

Energy & Commerce Health Subcommittee

Hearing on “The Long Haul: Forging a Path Through the Lingering
Effects of COVID-19”

April 28, 2021

Recorded Hearing Available [Here](#)
[Hearing Memorandum](#) from Chairman Frank Pallone

Witnesses

Panel I (Federal)

Francis S. Collins, MD, PhD
Director
National Institutes of Health
([Link to Written Testimony](#))

John T. Brooks, MD
Chief Medical Officer, CDC COVID-19 Response
Centers for Disease Control and Prevention
([Link to Written Testimony](#))

Panel II (Provider/Patient)

Steven Deeks, MD
Professor of Medicine
University of California, San Francisco
([Link to Written Testimony](#))

Jennifer Possick, MD
Associate Professor, Section of Pulmonary,
Critical Care, and Sleep Medicine
Director, Post-COVID Recovery Program
Winchester Center for Lung Disease
Yale-New Haven Hospital
([Link to Written Testimony](#))

Natalie Hakala
Patient
Eugene, OR
([Link to Written Testimony](#))

Lisa McCorkell
Patient
Oakland, CA
([Link to Written Testimony](#))

Chimere Smith
Baltimore, MD
([Link to Written Testimony](#))

Opening Statements

Subcommittee Chairwoman **Anna Eshoo** (D-CA):

- This is the first congressional hearing focused on Long COVID.
- Initial studies hint at “alarming scale” of people suffering from Long COVID – could be millions of patients suffering these symptoms.
- Health system is facing an “avalanche” of patients with these conditions, and many long haulers struggle to be taken seriously by the medical system, esp. black women and women of color.
 - Expect that Long COVID will further uncover our failures in appropriately treating chronic disease more broadly.
- “For sure, federal leadership is going to be needed to coordinate and address the swell of long-haul COVID patients. We may need a nationwide network of Long COVID clinics with multi-disciplinary clinical teams.”
 - Long COVID patients are seeing gaps in the benefits available to them, including disability insurance, workplace accommodations, and comprehensive insurance coverage.
- NIH about to announce millions in funding for long COVID researchers.

Subcommittee Ranking Member **Brett Guthrie** (R-KY)

- Guthrie and Eshoo introduced legislation (the Ensuring Understanding of COVID-19 to Protect Public Health Act) to require NIH to study the long-term impacts of COVID – this ended up as \$1.15 billion for NIH enacted in the 2020 year-end omnibus.
- Pleased to learn that the National Institute for Allergy and Infectious Diseases (NIAID), in collaboration with other NIH Institutes and Centers (NIH), hosted a workshop on PASC in December 2020
- People have reported that Long COVID symptoms are preventing them from returning to their jobs and completing daily activities.
- Each long COVID case seems to be different – varying symptoms and severity.

Full Committee Chairman **Frank Pallone** (D-NJ)

- Still developing a full picture of “long COVID” – for some, the continuation of their symptoms and management of their care can be more of a battle than the initial onset of the virus.
- One study of 4,000 patients found that 15% of COVID-positive patients developed Long COVID – more information is needed, but this raises an alarming trend.
- Studies also indicate that Long COVID is prevalent among health care workers.

Full Committee Ranking Member **Cathy McMorris Rodgers** (R-WA)

- Long-term impacts of COVID are incredibly concerning.
- We need better understanding of symptoms and treatment for Long COVID – the University of Washington’s study found that nearly one-third of COVID patients reported long-term symptoms.
- [Seattle Times](#) recently shared the story of a COVID “long hauler” – long COVID exacerbated underlying lung condition, requiring surgery.
- No diagnostic mechanism for Long COVID, and limited treatment options are available.

Testimony (Panel I)

Francis Collins:

- We've heard troubling stories of people who are suffering persistent symptoms months after coming down with COVID, even those without initial symptoms or with mild cases initially.
- Speaking directly to patient community: some of you have been suffering for more than a year without answers or treatment options, sometimes facing skepticism about symptoms. We hear you, and we believe you.
- Current studies show somewhere between 10-30% of people infected with COVID develop long-term symptoms.
- Need to study tens of thousands of COVID patients and need diversity in the subjects.
- NIH is launching an unprecedented "meta-cohort" – using existing longitudinal studies, EHRs from major health systems, etc. Will give researchers access to existing data.
- NIH will invite patients (esp. from patient groups like LCA/Body Politic/Survivor Corps) to participate in studies.
- NIH has already received 273 applications for long covid research funding.

John Brooks

- Based on studies to date, CDC distinguished three categories of post-covid conditions:
 - Long COVID: range of symptoms that can last for months.
 - Long-term damage to one or more body systems or organs.
 - Symptoms due to prolonged treatment for COVID.
- CDC is working to enhance collection of demographic data to advance health equity and address disproportionate impact of Long COVID.
- CDC is working on interim evidence-based guidance for clinicians.

Questions and Answers (Panel I)

Chairwoman Eshoo:

Q: "The Biden Administration has developed a really wide-ranging whole of government response to the acute impacts of COVID-19, including the formation of the White House COVID Response Team and the COVID Health Equity Task Force. But I don't think there has yet been a similarly public, coordinated, and comprehensive effort to address this multi-faceted issue that we are having the hearing on today, because, as you both noted, it's a crisis for patients and has an effect on our health care system. And there are so many issues that are attached to this. What I would like to know is, who's in charge of leading this effort? In listening to both your testimonies, you're both in the same lane. But is there one person, outfit, or task force in charge of this?"

A: Collins: – "It's a very appropriate question. I think we have excellent relationships between NIH and CDC. Dr. Brooks works intensively with Dr. [Andrea] Lerner and my staff. We're working with FDA also in this space, and also with CMS. But you're right, there is no sort of supervisory, top level oversight..."

Q: "Do you think we need one?"

A: Collins – “I have to think hard about it, because sometimes it can be a good thing or sometimes it can get in the way of a more organic approach.”

A: Brooks – “We are collaborating intensively, and this is sort of standard for how we often address these emerging problems, that we work hand-in-hand very closely on both the natural history and epidemiology side, together with the clinical side, because both are needed for a coordinated response. And we have regular calls with NIH. At this time, we’d have to think about whether a coordinating body is necessary. I think we’re working very well right now together... While we’re in the preliminary phases of really beginning to define what this is, it may be some time before we have a lot to bring to some of these other groups, particularly groups like HRSA, to trot this out. I will say, though, we have already been in touch with CMS about case definitions, as well as the SSA”

Q: How long is it going to take to develop the meta-cohort response, and in the meantime, what can we tell our constituents that are undergoing these symptoms today?

A: Collins – we are moving forward on an unprecedented timetable. Funding made available in December, NIH released call to all entities by February. Expecting to make awards on grants (approx. 273 applications received) within the next 3 weeks.

Ranking Member Guthrie

Q: Can you speak to anecdotal reports that vaccines are causing improvement in people with Long COVID?

A: Collins – some anecdotal reports that getting the vaccine has benefitted, in some cases dramatically, Long COVID symptoms in just a few days. But hard to get good data so far. Interesting reports, but really need the larger scale of research to understand what it means.

Q: Recent study found that nearly 13% of COVID patients received their initial diagnosis only when presenting with Long COVID. How can we diagnose these Long COVID cases earlier, and what other diagnostics are needed to ID long COVID?

A: Brooks – there are also people who develop long COVID symptoms with no record of testing, and we can’t necessarily confirm whether they were infected with COVID. Need to keep that in mind when developing case definitions. Need to make sure that this condition is recognized by providers. Need to also take patients at their word about their symptoms – can’t ignore or minimize.

Q: How is NIH leveraging existing longitudinal community-based cohorts and what more can be done?

A: Collins – All of Us is massive, diverse study for NIH, aiming to have 1 million Americans included. Already up to over 300,000 participants, including many who had COVID and/or Long COVID. That cohort will be part of our meta-cohort, and we have their historical information, including potential predisposing factors.

Chairman Pallone

Q: More details about what CDC has seen about incidence and prevalence of Long COVID so far?

A: Brooks – CDC has been doing cohort studies since early last spring. That together with external research find that it’s common – could be as much as 2/3 patients with COVID have some post-COVID conditions (e.g., made a related clinical visit within 1-6 months after diagnosis). For some, the condition gets better, but for others it goes on for months. Larger numbers in studies will let us hone in on what the precise numbers look like.

Q: Can you explain more about what meta-cohort means and how that will help?

A: Collins – It’s about utilizing longstanding cohort studies (All of Us, Framingham [Heart Study], etc.), and involving people enrolled in COVID treatment trials – did that have an effect on whether they developed long COVID?, as well as data from “citizen scientists” and patient support groups.

Q: How is CDC planning to keep providers informed on diagnosing and treating patients with Long COVID?

A: Brooks – webinars and regular calls, regularly updated interim guidance, sharing info with patient groups.

Ranking Member Rodgers

Q: Re: recent letter from Reps. Griffith, Guthrie, Rodgers to NIH about understanding origins of pandemic – do you believe that it is in the public interest to have a comprehensive scientific investigation into COVID origins, including potential links to laboratory origin?

A: Collins - Yes, do believe it is needed. There is an effort between several federal agencies to put forward to WHO the necessary components for a follow up investigation. NIH is working on a detailed response to the letter.

Q: We’re learning that children are better protected from some of the most severe symptoms, but that some are getting Long COVID. What do you know about long COVID in children?

A: Collins – this is a critical part of the meta-cohort. Children can get Long COVID and may even seem that around 11-15% of kids with COVID infection can get long-term consequences – can be devastating. There is also a separate problem – MISC – that some children can get – autoimmune condition that is related to COVID but has a different pathogenesis than Long COVID – we already have more info on how to treat MISC in kids.

Q: Can you speak to how post-COVID conditions are similar to those seen in other infectious diseases?

A: Brooks – post-COVID complications comparisons are most often drawn to ME/CFS. Need to be cautious, though, that we can’t always tie a new thing to something we know. Long COVID is creating extreme fatigue, chronic difficulty breathing, loss of smell (unique to this infection). What we are doing now to understand post-COVID conditions can likely help us better treat/understand conditions like ME/CFS.

Rep. G.K Butterfield (D-NC)

Q: Is the CDC tracking race and ethnicity in its long-term studies to understand disproportionately impacted communities?

A: Brooks – We absolutely are, as well as other SDOH. EHRs get tricky, because you have to rely on what clinicians have entered, rather than self-identification.

Q: How is NIH planning to address data standardization, and what barriers are there to effectively using the meta-cohort data?

A: Collins – We are relying on common data elements to effectively compare data across studies – both preexisting and developing new CDEs. The metacohort will have three core facilities – a clinical science core to develop clinical measures, a data science core to focus on CDEs and building a dataset, and a biorepository to obtain blood and other samples and store them safely.

Rep. Fred Upton (R-MI)

Q: What has NIH learned in the year since the launch of the RADx program?

A: Collins – We developed innovative testing capabilities now available at the point of care rather than a separate laboratory, and now even home testing has become a reality due to RADx. We developed a “shark tank” process to identify most promising avenues and have been successful in allowing about 2 million tests to be conducted each day. We learned NIH can move very quickly when faced with a crisis in novel ways, which we are now doing in response to Long COVID.

Rep Doris Matsui (D-CA)

Q: We know that COVID can also lead to neurological problems in addition to respiratory issues. Can you explain findings from NINDS’ study of brain tissue samples from people who died from COVID?

A: Collins – There was evidence that virus was not actually present in the brain, which could have meant it did a “hit and run” or that the brain problems were a result of damage to blood vessels. We need to understand whether the brain impact is different from organ/body, etc. We need to collect as much data as possible and especially to do lots of bioimaging in the brain.

Q: What role can EHRs play in better understanding Long COVID and future pandemics? Are there similar challenges to using EHRs for monitoring mental health of Long COVID patients?

A: Brooks – Yes – EHRs do require someone to input the data and recognize a mental health problem. Many providers are good at this but some need more training. With HER data, we can also look at what drugs might have been prescribed, etc. – but these are indirect indicators of a person’s illness journey. This is why cohort studies are so important.

Rep. Michael Burgess (R-TX)

Q: Observational data suggests that the best bet for preventing Long COVID is vaccination. Can this be a teachable moment for those “on the fence” about getting the vaccine?

A: Collins – Thanks to the Doctors Caucus for their efforts so far on public education. The general public has not generally appreciated the risks of Long COVID. We can’t be the government “shaking its finger,” but need to educate about the benefits of the vaccine.

Rep. Kathy Castor (D-FL)

Q: What are some analogous long-term studies of infections that we can relate to for Long COVID?

A: Collins – one example is HIV/AIDS, where we can now suppress lifelong consequences with anti-retroviral therapy. I would love to get there with Long COVID in terms of having a long-term treatment. But we are in new territory with a respiratory virus that can create long-term symptoms even in people who don’t end up in the hospital initially.

A: Brooks – We can also compare to polio. Thanks to the early cohort studies conducted on patient lifespans, we were able to understand post-polio syndrome.

Rep. Morgan Griffith (R-VA)

Q: Does the fact that a patient has had COVID change the approach for doctors treating particular Long COVID symptoms?

A: Collins – There are now more than 60 clinics specifically set up to provide medical care to Long

COVID sufferers. It seems that some pulmonary and cardiac rehabilitation is helpful, along with treatments for brain fog that we have developed for TBI/concussion treatment.

Q: If someone wants to participate in an NIH study, who should they contact?

A: Collins – Go to www.clinicaltrials.gov. We want tens of thousands of participants.

Q: Vaccines are not currently recommended for people who have tested positive for COVID within the last 90 days. Why is that?

A: Brooks – The recommendation is that people do not have to get vaccinated within 90 days; they could wait, or get vaccinated if they can. The concern is that the residual immune response from the infection could blunt the benefit from the vaccine.

Rep. John Sarbanes (D-MD)

Q: What is the intersection of these Long COVID cases with chronic conditions? What implications could there be in terms of the workplace, SSA, and employment generally? We are likely going to be seeing more cases of permanent disability coming forward related to Long COVID.

A: Collins - We have to learn how to manage individuals with Long COVID, with PASC, with significant organ damage, those who have been extremely ill in an ICU for weeks, etc. At NIH, we are studying the causes of the overlap between Long COVID and chronic fatigue.

Q: What are some of the implications of Long COVID on the health care workforce, particularly how it might affect certain specialties and shortages in the medical field?

A: Brooks – There is no designated post-COVID specialist yet. Maybe there will be, but now it pulls from multiple specialties, predominantly pulmonary disease, rheumatology, neurology, neuropsychology. So we will have a major demand for care within those specialties. Eventually, clinician organizations will write guidelines, but we are helping in the short term.

Rep. Gus Bilirakis (R-FL)

Q: Is there a consensus as to how long a person is immune once they have had COVID?

A: Collins – We don't have as rigorous an answer as we'd like, but probably a few months, depending on the variants and how they interact. The vaccine provides you with better, broader immunity than getting the virus.

Rep. Peter Welch (D-VT)

Q: What is the medical consensus on differentiating between a complaint that is related to Long COVID and what is not?

A: Collins – This is a serious challenge. Hopefully, getting a large collection of people suffering with these symptoms, combined with machine learning, will help us identify a uniform view of the typical cluster of symptoms.

A: Brooks – We are scanning datasets to see what kind of visits people are making, interviewing clinicians to see if their experience fits our definitions, and bouncing ideas off of patients and patient advocates.

Q: How can we develop additional efforts to get data from underserved communities?

A: Brooks – This is critical. We over-enroll minority communities in studies, we focus on people who are not in the spotlight in various ways.

Rep. Larry Bucshon (R-IN)

Q: What percentage of the \$1.15 billion is going to be directed towards potential therapies for Long COVID?

A: Collins – We are aiming to initiate therapeutic interventions as soon as we have the meta-cohort together. We are not just admiring/observing the problem – we want to develop solutions.

Q: What treatments are already being considered?

A: Collins – some promise in using anticoagulants, and potential uses for steroids or other immunosuppressants, intravenous immunoglobulin, and others. We don't know if Long COVID is due to a persistence of the virus in the system, or an autoimmune response.

Rep. Kurt Schrader (D-OR)

Q: Since Long COVID symptoms are common from other disease states, how are we ruling out whether the symptoms are caused by COVID or just coincidental?

A: Collins – Easiest way is to have a clear definition that they had the acute virus (e.g., a positive test if available, or an antibody test). But there are lots of people who did not have access to testing, and antibodies may have faded, and we need to take care of those people as well. Hopefully, as we study Long COVID, we also learn about CFS, and vice-versa.

Rep. Neal Dunn (R-FL)

Q: So many long-haulers struggle with getting their providers to “believe” them about their symptoms. Do we need to scale up our ability to test for past COVID infection, not just through antibodies but T-cell immunity as well?

A: Collins – this would be a good Shark Tank opportunity. We haven't yet arrived at a consensus on how to assess T-cell response.

Q: What are educational resources you can direct physicians to in order to better understand Long COVID?

A: Brooks – This is something we've been working on since we first recognized Long COVID. We hold regular webinars and calls for clinicians, often attended by thousands. We primarily use these to raise awareness, and then publish papers and guidelines when they are developed. First set of draft interim guidelines is currently undergoing CDC clearance and should be released shortly. These were drafted in collaboration with multiple physician groups and advocates/patients.

Rep. Tony Cardenas (D-CA)

Q: What is the relationship between SDOH, COVID, and Long COVID, and how can we respond to these interactions?

A: Collins – This is profoundly important. SDOH have played a major role in who is most affected by the pandemic. It is because of access to care, not genetics – it's clear that the health system does not give equal treatment to everybody. People with Long COVID from underserved populations are less likely to get the medical care they need, because of systemic inequities. So we need to implement care in an equitable, just, and fair way.

A: Brooks – it has been unpleasant to see these inequities, but this is an opportunity to start making change. First, we need to listen to these communities.

Rep. John Curtis (R-UT)

Q: What trends have you seen so far in who gets Long COVID?

A: Collins - Initial seriousness of the illness is somewhat of a predictor – if you were initially in the hospital, you have a higher likelihood of Long COVID – but you can still get it if you weren't initially hospitalized. Older people have a higher likelihood, as do women and those with higher BMIs. Beyond that, we aren't seeing a lot of predictors, and so we don't have the right answers yet.

Q: Where do people go if they think they are suffering Long COVID symptoms?

A: Brooks – start with a primary care clinician, and if they are further concerned, try to seek out a post-COVID clinic in their area. Right now, those clinics are generally affiliating with academic centers and large urban hospitals – may not be accessible to everyone.

Rep. Raul Ruiz (D-CA)

Q: What can CDC and Congress do to address barriers to accessing post-acute COVID care clinics and increase access for all populations that need treatment? We need to ensure that as we build a system of post-acute care for Long COVID, that we don't just use traditional systems of tertiary care only available in affluent hospitals.

A: Brooks – This is a critical question. We've put \$3 billion towards building vaccine confidence in underserved communities and offered \$2.2 billion in funding opportunities to help address health disparities. We've also invested \$300 million into community health workers from underserved communities. We also work with community-based organizations and workforces, as well as allied partners and pharmacies and other national organizations that are trusted messengers.

Q: What do we know about the rate of Long COVID in children who had MISC?

A: Brooks – luckily, we haven't seen a lot of Long COVID in these children. We have developed better case definitions and provider information on MISC, and are distributing that information to minority communities.

Rep. John Joyce (R-PA)

Q: Have people treated with monoclonal antibodies gone on to develop Long COVID, and what role do these therapeutics play in preventing Long COVID?

A: Collins – We are enrolling therapeutic trial participants in our meta-cohort, many of whom are on monoclonal antibodies. We are currently running six “master protocols” on therapeutic agents that may help treat COVID and Long COVID.

A: Brooks – We are also looking into some types of pre-exposure prophylaxis for COVID, to prevent infection when exposed or when one faces the potential of being exposed to COVID.

Rep. Debbie Dingell (D-MI)

Q: How has COVID impacted primary care physicians, and how do we prevent them the right tools?

A: Brooks – The health care workforce has been really slammed by the pandemic. We need to help providers learn about Long COVID, how to recognize it, and how to refer patients properly. This means building the subspecialties that are well-equipped to treat Long COVID, including PM&R, rheumatology, pulmonary medicine, neurology. We hope that what we learn about managing and treating Long COVID will help patients with ME/CFS and other chronic conditions.

Q: Does NIH have the resources it needs for this issue, and what can Congress do to support you?

A: The \$1.15 billion is what we need right now, but we don't yet know what we'll need in the future. We need the resources to develop many large clinical trials, and we may need to come back to Congress for more.

Rep. Ann Kuster (D-NH)

Q: Have you heard of any other types of treatment that don't entail intervention, but helping the person live with their Long COVID symptoms?

A: Brooks – Yes – pulmonary rehabilitation seems to provide some benefits, as does cardiac rehabilitation and cognitive interventions to help with brain fog. The metacohort will help us better understand what works.

Rep. Robin Kelly (D-IL)

Q: How do we help employers understand what workers with Long COVID are facing, and how do we prevent discrimination in the workplace?

A: Collins – Many Long COVID patients may not be able to work full-time or at all. We need to get information into the hands of the SSA, for disability claims. We also need a good connection with CMS so that coverage for Long COVID-related medical expenses doesn't end up bankrupting individuals. CDC and NIH are working closely with CMS to come up with an ICD-10 code, so that these reimbursements can take place more readily.

A: Brooks – We spend a lot of time with the employment community to help people with disabilities or medical conditions be able to work if they can. We need to make sure that everyone knows this is a real condition that must be taken seriously. Our interim guidelines will help clinicians start to describe what's going on.

Rep. Buddy Carter (R-GA)

Q: I have a staffer who has been diagnosed with Long COVID. What do we know about how the vaccine may help?

A: Collins – There is intriguing emerging data to support this. Survivor Corps also did a survey of 500 individuals with Long COVID who got vaccinated – 40% reported improvement in their symptoms post-vaccination. We also have to make sure that we are speaking about the mental health consequences of Long COVID, not just the physical symptoms.

Rep. Nanette Barragan (D-CA)

Q: Is there any data about why young people may be more impacted by Long COVID?

A: Brooks – We know that the largest numbers of new COVID infections in the country are among adults below age 39, so they may be overrepresented in the post-COVID data as well. We think it merits close attention.

A: Collins – The data seems to indicate that older people are more likely to get Long COVID after a COVID diagnosis, but Long COVID still seems to be prominent in young people as well.

Q: Should Congress be doing more to address SDOH, including fully funding the CDC's SDOH program to help those most impacted by the pandemic?

A: Brooks – We will get back to you with an answer for the record on the funding issue.

Rep. Angie Craig (D-MN)

Q: With the need for such multi-disciplinary care to treat Long COVID, how should individuals with Long COVID symptoms seek treatment, and where should they start?

A: Brooks – We want to get people to the right place as soon as we can. Individuals should start with their primary care physician and use that as a cue to seek a specialty referral.

Q: What is happening at NIH and other federal agencies to learn from academic medical centers to help develop care models for Long COVID?

A: Collins – These centers are critical partners for us. Individuals need a way to coordinate the “big picture” for Long COVID treatment so patients don’t bounce around to different specialists – these centers are starting to do that.

Rep. Kim Schrier (D-WA)

Q: What do we know about how Long COVID presents in children?

A: Brooks – There are some of the same symptoms – pulmonary conditions, shortness of breath/cough, and persistent fatigue. There is some amount of “brain fog,” which is probably neurocognitive in nature.

Rep. Lori Trahan (D-MA)

Q: What is the relationship with Long COVID and ME/CFS?

A: Collins – We have been concerned for years about the lack of understanding of ME/CFS and what causes it. We have a lot more research in progress, including four centers of excellence on CFS. We are studying Long COVID with the same mindset and will discover whether there is any overlap.

Rep. Lizzie Fletcher (D-TX)

Q: Once we get past the acute phase of the pandemic with vaccinations, we are still going to have a health crisis on our hands. How can we educate the public on how to recognize symptoms and access care, especially if there is not a Long COVID clinic nearby?

A: Collins – This hearing is a good first step for education.

A: Brooks – We are working with clinicians to educate them through webinars, phone calls, and the interim guidance. Currently, we see Long COVID clinics centered primarily in urban and academic centers, but we expect that to eventually be basic care for people with Long COVID.

Rep. Jan Schakowsky (D-IL)

Q: We now have vaccines and therapeutics for acute COVID that are affordable because of waivers and our legislation. But will people with Long COVID be able to afford the care they need?

A: Collins – Let’s hope that in a year we have a sense of what is the optimal medical management for Long COVID. We’ve already started conversations with CMS, especially since third-party payments tend to follow Medicare and Medicaid. We need to make sure we are not layering additional problems of cost on people suffering from Long COVID. CMS, CDC, NIH, and FDA are going to have to be in lockstep to make sure we don’t stumble and can find things that are affordable that help people.

A; Brooks – Establishing a uniform case definition is a fundamental first step.

Rep. Kathleen Rice (D-NY)

Q: What has CDC learned from the partnership with Kaiser Permanente studying Long COVID?

A: Brooks – We are seeing a significantly higher burden of people seeking care 1-6 months after their COVID diagnosis (about 68%). About 38% sought care with a specialist that might be working on a body system affected by COVID, such as a pulmonologist or rehabilitation doctor.

Testimony (Panel II)

Natalie Hakala

- Diagnosed with COVID July 4, 2020 – had a mild case in the first two weeks, then developed chest pains, shortness of breath, and difficulty breathing.
- Underwent several tests, and most came back completely normal. Cardiac MRI showed inflammation around the heart, and was diagnosed with pericarditis.
- Started cardiac rehab in October – slow improvement began.
- Only now is able to stand for a few hours today, and can jog for 15 minutes total.

Chimere Smith

- I am a black, poor, disabled woman living with Long COVID.
- Over the last year, black women lost more jobs than any other race. Long COVID is another weight that impacts black people disproportionately. My doctor ignored my cataracts that developed due to COVID, and I lost my vision for five months.
- I was rejected three times for an NIH study. There are currently no studies that specifically focus on black people with Long COVID.
- We need medical care that reflects equitable, cost-effective, and timely education and treatment.
- Post-COVID clinics cannot do this alone in urban communities.

Lisa McCorkell

- First symptoms began on March 14, 2020. After a month, I was in worse health than the initial stage – couldn't walk for more than 20 seconds at a time.
- Body Politic has conducted several patient surveys documenting symptoms and Long COVID experiences.
- Patients aren't just dealing with their symptoms – they are dealing with barriers to care, financial stability, and recovery. Patients may be denied access to a post-COVID clinic because they don't have a positive test, as well as referrals, health insurance coverage, paid leave, workers' comp, disability benefits, and workforce accommodations.
- Waiting lists for post-COVID clinics keep getting longer, but many are being told that their symptoms are in their head, especially people of color, women, and LGBTQ community.

Jennifer Possick

- Pulmonologist working at a post-COVID clinic.

- After seeing waves of patients with Long COVID symptoms, we assembled a team of pulmonologists, PTs, social workers, cardiologists, neurologists, and psychologists, all with COVID experience.
- Our patients are seriously impacted – they’ve used up their paid or sick, have left or lost jobs, have difficulty accessing workers’ comp, FMLA, and/or accommodations.
- We are a well-resourced program at an academic medical center, and even we are swamped by the need in our community.
- We must increase public awareness of Long COVID, ensure early and equitable access to care (which cannot be confined to specialty centers), and address the socioeconomic consequences of Long COVID.
- Clinicians must also be liberated from prior authorization and appeals processes to focus on patient care.

Steven Deeks

- Many more things about Long COVID are not known than are known.
- We don’t have a standard way of measuring this condition – all cohorts and clinics are doing it differently, and we don’t have a good sense of what’s going on.
- We need more engagement from industry on drug development and other aspects.

Questions and Answers (Panel II)

Chairwoman Eshoo

Q: We already have community health centers across the country, which have received heavy investment in the COVID response packages. Can these be helpful in replicating the multidisciplinary clinic structure for areas that do not have access to academic institutions?

A: Possick – There are different kinds of post-COVID clinics, and most have been stood up as grassroots efforts. Now, we need to bring that multidisciplinary structure back out into primary care, especially community health centers, so that we don’t leave people behind.

Q: What is the most important thing you want Congress to understand about Long COVID?

A: Smith – Black women have historically not been believed for so many chronic conditions. We need to ensure that black people in underserved communities received education and care that is comprehensive to us.

A: McCorkell – Making sure that there is equitable access to care and research is the most important thing. It needs to be affordable care as well. We need to also make progress with workplace accommodations and the safety net.

Ranking Member Guthrie

Q: Do you have any insight into why some health care providers are dismissing the concerns of patients with Long COVID?

A: Possick – implicit and cognitive bias are not new issues. Particularly with Long COVID, we don't fully understand the conditions and providers don't necessarily know what to look for. The CDC's calls with providers have been essential to communicate what is being learned and for providers to come together and build a consensus understanding. We need to come up with clinical criteria and a more codified diagnosis or diagnoses.

A: Physicians tend to want to measure conditions and prescribe treatments – both things that are currently hard to do with Long COVID. Tests are not clearly available for Long COVID – symptoms are hard to quantify and vary from person to person.

Rep. Matsui

Q: Patients with Long COVID are facing added challenges beyond the challenges we are all facing with the pandemic. Long COVID patients are often first referred to providers specializing in respiratory or rehabilitation medicine. What strategies did your pulmonary practice take to meet the needs of patients with Long COVID?

A: Possick – We deliberately created an in-clinic and a beyond-clinic model that was multidisciplinary. We assembled other stakeholders and specialties, and most importantly built collaboration between our social worker and psychiatry services.

Q: How does mental health treatment fit in with the integrated care needs for Long COVID?

A: McCorkell – Clinicians need to understand that patients are dealing with a new chronic illness, being newly disabled, as well as living during a pandemic. There may be secondary mental health effects, like anxiety, that are not the cause of Long COVID symptoms but another symptom. We need to make that treatment available but as a secondary treatment, not a primary treatment. Also, we need to prioritize a Medicare reimbursement strategy for the clinics that are providing great care.

Q: Is integrated care the best approach for Long COVID?

A: Deeks – Yes – we need physicians, physical therapists, psychiatrists, social workers, patient support groups, and more. We also need to find a way to navigate these complicated economic issues with this model.

Rep. Dingell

Q: Can you share more about the patient-led research groups that have formed?

A: McCorkell – Our patient research collaborative formed in April 2020. We joined the Body Politic support group, and several of us found others that have research backgrounds and also Long COVID symptoms. Doctors were gaslighting us, and we weren't able to get tested. The first real research on Long COVID was through a survey we did with 640 respondents. We have had a lot of outreach and contact with NIH researchers, and have applied for part of the funding that NIH is providing. We need to make sure that research that is funded incorporates the patient voice.

Rep. Burgess

Q: Are there additional diagnostic and/or interventional help that we can provide to the frontlines via telehealth?

A: Possick – Telemedicine has been indispensable. We need better supports and infrastructure to make it more equitable and accessible. For some patients, it will be easier to receive treatment virtually if they can't easily leave the home.

A: Deeks – We should consider doing what was done with the HIV/Ryan White Clinics program – putting money aside in urban centers to provide integrated care to disenfranchised, un/underinsured people.

Rep. Griffith

Q: I have a friend with Long COVID, and his doctors are telling him that simply exercising more should solve his breathing problems. Does that make sense?

A: Possick – We've seen great value in different kinds of rehabilitation therapy for some patients, but this may not be true for all patients. It's not just physical rehabilitation, it can involve speech, cognitive, occupational, pulmonary, and cardiac rehabilitation. The appropriate solution for any given patient requires assessment by a professional in physiatry or physical therapy. We also need providers and patients to understand that recovery from Long COVID may not be linear.

Rep. Kelly

Q: What areas of the health care system can be improved for minorities?

A: Smith – I wish I had doctors who documented my experience and the narratives I've shared about my own condition. Medical records often don't align with what I've told my providers, and often the missing information is critical for future treatment, participation in research, and accessing benefits.

Q: What barriers are keeping people from receiving the equitable post-acute care that is necessary?

A: Possick – trust of the medical system is one, especially for underserved populations. Accessing medical appointments and treatment (including travel, getting time off, etc.) can be prohibitively difficult. It can also be hard to navigate the system for workers' comp, disability, etc.

Rep. Bilirakis

Q: Is there a universal definition for long-term COVID? How does that lack of standardization impact research and how can we address this?

A: Deeks – there's not even an accepted name, let alone a definition. There are efforts underway to develop these, but we may end up with everyone using different definitions.

A: Possick – If there was a uniform ICD-10 code for post-COVID conditions, it would help, though it would be a relatively blunt instrument. It's hard to pull the right information out of a chart currently to identify all the right patients.

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Rep. Schrier

I am thinking of all the things Congress can do to help. It sounds like we need to work with CMS to get an ICD-10 code, and we need to strengthen our social safety net and health care coverage, and we need a new RADx or Warp Speed program to develop possible Long COVID therapies.