeling, that feeling of just having no one to turn to is so relatable and so scary.

But before we all react I wanted to take a moment to introduce our panel. We have an amazing group with us today. Joining us today is Dr Wes Ely, Co-Director, Critical Illness, Brain Dysfunction and Survivorship Center at Vanderbilt University; Dr. Gary Gibbons, Director, National Heart, Lung, and Blood Institute: Dr. Kavita Patel, a nonresident Fellow at the Brookings Institution; Dr. Steven Phillips, Vice President for Science and Strategy at the COVID Collaborative and we are also joined today by two Long COVID patients and advocates: Hannah Davis is the Co-Founder, Patient-Led Research Collaborative and is a Long COVID patient herself and Chimére Smith, a Long COVID patient who is advocating for others in her community.

So let's dive right in by talking about the tape we just saw. I can certainly relate to the pain and the suffering that these people are experiencing and as I said what struck me the most is just the sheer lack of acknowledgement that so many Long COVID patients have dealt with, that I myself witnessed as a patient. So Dr. Patel, I want to turn to you first, Why and How do you think this happened? and Why do you think so many people with Long COVID really feel that they have been ignored?

6:28 **Dr. Kavita Patel** – Thanks for having me. I want to say this is like a bucket list of mine because I have been learning from a lot of my co-panelists and having to apply some of these things in real life.

So my primary identity that I come here today (cause I wear a lot of hats in my life) is really the primary care physician in a federally qualified health center that at one point in time had about a 2/3 positivity rate of Covid, mostly brown and black communities in the very, very, very socio-economically devastated part of Maryland. Chimére I think is close to where I am clinically, but what I saw unfolding as people were coming -- either out of ICUs, out of hospitals or never needed to go to the hospital but were coming back in the clinic when we were in person were just a lot of voices that were scared to actually even talk about symptoms that might be even perceived as Long COVID because of what we just heard and kind of passionately and, I think Fiona you've spoken about this before, that outright they get dismissed and if any of you have read Malcolm Galdwell's book '*Blink*' you'll understand why that fear is very valid and pervasive .

It was interesting to me because I'd been primed learning and listening to others on this panel, like Wes that I had to look for it -- and people were scared to tell me – young women, mothers who were scared to give it a voice because it would be immediately dismissed, they'd been told that they were crazy, there were cultural norms that went with it that they were broken, or that they weren't X,Y, Z enough. And I think that doing work in primary care it reminds me of a lot of the stigma I see with depression and with mental health and things kind of converge in a way that actually hinder clinical curiosity, so you can't really feel that in a 15-minute visit that you can try to understand what is happening. The instinct, even among the best of doctors, myself included at times, is to just move on to the things you know you can do and that is not dealing with Long COVID or before we even called it Long COVID we were trying to understand: Is this a reinfection? What does this mean? We were looking for blood tests to try and validate things and when we couldn't find like the tidy results we like in clinical medicine it made a lot of us frustrated and it still does and I'm still frustrated to this day because I have people where my only answer is "I really don't know and I have no idea how to help you and I will try to find out." That is incredibly unsatisfying for clinicians who are trained in western medicine to have answers and differential diagnoses.

And it is even more frustrating, I think, for the families of my patients and I think we may be able to talk about this Fiona. I see both the sadness and desperation, not necessarily only in the eyes of the person in front of me but if you look around them it has this ripple effect that is I think very devastating and hard for me to even acknowledge.

9:39 **Fiona Lowenstein**
I think those fears are so widespread. I am glad you brought up the families as well. I think we will definitely get to that.

Dr. Ely I want to go to you next as I know you are also on the front line of this as a critical care physician and I think when people think about the hospital setting they are thinking of acute Covid but we know that sometimes Long COVID patients also sometimes require hospitalization. Dr. Ely, are you seeing those similar fears in the patients you are treating? and What has been your experience in treating Long COVID in your daily ICU care?

10:07 **Dr. Wes Ely**
Sure, and thanks for having me and I really appreciate all the things that Dr. Patel said. I really think that she is on point there. You know one of the things that grabbed me in that video of all those patients, that just grabbed my heart was that you could tell that they were speaking from a place of sincerity and honesty about their own lives and they are, let's be clear about this point, **they are the experts of their own illness**. And what they were being told was that they weren't the expert of their own illness. This is a disease that is a pathophysiological consequence of infection by SARS-CoV-2.

This is not a psychosomatic illness and when people are made to 'believe' that they dreaming this up, that it is psychosomatic that is really, let's call it what it is, it is a form of testimonial injustice.[2] People are being silenced and everybody in society right now is about "Let's fight against injustice." Well, this is a public health crisis and there is a driving unmet need for us to acknowledge that the patient is the expert in her/his/their disease and we need to quell this notion that it is okay to say that it is in their minds.

The other thing I wanted to say, you brought up the intensive care unit, you know I am an ICU doctor and I work at Vanderbilt University and I run a research program called the CIBS Center[3]-- Critical Illness, Brain Dysfunction and Survivorship – so the "S" that anchoring letter in CIBS is all about survivorship and this disease in the ICU. When I take care of somebody on life support, when they get out my job is not over. If

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[2] Testimonial injustice, wherein a speaker receives an unfair deficit of credibility from a hearer owing to prejudice on the hearer's part -- https://oxford.universitypressscholarship.com/view/10.1093/acprof:oso/9780198237907.001.0001/acprof-9780198237907-chapter-2

[3] https://www.icudelirium.org/cibs-center/overview

I think my job is over when they get out, I am failing at my job because every human being is of inestimable value and worth and no amount of disease reduces their dignity or their value. When they leave the hospital they are going to suffer from either PICS, which is post-intensive care syndrome which is the acquisition of a dementia, you know cognitive impairment, depression, PTSD and muscle and nerve disease or then 100 days later-ish develop this entire spectrum of pathophysiological consequences of Long COVID. If I am not willing to follow that person into their survivorship then I need to re-question my vocation as a physician and I think there are a lot of structural things we need to address and I am going to quit talking, I've been giving too long of an answer.

Later on I hope we can come back to what the primary care doctors are finding so difficult in saying, "I don't know." And how their life really is very difficult to see millions of new people that wouldn't have required care before but now all of a sudden they are inserted into our system when our system is not built to accommodate them, but let's get back to that later but those are my thoughts for now Fiona, off the top of my head.

13:04 **Chimére Smith**
And Fiona I'd like to speak to what Wes and Kavita are saying. I especially understand about coming to an awakening last year, probably around May or June when I realized that what was happening to me, the constant going to the hospital, going to Johns Hopkins, it seemed like every other day I was going and I was left in rooms for hours and hours and then would have doctors, usually white male doctors who would look at me and say, "Oh, there is nothing wrong, everything is fine, go home and if something is wrong just take two weeks and you will be fine". And I often think that my two weeks has never come.

So thinking of injustices I remember thinking at the end of June, before I spoke out, I said to myself, 'for some reason everything I am experiencing feels like racism and sexism in health care and it felt like injustice'. And when I started to think about it I said, 'I have to speak out about this' – at that time George Floyd had just been killed and I thought I wish I can be out there protesting with other people but what I do remember is that I said, 'if I can't be out there because I was so sick, what I could do was to speak for my community of people who perhaps had Long COVID who may not have known what they were experiencing' and I also thought about my low income families of the students I taught and I said "I can't imagine that what is happening to me, you know the dismissal, me being accused of needing further psychiatric treatment, me being accused of being a recreational drug user because I was explaining bizarre symptoms and cognitive impairment and eventually a loss of vision.

I could not imagine that continuously happening to my students and their families. And they often live in the same household and so I had to speak out.

You know I did try and address those injustices and Wes is right it is injustice, it is not fair and plenty of people are still suffering up to 20/24 months later because at the very beginning of Covid and now Long COVID we weren't doing our work we weren't paying attention, we were so quick to make people wrong or to send them on their way or to pass the buck that we didn't address what needed to be addressed. I believe had we addressed it from the beginning a little bit better than the millions and millions of patients who have Long COVID now, possibly could have been avoided.

15:56 **Fiona Lowenstein**
I agree completely Chimére and I think a lot of us who got sick in the first wave kind of had the experience of being the canary in the coal mine, the guinea pig and we know medical racism is real and we know medical sexism is real. We are hearing about that now, we are hearing about disbelief of patients and we are hearing, you know, that these health care systems really aren't equipped to deal with this. And I want to ask you Dr. Gibbons, you know, you are the Director of the National Heart, Lung and Blood Institute. What do you see as the next step in treating Long COVID and dealing with this crisis?

16:27 **Dr. Gary Gibbons**
Well thank you for that.

Well first it begins, as you began, with the patients suffering this devastating disorder and as we always do as clinicians, come alongside them.

Wes said it well, it tugs at your heart and indeed one of the early things that the NIH did in responding to this recognition of this syndrome was to first heighten awareness, that this is real, that is not a psychosomatic illness. Wes indicated that this is related to the SARS CoV-2 infection and its effect on the body. Just like it affects the lungs and creates the blood clots and pneumonias, this is one of the consequences of that infection. And in fact we presented that to members of Congress last fall, alerting them to what was emerging. This pandemic, this virus is teaching us something every two months in its twists and turns and we recognized this relatively early to the point that Congress, fairly rapidly created an appropriation to study Long COVID in December/January of last year. And when you think about it that was relatively fast for Congress to do anything – recognize the problem and then appropriate funds in a relatively short period of time and that has put us in the position of this year of putting together programs as rapidly as we can to try and understand it, figure out the risk factors for Long COVID and eventually what is driving it, to understand that pathophysiology.

We always want to understand to target effective interventions, to prevent and treat it and end the suffering and that is enabled us to launch RECOVER[4] – Researching Covid to Enhance Recovery that is this initiative in which we started, as you started, with listening to patients. And I appreciate that there are some on this panel who were participants in those listening sessions and quite frankly again, it tugged at my heart, for sure, to hear the stories, the testimonials, the lived experience of patients suffering from Long COVID and that was critical to formulating the initiative.

In fact those listening sessions were a direct part of our coalescing principle around doing this research, in partnership with patients suffering from Long COVID, and indeed invited patients to be at the center of this effort and participate and quite frankly, again, there were a few of you on this panel that joined us as we were formulating this initiative. At the table alongside researchers in the traditional groups that do these things, as partners at every level. We look forward to maintaining that sort-of patient centered focus. I will stop there.

19:52 **Dr. Kativa Patel**
Dr. Gibbons, can I ask though? -- I trained as a health services researcher. I have a deep respect for the research trajectory. I think many of us are frustrated and I am asking "How will you make sure that RECOVER, which is incredibly important, how will you balance relaying information or insights in a real learning environment?" Because I will be honest, I get more insight on twitter as to what to do than I have, frankly, from sending people to tertiary or quaternary or large centers where they have Covid clinics because they are full. It is hard for me to tell people, you know, you might not get in for six months. Is there some appreciation for how to balance that? -- which is generally not something you can see with large research efforts, you know expediency is not necessarily the objective.

20:45 **Dr. Gibbons**
So I think if I understand your point, Kativa, is that this is the challenge in real-time in the pandemic where were are trying to understand a new disease, raise awareness of that, understand to the point where were could prevent and intervene and treat it all at the same time and ensuring that providers have the information they need to address this with their patients, all in real time, in the middle of a pandemic.

So yes, this is challenge, but that is really one of the reasons you put together these panels because this is going to be a collective effort. That is why we were engaging all of the stakeholders in the whole ecosystem in order to address this. So we need patient advocacy groups like this, we need to leverage the social media platforms that you all are engaged in to be amplifying voices and authentic voices because it is your lived experience.

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[4] https://www.nhlbi.nih.gov/news/2021/covid-19-nih-study-long-term
https://recovercovid.org

As Wes said, and I totally agree, patients are the experts of the disease and how it is affecting them and that is why we want to join with your voices in a collaborate effort as partners. That is the only way, I think, this can be effectively done in a timely, rapid way that you are describing and that is why we want patients to be at the table as we design the research, as we execute it, as partners in participating in it, as well as, as you are indicating – disseminating what we know and hopefully part of the front line of implementing the kind of interventions we hope will reduce the suffering.

22:32 **Fiona Lowenstein** –
I think we have a thought from Steven, do you want to chime in?

22:34 **Dr. Steven Phillips -** Just listening to this great panel it just strikes me that we're all on the same wavelength of mutual support, meaning that we have some primary care clinicians, we have an ICU specialist, we have Long COVID patients, activists and we all represent a very symbiotic community here. We're in violent agreement here that patients need to be listened to, they need to be trusted, they need to have a responsive medical care system where physicians listen, work them up in ways that are consistent with their symptoms.

I keep wanting to turn us toward the solution as well as a graphic statement of the problem, which I think we stated quite eloquently and I think the solution is partially to recognize that we are operating in two paradigms. There is a biomedical paradigm that about half of the panel are a part of. They have been through conventional medical training and are medical practitioners and others are patients and patients are in the patient-centric paradigm.

The reality is that we have about 500,000 medical practitioners in this country that are aligned pretty much in modes of practice and healthcare that are bio-medically centric in terms of culture, philosophy and practice and then we've got Long COVID patients that represent a pandemic within a pandemic. It is incredible what their numbers are, probably millions to tens of millions, of patients will have Long COVID symptoms and at this point self-diagnosed and self-identified, which by the way is not a problem. It is probably the first self-identified illness in the history of humankind. The question is how will these two paradigms that have been acculturated to think and act and perform differently reconcile their differences and there are some, I think, powerful examples of things we can all be doing on both sides.

25:05 **Fiona Lowenstein**
I think actually Hannah embodies one of the solutions here, that is exactly what you are talking about. You know … let's go to Hannah. I want to hear a bit more about, you founded, co-founded, the patient-led research collaborative, which really puts patients in the driver's seat as researchers. Can you tell us why this was needed and why you created that initiative?

25:25 **Hannah Davis**
Yes, I think it is a false dichotomy pitting patients and practitioners against each other especially right now as we found 20% of people with Long COVID were practitioners, you know were in the medical field of course they were the ones directly involved with patients and we have doctors in our group now who are both doctors researching Long COVID and patients with Long COVID. So I think that is kind of a direction we want to see happening more. This is not one versus the other.

I do want to address this self-diagnosed issue. There is kind of a collective amnesia about what happened in the first wave. We know now that 1-3% of cases in March 2020 were recorded. That means 97-99% of people who got Covid in March 2020 did not get recorded tests, so what are you going to do, you have to self-diagnose. We also know now that 1/3 of people don't make antibodies and that 2/3 of people with mild cases serorevert by 60 days, so that is literally millions of people who got sick with Covid who don't have that proof of Covid. So the solution is not to put them in that class of self-diagnosed but to recognize the historical events that were happening at the time, which is that testing was not available outside of hospitals until May basically, that's many millions of people, and I think that is one of the things we as patients constantly have to keep advocating for and we include in our research.

I think for the patient-led research collaborative[5], one of our goals very early on, our whole reason for existing really was that we had no answers.

A lot of us, in particular, were not having the respiratory Covid, we were having the neurological Covid, including myself and Chimére, that no one was talking about back then. So our first goal was to get an understanding of these symptoms. When we joined Body Politic and we saw literally thousands of people saying like 'you know I cannot remember my son's name,' 'I almost got hit by a car because I didn't look both ways to cross the street' we knew that this was a phenomenon that was happening around the world and we wanted to get it out there. You know, basically what we want to do is answer the questions that patients have just non-stop – that impact their lives.

Early on when we started talking about this cognitive dysfunction we heard this is only in older patients.

So one thing that patient-led research did is that we analyzed that, we said 'What kind of cognitive dysfunction are you having, what kind of memory loss are you having and we found that those symptoms were as common in the 18-29 year-old group as in the 60+ group. This is widespread, this is not discriminating by age. So that is an answer we could give patients.

So another one was because we had a huge cohort without positive PCR tests and without antibodies, we actually looked at the cohort that tested negative versus the cohort that tested positive and what we found was that the difference in those cohorts was not in the symptoms or in the symptom trajectory over seven months but in the amount of time it took for them to get tested. So the positive cohort got tested at an average of 6 days, negative cohort got tested at an average of 43 days. You have an answer there and patients can take that to their provider and there is now a peer review published paper [6] and say this is the cohort I am in, my symptoms are the same and I didn't get the PCR test because I wasn't wealthy, I wasn't connected or I wasn't hospitalized. So I think …

29:20 **Fiona Lowenstein**
The issue of testing and how to actually diagnose this disease when these tests are sometimes hard to access, sometimes unreliable, I mean a new T-cell based test was able to find evidence of Covid in 42.5% of people with Long COVID[7] that had no antibodies.

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[5] https://patientresearchcovid19.com

[6] 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 Aug;38:101019. doi: 10.1016/j.eclinm.2021.101019. Epub 2021 Jul 15. PMID: 34308300; PMCID: PMC8280690

[This is a report on the general issue -- https://www.wmar2news.com/news/coronavirus/long-covid-impacting-patients-who-never-tested-positive-for-the-coronavirus]

[7] Unable to find the test Fiona is referencing. The area of T-cells and Covid-19 testing is definitely being explored. For example,

Sheridan, C. COVID-19 testing turns to T cells. *Nat Biotechnol* **39,** 533–534 (2021). https://doi.org/10.1038/s41587-021-00920-9

https://www.nature.com/articles/s41587-021-00920-9#citeas

This study has a smaller number -- Steiner S, Schwarz T, Corman VM, Sotzny F, Bauer S, Drosten C, Volk HD, Scheibenbogen C, Hanitsch LG. Reactive T Cells in Convalescent COVID-19 Patients With Negative SARS-CoV-2 Antibody Serology. Front Immunol. 2021 Jul 12;12:687449. doi: 10.3389/fimmu.2021.687449. PMID: 34322120; PMCID: PMC8312095.

https://pubmed.ncbi.nlm.nih.gov/34322120/

Another study – which is not yet reported in a journal, it appears: https://www.cam.ac.uk/research/news/biological-fingerprints-of-long-covid-in-blood-could-lead-to-diagnostic-test-say-cambridge (Mark Wills, Nyarie Sithole)

So thinking about this I want to pivot a little bit and ask you Dr. Patel about the recent controversial study[8] that came out that actually used these tests, despite the issues, to try and prove that a majority of Long COVID patients may not have ever had Covid, implying that, you know, symptoms might have been psychological, now to me this seems like something that can do real harm to patients with a real disease and I know Wes you have been talking about this on twitter, so I want to go to you next, but Dr. Patel can you tell us a little bit about your thoughts on that study and how to diagnose this illness in general?

30:07 **Dr. Kativa Patel** I'll just say briefly that anyone who thinks that they have a black and white clarity about the demarcations for this is honestly being deceitful because to the point that this is a novel virus and there is so much that we don't understand and my concern, about not just that study, but it has spurred a viral phenomenon to your point of making people feel less inclined to ever come forward or not advocate for themselves because it just takes that many more efforts to try and find someone, and by the way it doesn't need to be a physician, it can be anyone, it can be a dentist, to find someone outside of the health care profession but someone who understands.

And my bigger concern, unfortunately, I can't help but go to policy implications and I will let Wes and other talk about some of the studies in detail. My concern is that this kind of study makes denying coverage possible or makes and creates barriers to even more comprehensive care because as we get past the public health emergency time period it is very clear to me that we are going to have a number of people because for the longest time I did not even have an ICD-10 code to document so I was documenting things like fatigue, stomach pain, back pain, joint pain and we are going have so many people where that is all I can do, target symptoms and never actually fully acknowledge that these things are related.

And also to your point we do a lot of damage by associating one diagnostic criterion for something that we don't fully understand and we have seen this from my co-physicians on the panel and patients it has been a problem with other inflammatory diseases so I get very nervous when I see studies like that then somehow become de facto the science by which we use and it tends to be used (and I'm going to say something, I try not to be super inflammatory but I see this) it tends to be then used by the very same people who don't want to deal with this and want to try to push it aside because it is not something that is easy to deal with.

It becomes a way to say, "Well they don't meet this specific and they don't have this specific cell response therefore it can't be this, refer to behavioral health," and I see that referral a lot and then it also minimizes and marginalizes that there actually is an important role in behavioral health that it is part of a collaborative effort, not just a default because this person is crazy.

32:50 **Chimére Smith**
Let me say this Fiona before you get to Wes.

As a patient, I know that it is so easy, as Hannah mentioned, to play patient versus doctor but I will say this, last year I had so much trust in doctors. I thought my CareFirst card was my golden ticket to get great care. As you all know that didn't happen for me. Everything I found out about Covid and Long COVID and everything I started to share with other people about my experience happened from support groups. The very first intricate survey that I did was with PLRC. It was one of the first surveys that really delved into exactly what my neurological symptoms were because that is what I suffer from the most. I think that what needs to happen is in any injustice there has to be an upset. There can't be a reconciliation of injustice until there is some type of upset. And like Steven said, as patients what we see is that this is the largest movement of patient engagement, patients who care, who are creating their own research studies and their own research groups and their own support groups.

But I think what has to happen is and I am still suffering from it now because I recently was diagnosed with severe depression from Long COVID as part of my symptoms as well as PTSD. And because of all of the dismissal, all of the racism, all the sexism I experienced with a doctor telling me in July of last year that

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[8] Matta, J. Wiernik, E. Robineau, O. et al. Association of Self-reported COVID-19 infection and SARS-CoV-2 Serology Test Results with Persistent Physical Symptoms Among French Adults During the COVID-19 Pandemic. JAMA, Internal Medicine, November 8, 2021.

Covid did not impose or cause any neurological symptoms. He wanted to tell me how many schools he went to but he would not listen to me about the fact that I thought I had XXXX neuralgia until the very end of my stay, he was like, "oh I think you have it."

So I think what needs to happen, it is going to take time for patients to lose sort of like a resentment towards the medical community – I hate to say that -- but I think unless we get real about that it is going to be difficult to try and find some balance.

For me, I am very afraid now. I have been scheduled for seven appointments between now and the end of the year and 2022 and I am desperately afraid to go back to a lot of those doctors because my fear is still almost two years later that I still run into doctors who still have no idea what I am talking about and they refuse to listen. All those medical records I have, all those things I have been a part of and they still don't listen.

And I think for some patients and with good reason, we have developed post-traumatic stress from dealing with doctors. Right, good bad or indifferent and I think that is something we really need to talk about and something we need to move through, not move past, not move past. I am in therapy about how to approach doctors going forward, what are my future interactions with doctors so that I can get the best care possible, because honestly I am afraid.

36:19 **Dr. Wes Ely**
I want to say Chimére that … I want to apologize on behalf of the medical community for what we have done for you …. ['THANKS *from Chimére]

We have injured you and I carry a moral injury because I know I have hurt people along the way in the way I cared for them in the ICU in the way that I cared for them in survivorship. During Covid I had to process my own shame and grief and the weight of this and I wrote a book[9] called "*Every deep, drawn breath*" and it is raising money for Covid survivors … because we have to do something to come back from this. But you know I watched you nod during the video when one of the patients talked about suicidality and I saw you nod. I had a piece in Stat News[10] a few weeks ago called "Silencing Long COVID patients."[Link has a different title.] And there was a beautiful Atlantic[11] story that I linked to it about the physical pain and suffering caused by being silenced. It creates an injury that all of you are telling me about and I hear you and we all need to listen better to you so first I wanted to apologize to you.

I am thinking right now about one of my patients who had Covid and she has gone deaf. She's lost her hands and feet too so she has had a lot of problems from Covid. Another of my patients is blind from Covid. Those are easy things to see but unfortunately, many of the people suffering from Long COVID have on the exterior what looks to everybody else as normal. If you look at Hannah or Fiona, everyone looks at them and thinks "Oh, they look normal, they're not sick" --or you Chimére -- but what happens is that doctors in western medicine like Kavita said earlier were taught to look for structural things that they can pin their hat on. They are taught to test for a diagnosis and if the antibody test comes back negative, they don't [the patient doesn't] have that problem.

Well in Long COVID, the pathophysiological response is not following that rule set. Period. End of story. You cannot diagnose this with antibodies. There are way too many people who don't have the antibodies. Beautiful study in Lancet Respiratory Medicine[12] just showed that 40% of elderly patients months after they had documented Covid had no detectable antibodies. So this is out.

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[9] https://www.simonandschuster.com/books/Every-Deep-Drawn-Breath/Wes-Ely/9781982171148

[10] https://www.statnews.com/2021/10/22/dont-give-covid-19-long-haulers-the-silent-treatment/

[11] https://www.theatlantic.com/family/archive/2021/03/psychology-of-silent-treatment-abuse/618411/

[12] Does infection with or vaccination against SARS-CoV-2 lead to lasting immunity? https://www.thelancet.com/journals/lanres/article/PIIS2213-2600(21)00407-0/fulltext

This is a clinical diagnosis and we have to believe you. One of my patients said to me, "I wish my hand was cut off because then people would see that there was something wrong with me." His name is Auden Housely – he allows me to use his name.

I want to put out some solutions here. Some of the solutions that I am thinking of are as follows. I 'll give you three.

One of them is Hannah Davis and Fiona. This is [showing paper] Hannah's paper that she published in e-clinical medicine[13]. It is a beautiful paper. Hannah you did such a great job first authoring this paper with real data to help wake up doctors like me that this is a patient-led, literally your group is called patient-led, research program and it is such a beautiful bridging between people in academics like myself – I mean I am at the bedside some, I am a real doctor, I play one on TV anyway. But also people in academics where this ivory-tower stuff is being bridged by people like Hannah who are giving us real numbers and real data from these groups. And we have to keep that going and growing.

Second solution, this is not a technology driven disease in my mind because the doctors fail Chimére if we go in and say, "Okay Chimére you are here, I'm going to test this, this and this." Five minutes of time with you, that's enough. No. That is not enough. I need to say not "What's the matter <u>with you</u> Chimére" but I need to switch the preposition to "to" and say " What matters <u>to you</u> Chimére?" and then I need to shut up and listen to you tell me what matter to you and that is about switching technology from first -- putting technology second. First is touch. I need to touch first, technology second and that is a way to rebuild this community that has injured you Chimére. Every doctor can restructure, we can walk in the room and say "What matters to you, let me listen." We do need to restructure. I would like to know what Kavita, Gary others say. We need to give people longer time slots to these Long COVID patients because these 15-minute time slots don't work.

And the last thing I want to say and I will shut up is, we can teach people compassion. Compassion is not something innately born inside of every human being but it is an instrument of healing that can be taught. I, in forty seconds, this is scientifically shown, I in forty seconds can establish something that builds trust between you and me by saying: "Chimére, I don't know what you are going through. I know you are suffering. I don't understand it but I will not leave you and I don't know what I want to know to take care of your Long COVID but I will form a promise to you, a covenant, that I will stay with you in this and what I don't know I will tell you that I don't know and I won't disbelieve you. And that is how we can start to move forward with this Long COVID community.

41:43 **Hannah Davis**
I just want to add one point that is missing from a lot of these conversations is that a lot of people kind of don't know what the next steps are, especially people who are outside of the post-viral field. For me all of my tests came back normal, until I started seeing a myalgic encephalomyelitis doctor then none of my tests came back normal.

I think one of the big things Long COVID providers can do is learn the right tests from people who have been in the field for decades. So natural killer cells, for example, the natural killer cell function diminishes over time in Long COVID patients. T-cells are dysregulated, ferratin is often low, if it isn't extremely high, cytokines are abnormal. You know there are so many tests that can be done and treated for things like dysautonomia, it's not perfect but you can do things like midodrine or beta blockers as well as compression and electrolyte tablets.

I think that one of the gaps that, for me, has really been missing is learning from those experts and post-viral research and myalgic encephalomyelitis research is a tiny, tiny field. I think there are like 17 providers in the whole country. The wait lists right now are over a year-long but those are the experts and they have put out an amazing pdf on tests you can do and treatments that are available. [14]

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[13] Davis HE, Assaf GS, McCorkell L, et al -- see Footnote 6
https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370(21)00299-6/fulltext

[14] https://mecfsclinician coalition.org/clinical-management/

There are no real cures available there are no real life changing treatments available and for that we need more research and recognition but it is something that we really need that information distributed much, much more broadly and that is kind of one of the things we are focused on. Showing that there are all these areas like brain stem dysregulation, abnormalities in the blood. There is so much good research out there that just needs to be highlighted and sent around to all physicians.

42:38 **Dr. Kavita Patel**
Hannah, can I just ask, is anybody familiar with ways that people, I don't want to call them patients, they can be family members, but people, friends can help kind of navigate the system.

Because frankly I'm a pretty smart doctor and I know a lot of people but it is so hard. I know I would not order those tests. I would not feel comfortable and I am board certified in everything but I wouldn't even know how to figure out … I mean I can call Wes, I can call a friend at Sinai, I call someone at Yale, they can't help my person there.

Is anybody in any of these groups or the NIH kind of creating a way to say, here are five questions you can ask if your care provider is going to have some of this knowledge? Or, here is how you can find? It is hard to get access to these appointments, its hard to navigate and my typical patient has, you know, a job that doesn't pay well and drives for Lyft, to and from, making money and has kids that he or she needs to take care of. How do we do this if people don't have the time to navigate it? Is anybody developing those kinds of incredibly practical resources?

45:01 **Fiona Lowenstein**
I do just actually want to ask Dr. Gibbons quickly, kind of what your thoughts on this are. We know that research is the next stage on this and I would like to have you respond to Kavita specifically. How are we trying to bridge this gap? and What advice do we actually have for people who are navigating the system?

45:19 **Dr. Gary Gibbons**
Well it is a great point and as one of the challenges of a fast moving, dynamic pandemic, people are trying to understand a novel disease and so one of the elements that I think Hannah brought out is trying to convene together both lived experience as patients about what is going on. But also as Hannah was indicating there are other post-viral syndromes that could be informative in terms of their length of study, certainly ME/CFS is one of those examples. Wes alluded to some of his work on post-ICU syndrome. There are things about post-Lyme etc. There may be some common themes about some of these responses to these microbial or other injuries that we can all learn from and it doesn't mean that they are all going to be perfectly overlapping and the same but I think by bringing together, and really actually as part of the research, comparing and contrasting what we are finding and sharing that across these various experts, particularly in a multi-disciplinary way.

I think that is part of it, so that is one of the things we are trying to do in RECOVER is create those sort of cross-disciplinary teams that are not only inclusive of scientists but as we tried to indicate with patients as partners in this. So that is one.

You may have already seen a recent output from the NICE National Institute for Care Excellence as well as the WHO that are convening internationally. [15] They are trying to hone down on things that can help us speak the same language, what we call case definitions of what we are talking about with these syndromes -- such that we can actually talk to each other and compare information across studies. That will be

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[15] https://www.nice.org.uk/guidance/ng188 -- accessed November 29, updated Nov 11, 2021 – among other items the existing commentary on identification was updated [although it appears, from a cursory look, that they stayed with the same definition.]
https://www.who.int/publications-detail-redirect/WHO-2019-nCoV-Post_COVID-19_condition-Clinical_case_definition-2021.1

important for us to convene these groups so that we are sharing information across borders, across disciplines and I think that will be an important element, certainly as it evolves one of the things that they can do is systematically go through what is out there, what do we know from Hannah's study as well as something that might come from the CDC.

Let's systematically put that together as a collective to figure out what do we know well, where are the gaps in what we need to know and how do we fill them.

So it was pointed out the various tests, lets really see, can we scale and how applicable are those tests to the broad spectrum of people with Long COVID. I think when we put that together we will be able to give coherent information both to patients and, as Wes was saying, to providers as well.

48:14 **Fiona Lowenstein**
Dr. Gibbons, when are we going to have, when are we going to see tangible results from this research that can actually inform policy decisions and help folks that feel they are struggling along?

I know there is a lot of excitement that this research is happening, but I think patients are also feeling resentful that there haven't been immediate answers. Do you have a timeline in mind of when we might actually see some of these conclusions?

48:34 **Dr. Gary Gibbons**
Well science moves at the pace of science. I know that is not going to be a satisfying answer but in order to do investigation, you have seen it in real time in this pandemic, you can't rush the result of a vaccine as promising as it is it takes time to do the systematic studies and put it all together but we are moving as fast as we can.

And we are also, to Chimére's point, we have to move at the speed of trust and I think that was also Wes's comment, we are doing this collaboratively with you and so I think the things that will be critical, for example, is to help us have inclusive participation whether it is from your communities as I think Wes was alluding to, this can be a great collaboration where we can bring together patients with ME/CFS, patients who have Long COVID to do the kind of comparative studies we are talking about. That will help us move more quickly.

One of the things that I think Hannah acknowledged in her work is that much of the study was white and not really inclusive of black and brown communities. We need to be sure that we are inclusive of those who have been most devastated by acute Covid and really be sure that they are included in our studies of Long COVID, that's going to take work and that's going to take time and outreach and building of trust as Chimére alluded to. So those are the things as fast as we want to go and understand this and relieve suffering it is also important that we move at the speed of trust and do it in a way that is deliberate in being sure we are getting good science done as well.

50:30 **Fiona Lowenstein**
So I want to ask you Chimére as you hear this, do you feel you can wait for science to move at the pace of science, as Dr. Gibbons said?

50:35 **Chimére Smith**
It can be a little frustrating because I feel like, I've almost been waiting for two years, but I will say this, I'm learning every day about science moving at the pace of science but what I like to caution health organizations and any other organizations who say that they are patient centered there needs to be a complete overhaul about what that looks like because there are so many different navigations and so many different layers to what it means to be truly patient-centered and I think that sometimes we have to delve into so many different topics about what that means.

For instance, being a part of these patient engagement practices and these studies also means being cognizant of patient energy and patient capability because, for instance, I can't be on a meeting for three and four hours, you know, trying to solve a problem. I need breaks. I need to be able to move. I have to be able to lie down. There are so many different areas of this that we have to be able to sharpen and fine tune if we really are going to be patient centered and we have to listen to patient voices.

What I believe, like I said before, there is no upset unless you really start. I think the major upset that needs to happen is that we have to completely start to think about the patient voice being a central voice. Now that does not negate from a doctor's voice but I think that in order to be successful with any sort of patient engagement we've got to stop the infighting of – the truth is Fiona, we've been right, we were right before, we were calling it Long COVID before a lot of people, we were galvanizing on social media. That is the reason why we are having this conversation, if we had not been, Hannah you, if we had not been hours and hours on Twitter, on Instagram or Facebook, there would be no conversation, so my thought is, just like I empowered my students before I had to stop teaching, their voices matter.

So if you are not willing to look at the patient voice seriously then everybody is doing a disservice and that is just the way I feel, science or no science, we are doing a disservice if we are not putting the needs of the patient at the forefront and the voices. Not just people who are implementing things and they are coming back to the patients and saying, "What do you think about this?" No I need to, we need to be at the table.

53.29 **Fiona Lowenstein**
You need to be at the table, you need to be drivers.

Steven, I know you understand the urgency of this crisis because you have declared Long COVID our next public health catastrophe. Obviously I agree with you, Chimére was saying we have been shouting this from the rooftops since we got sick.

What triggered that level of alarm for you? Can you tell us a little bit more?'

53:47 **Dr. Steven Phillips**
Well not only the alarm but now we hopefully we can get to the solution.

But just listening to the frankly the disappointment and anger from Chimére and Hannah in terms of how Long COVID patients are being treated, I think we have to look for solutions.

The catastrophe is the sheer numbers and the sheer level of functional impairment and debility that is unrecognized, undiagnosed, untreated so the numbers that we highlighted in our New England Journal piece conservatively stated 15 million American are or will be affected by Long COVID. They present with a range of up to 200 symptoms affecting any and every organ system in the body and as we have heard very eloquently from a number of physicians, the health care system is not organized structurally, professionally or culturally to handle this massive pandemic within a pandemic.

So what are the solutions and I heard Gary [Gibbons] actually hit the nail on the head, which is essentially, how do we get on the same page, how do we listen to each other and hear each other and I think that is the answer and if I could just challenge everyone on this panel and many on the audience. The light bulb went off for me in comparing a lot of what I am hearing of the AIDS activism of the 1980s and 1990s and I wish for us to go back to the HIV/AIDS playbook because I think ultimately what happened there and it took way, way too long, I am not advocating a ten or twenty year dog fight.

Ultimately what happened is that the AIDS activists turned frustration, anger and outright hostility toward the formal medical structure and the biomedical model and they turned it on its ear, to be listened to, to be respected, to have research that actually came to fruition in terms of curative medications.

I think the same playbook here would be well advised and I think we are very much in the early stages of frustration and anger and the playbook says, Why don't we try to understand what the biomedical system, standards, criteria, mindset is and let's see if they can understand more where we are coming from and it was not an easy process but ultimately I think the activists learned to operate and actually turned the levers of the biomedical enterprise to their benefit both on the research and by the way also on the clinical treatment side. If you remember some of the early hostility against AIDS patients, it is kind of like what I am hearing now.

So what I would plead for from all of us is to understand what Gary was saying in terms of case definitions, What is a case of Long COVID, granted there is not a clear handle, but why don't we listen to patients and why don't patients listen to some of the doctors who are well-informed and empathetic and lets figure out how to define it, lets figure out what the outcome variables are, in a standard way, just so we can study it. Right now you know what we are hearing is a lot of noise but not a whole lot of signal. How about we turn that noise into signal?

57:45 **Fiona Lowenstein**

I am glad that you are bringing up HIV/AIDS because I know that both Body Politic and the Patient-Led Research Collaborative have looked at lot at ACT-UP's work and really tried to incorporate that. So Kavita I want to ask you, because for me this feels like a pivotal moment in history, you know a moment to learn from those mistakes in the past, to redefine patient engagement as Chimére has said and as Hannah is doing and to tap into Disability Justice movement and to just do right by everyone who is made disabled and chronically ill by this disease.

But as Steven has pointed out this is not the first illness outbreak that has led to long- term illness. I mean we had HIV/AIDs activists who similarly had to fight to be heard and we also have people with myalgic encephalomyelitis who, as Hannah mentioned, are still fighting for that recognition. So Kavita, I want to ask you, how can we make sure that our approach to this disease stands on the right side of history?

58:36 **Dr. Kavita Patel**

I think that we have to start by not isolating it to the traditional medical complex. I think that we need traditionally called a 'health in all policies[16] 'approach. This affects all aspects of your life. I only see someone for 15 minutes maybe once a month, if I am lucky and 99.9% of their lives are lived in schools, around people, in jobs, can't keep jobs, disability is very interesting that you mention, like the complex process of filing for disability or even long term leave is so burdensome and that's left to who – it is just left to the individual.

I would love to see, as part of what I think is happening, where we are talking about infrastructure and economic recovery, I want to see this kind of baked into that in a meaningful way, so that we are like really looking at like a longitudinal process of care. Because I've got news for you, most of our doctors, like I'm putting on a nice face, I've put on makeup, I look really happy. We are all tired and I don't know if we can ask doctors to kind of, I agree with Wes's moral like how injurious my actions have been but I don't know that I can take more or ask more right now so we have to all do our part.

I will just end with that means supporting the family and we have to expand n of 1 and take it and family loosely defined and this is what we saw in HIV/AIDS that we needed to look at society and I can't help but think that until we have celebrities and really popular people on social media like a Kardashian people didn't actually notice Long COVID as much and I'm willing to even ride that wave if it will get people to actually talk about it and talk about it not just in clinics and hospitals but to talk about it in classrooms and to teach about it just like we do all sorts of injustices.

1:00:25 **Fiona Lowenstein**

Absolutely, we only have a minute left so I just want to go quickly to each person here to get your reaction on that. Dr. Ely,

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[16] Health in All Policies (HiAP) sometimes also known as Health Equity in all Policies https://www.cdc.gov/policy/hiap/index.html

1:00:30 **Dr. Wes Ely**
Yes, I'll tell you three things. One thing is that in addition to the HIV/AIDS playbook, we have to recognize there is one big difference here in the societal implications of Covid is that people who never got the virus have also been injured. We have not mentioned them once and that is silencing them as well because there is a lot of PTSD and depression in people who never got the virus because it happened to the whole society, so lets not forget those people.

Secondly, we have tons of support groups here in the CIBS center for example, we take people from all over the country – spouse support groups, covid support groups, ICU survivor support groups, these support groups need to be expanded on a much larger scale. Chimére mentioned that. That's a second bigtime solution and its got to happen. We have all these Zoom groups within the CIBS center but it's going to have to grow out much bigger than that nationally.

And thirdly, what Kavita said is right on, people cannot navigate disability and they are losing their electricity, their lights, they can't get on their internet anymore so they can't apply for disability or insurance. So for example with every penny I get from this book we are hiring in the CIBS center. It shouldn't rest on a private organization, I mean we are a public research organization but even so, we are hiring social workers and insurance specialists to help Covid survivors figure out how to get their insurance and disability. So we are going to do that for our patients, but what about on a national scale employing these social workers and insurance people to help all these people to navigate because it is a nightmare and they just can't do it.

1:02:04 **Fiona Lowenstein**
Absolutely, thank you so much for pointing that out that holistic approach. Dr. Gibbons final thoughts from you.

1:02:10 **Dr. Gary Gibbons**
I love your focus on taking that holistic approach both to patient engagement, that collaborative shared decision-making and co-creation with researchers and clinicians. And really I thought Steven's point was well made, we are all on the same team here. We recognize this is a devastating impact and it is really going to take all of us collectively working together, sharing our knowledge and its an ambi and broad omni-directional exchange with, again, the lived experience experts of patients as well as investigators and providers to figure this out and it is going to take teams to collaborate on this and eventually systems, as Dr. Patel was indicating, are going to have to re-arrange and accommodate themselves and I think we are going to have some innovative approaches.

Just one other thing that resonates, another parallel to AIDS is some of the rare disease communities that had the same sort of challenges of caregivers not really understanding their disease and them having to form support groups, some of those foundations actually are driving clinical trials now, of their disease. So we have seen similar models work and I think it can apply here as well. I'll stop there.

1:03:39 **Fiona Lowenstein**
Hannah, I'd love to hear your final thoughts. What are your hopes for this NIH research? What would you say to someone dealing with Covid right now?

1:03:49 **Hannah Davis**
I mean I think we all really feel our biggest hope would be RECOVER and we were really excited about it but I think right now as someone who participated, they are failing in patient engagement. We definitely are not being treated as partners. We need a structure that holds the researchers accountable to patients, some kind of board or something, you know patients at every site. There is a lot that needs to be done there specifically.

As someone who has Long COVID I would again say, you know, there is so much information out there it is possible to get some treatment, look to myalgic encephalomyelitis doctors.

There is new, interesting research on microclots[17] in Germany and South Africa that are pretty promising, as well and, of course, Body Politic which is a life saver for many of us.

1:04:49 **Dr. Gary Gibbons**
Hannah, we can do this offline, of course but if there are things that RECOVER is falling short, don't hesitate to contact us. We are trying very hard to engage patients at every level, Steering Committee, Executive Committee, decision making so in addition to co-creating the protocol and design so we are committed to this and if we are not getting there and it at the level of the consortium and at the local level, if it is not working give us that feedback, let's see how we fix it together.

1:05:13 **Hannah Davis**
Thank you I will reach out to you.

1:05:13 **Fiona Lowenstein**
I am glad to see that conversation is starting and clearly we have made some progress just here today. Thank you all so much. Unfortunately we have reached the end of our time. I think we could go on talking about this for many more hours and hopefully we will continue to.

I would like to thank Dean Williams and the Harvard School of Public Health for highlighting this incredibly important topic and keeping it in the forefront of our minds. Long COVID is not going away any time soon and I am so grateful to all of you who tuned in today.

Now if anyone watching today is dealing with Long COVID, please see the resources on your screen. These are some support groups and advocacy groups. This is only a partial list a longer list will be available on the website later today for those interested. Thank you for tuning in and have a great day.

Resources on the screen --
Body Politic
Wearebodypolitic.com/covid19 – on Slack

Patient-Led Research Collaborative
Patientresearchcovid19.com

#MEAction
meaction.net

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[17] For example -- Pretorius E, Vlok M, Venter C, et al. Persistent clotting protein pathology in Long COVID/Post-Acute Sequelae of COVID-19 (PASC) is accompanied by increased levels of antiplasmin. *Cardiovasc Diabetol*. 2021;20(1):172. Published 2021 Aug 23. doi:10.1186/s12933-021-01359-7
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8381139/