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THE LONG HAUL: FORGING A PATH THROUGH THE LINGERING EFFECTS OF COVID-19

VIRTUAL HEARING

BEFORE THE

SUBCOMMITTEE ON HEALTH

OF THE

COMMITTEE ON ENERGY AND COMMERCE

HOUSE OF REPRESENTATIVES

ONE HUNDRED SEVENTEENTH CONGRESS

FIRST SESSION

APRIL 28, 2021

Serial No. 117–25



Published for the use of the Committee on Energy and Commerce
govinfo.gov/committee/house-energy
energycommerce.house.gov

U.S. GOVERNMENT PUBLISHING OFFICE
47–313 PDF WASHINGTON : 2022

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THE LONG HAUL: FORGING A PATH THROUGH THE LINGERING EFFECTS OF COVID-19

WEDNESDAY, APRIL 28, 2021

HOUSE OF REPRESENTATIVES,
SUBCOMMITTEE ON HEALTH,
COMMITTEE ON ENERGY AND COMMERCE,
Washington, DC.

The subcommittee met, pursuant to call, at 11:26 a.m., via Cisco Webex online video conferencing, Hon. Anna G. Eshoo (chairwoman of the subcommittee) presiding.

Members present: Representatives Eshoo, Butterfield, Matsui, Castor, Sarbanes, Welch, Schrader, Cárdenas, Ruiz, Dingell, Kuster, Kelly, Barragán, Blunt Rochester, Craig, Schrier, Trahan, Fletcher, Pallone (ex officio), Guthrie (subcommittee ranking member), Upton, Burgess, Griffith, Bilirakis, Bucshon, Hudson, Carter, Dunn, Curtis, Joyce, and Rodgers (ex officio).

Also present: Representatives Schakowsky, Doyle, Clarke, and Rice.

Staff present: Joe Banez, Professional Staff Member; Jeffrey C. Carroll, Staff Director; Waverly Gordon, General Counsel; Tiffany Guarascio, Deputy Staff Director; Perry Hamilton, Clerk; MacKenzie Kuhl, Digital Assistant; Aisling McDonough, Policy Coordinator; Meghan Mullon, Policy Analyst; Kaitlyn Peel, Digital Director; Tim Robinson, Chief Counsel; Chloe Rodriguez, Clerk; Kylea Rogers, Staff Assistant; Kimberlee Trzeciak, Chief Health Advisor; C.J. Young, Deputy Communications Director; Sarah Burke, Minority Deputy Staff Director; Theresa Gambo, Minority Financial and Office Administrator; Grace Graham, Minority Chief Counsel, Health; Caleb Graff, Minority Deputy Chief Counsel, Health; Nate Hodson, Minority Staff Director; Peter Kielty, Minority General Counsel; Emily King, Minority Member Services Director; Clare Paoletta, Minority Policy Analyst, Health; Kristin Seum, Minority Counsel, Health; Kristen Shatynski, Minority Professional Staff Member, Health; Olivia Shields, Minority Communications Director; Michael Taggart, Minority Policy Director; and Everett Winnick, Minority Director of Information Technology.

Ms. ESHOO. The Subcommittee on Health will now come to order.

Thank you, Members, for your patience, and the witnesses. We had technical difficulties because of, evidently, a potential tornado somewhere in our country. So thank you to the team for getting us connected. And I want to welcome everyone to our very important hearing this morning.

Due to COVID–19, today's hearing obviously is being held remotely. All Members and witnesses are participating via video conferencing.

As part of our hearing, microphones will be set on mute to eliminate background noise. Members and witnesses, you will need to unmute your microphone each time you wish to speak. Documents for the record—and this is for all the Members and their offices—should be sent to Meghan Mullon at the email address that we provided to your staff. And all documents will be entered into the record at the conclusion of the hearing.

The Chair now recognizes herself for 5 minutes for an opening statement.

OPENING STATEMENT OF HON. ANNA G. ESHOO, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CALIFORNIA

This morning's hearing is to examine the trends and research into long COVID, a chronic syndrome occurring in patients infected by COVID–19. This is the first congressional hearing focused on this issue. The few large-formal studies conducted on long COVID hint at an alarming scale of people with the illness.

Last week, CDC published a study finding that among adults with COVID who did not require a hospital stay, two out of three had at least one outpatient visit 1 to 6 months after diagnosis. People with long COVID report experiencing different combinations of symptoms, including fatigue, brain fog, headache, loss of smell or taste, shortness of breath, and chronic pain. Since this disease affects multiple body systems, the symptoms can be much more extensive.

This research suggests that in the United States, where there have been more than 32 million confirmed COVID–19 cases, there could be millions of long-haulers with chronic symptoms. Our health system is facing an avalanche of long COVID patients, and I hear every day from constituents suffering from the long-term effects of the virus.

Our expert witnesses today will provide the latest information on the lingering effects of COVID–19 and the limited options for treatment. We will also hear firsthand from long-haul patients. They will provide a perspective that we wouldn't get from statistics and medical studies. So we are very grateful to them for their willingness to share their experience with us. And certainly they will underscore the human cost of long COVID.

Long-COVID patients don't fit the common narrative of COVID–19—a patient being an elderly person, for example, with preexisting conditions. And they cover, really, right across our communities. They are elite athletes, they are midcareer professionals. And because of this, many long-haulers struggle to be taken seriously by our medical system, especially—and here we go again—especially Black women and women of color.

My fear is that, as acute COVID uncovered our Nation's failures at emergency response and equitable healthcare, long COVID will uncover our failures at fairly treating chronic disease and disability.

For sure, Federal leadership is going to be needed to coordinate and address the swell of the long-haul COVID patients. We may need a nationwide network of long-COVID clinics with multidisciplinary clinical teams. Long-COVID patients are also finding gaps that need to be filled in our safety net, such as disability insurance, workplace accommodations, and comprehensive insurance coverage.

There is hope on the horizon, though, having stated all the things that I have. In the next few days, the NIH will announce millions of dollars in grant funding for long-COVID researchers. Also, with every American adult now eligible for the COVID–19 vaccine, we will prevent future long-COVID cases, and in some cases perhaps reduce long-COVID patients' symptoms. These patients are showing us how to rebuild a better health system for the millions of Americans who are disabled or have chronic conditions.

[The prepared statement of Ms. Eshoo follows:]

PREPARED STATEMENT OF HON. ANNA G. ESHOO

This morning's hearing is to examine the trends and research into long COVID, the chronic syndrome occurring in patients infected by COVID–19. This is the first congressional hearing focused on long COVID.

The few large, formal studies conducted on long COVID hint at an alarming scale of people with the illness. Last week CDC published a study finding that among adults with COVID who did not require a hospital stay, 2 out of 3 had at least one outpatient visit 1 to 6 months after diagnosis.

People with long COVID report experiencing different combinations of symptoms, including fatigue, brain fog, headache, loss of smell or taste, shortness of breath, and chronic pain. Since this disease affects multiple body systems, the symptoms can be much more extensive.

This research suggests that in the U.S. where there've been more than 32 million confirmed COVID–19 cases, there could be millions of long-haulers with chronic symptoms. And our health system is facing an avalanche of long-COVID patients. I hear every day from constituents suffering from the long-term effects of the virus.

Our expert witnesses today will provide the latest information on the lingering effects of COVID–19 and the limited options for treatment.

We'll also hear firsthand from long-haul patients. These patients provide a perspective that we wouldn't get from statistics and medical studies. They'll share the human cost of long COVID.

Long-COVID patients don't fit the common narrative of a COVID–19 patient being an elderly person with preexisting conditions. They are elite athletes and mid-career professionals. Because of this, many long haulers have struggled to be taken seriously by our medical system, especially Black women and women of color.

My fear is that as acute COVID uncovered our Nation's failures at emergency response and equitable healthcare, long COVID will uncover our failures at fairly treating chronic disease and disability.

We'll need Federal leadership to coordinate and address the swell of long-COVID patients. We may need a nationwide network of long-COVID clinics with multidisciplinary clinical teams. Long-COVID patients are also finding gaps that need to be filled in our safety net, such as disability insurance, workplace accommodations, and comprehensive insurance coverage.

There is hope on the horizon. In the next few days the NIH will announce millions of dollars in grant funding for long-COVID researchers. Also, with every American adult now eligible for the COVID–19 vaccine, we will prevent future long-COVID cases and, in some cases, perhaps reduce long-COVID patients' symptoms. These patients are showing us how to rebuild a better health system for the millions of Americans who are disabled or have chronic conditions.

Ms. ESHOO. The Chair now recognizes my friend and ranking member of our subcommittee, Mr. Guthrie, for his 5 minutes for an opening statement.

It is great to see you.

OPENING STATEMENT OF HON. BRETT GUTHRIE, A REPRESENTATIVE IN CONGRESS FROM THE COMMONWEALTH OF KENTUCKY

Mr. GUTHRIE. Great to see you. Thanks, Chair Eshoo, for holding this hearing. And I want to welcome everybody, especially our witnesses that are with us today.

Unfortunately, over 31 million Americans have tested positive for COVID–19, and some of these Americans experience symptoms weeks and months after being infected with COVID–19. And today we will examine the long-term effects of this life-threatening virus.

These long-term effects are often referred to as post-acute COVID–19 or long COVID. We still have many questions about how individuals recover from this terrible virus.

Last May, I joined the—Chair Eshoo, Representatives Burgess, DeGette, and Trone, introducing the Ensuring Understanding of COVID–19 to Protect Public Health Act. And this bill requires NIH, in consultation with CDC, to conduct a longitudinal study on the health impacts of COVID–19.

At the time, we were just starting to learn about COVID–19 long-haulers and some of the side effects this virus has on a percentage of Americans post-COVID–19 infection. At the end of last year, Congress came together to include $1.15 billion in the December funding package for just this reason, to learn more about this issue.

While we know more today than last year, we still have many unanswered questions. In America, we are fortunate to have access to the best medical experts in the world, who are diligently working to quickly find answers to these questions.

I want to thank Dr. Collins and Dr. Brooks for being here today to explain what is currently understood about this condition and provide an update on what NIH and CDC are doing to further study long-term COVID.

I also want to thank the witnesses on the second panel. I look forward to hearing and learning from you more about how you are helping patients with long-term COVID, and for the patient witnesses, how COVID–19 is still impacting you.

I was pleased to learn that in December, the National Institute of Allergy and Infectious Diseases, in collaboration with other institutes and centers of the NIH, hosted a workshop on postacute sequelae of COVID–19 to examine the knowledge gaps that we currently have regarding the long-term effects that some individuals are experiencing.

Additionally, I appreciate CDC efforts to educate the public on the symptoms that might present themselves as long COVID.

I want to help get people back to work and back to their daily lives before COVID–19. However, people have reported that long-COVID symptoms are preventing them from returning to their jobs and making it more difficult to do many activities they once easily could.

We must help patients receive proper treatments and learn ways to resolve these symptoms. I often hear of long-COVID cases, and each one seems to be different with varying symptoms and severity. Studying these patients will be valuable and instrumental in the many Americans' day-to-day life post COVID.

Lastly, I want to take this time to encourage all Americans to get vaccinated. There is no better protection for this terrible virus than one of the FDA-approved vaccines that are currently available. Long COVID can be avoided with vaccination. Operation Warp Speed and American innovation has led to three safe and effective vaccines being approved. Now it is time to put your guard down—or rather get—now is not time to put your guard down but, rather, get vaccinated to protect yourself and those around you.

Thank you, Chair. And I yield back.

[The prepared statement of Mr. Guthrie follows:]

PREPARED STATEMENT OF HON. BRETT GUTHRIE

Chair Eshoo, thank you for holding this important hearing today.

Unfortunately, over 31 million Americans have tested positive for COVID–19, and some of these Americans experience symptoms weeks and months after being infected with COVID–19. Today we will examine the long-terms effects of this life-threatening virus. These long-term effects are often referred to as post-acute COVID–19, or long COVID. We still have many questions about how individuals recover from this terrible virus.

Last May, I joined Chair Eshoo, Rep. Burgess, Rep. DeGette, and Rep. Trone in introducing the Ensuring Understanding of COVID–19 to Protect Public Health Act. This bill requires the National Institutes of Health (NIH), in consultation with the Centers for Disease Control and Prevention (CDC), to conduct a longitudinal study on the health impacts of COVID–19. At the time, we were just starting to learn about COVID "long-haulers" and some of the side effects this virus has on a percentage of Americans post COVID–19 infection.

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I was pleased to learn that in December the National Institute of Allergy and Infectious Diseases (NIAID), in collaboration with other institutes and centers of the National Institutes of Health, hosted a Workshop on Post-acute Sequelae of COVID–19 to examine the "knowledge gaps" that we currently have regarding the long-term effects that some individuals are experiencing.

Additionally, I appreciate CDC's efforts to educate the public on the symptoms that may present themselves as long COVID. I want to help get people back to work. However, people have reported that long-COVID symptoms are preventing them from returning to their jobs. We must help patients receive proper treatments and learn ways to resolve these symptoms. I often hear of long-COVID cases and each one seems to be different with varying symptoms and severity. Studying these patients will be valuable and instrumental in many Americans' day-to-day life post COVID.

Lastly, I want to take this time to encourage all Americans to get vaccinated. There is no better protection from this terrible virus than one of the FDA approved vaccines that are currently available. Long COVID can be avoided with vaccination. Operation Warp Speed and American innovation has led to three and safe effective vaccines being approved. Now is not the time to put your guard down but rather get vaccinated to protect yourself and those around you.

Thank you Chair, I yield back.

Ms. ESHOO. The gentleman yields back. And the Chair thanks him for essentially that call to arms.

The Chair now recognizes Mr. Pallone, the Chairman of the full committee, for his 5 minutes for an opening statement.

OPENING STATEMENT OF HON. FRANK PALLONE, JR., A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW JERSEY

Mr. PALLONE. Thank you, Chairwoman Eshoo.

We have been battling COVID–19 for more than a year now, and while much has changed in terms of our knowledge and ability to combat this disease, it continues to present these new health challenges. And over 30 million Americans have tested positive for COVID–19 over the last year, nearly 600,000 have died, and the loss has been devastating. And we are always mindful of the toll this pandemic takes on our families and friends and communities.

But over the last year, this subcommittee has played a key role in responding to the ongoing public health crisis. Today, we continue that crucial work as we discuss a consequence of COVID–19 that is perplexing the scientific community.

A growing number of individuals are experiencing the lingering effects of COVID–19 weeks and months after their initial infection. These lingering symptoms are being described as long COVID, and it seems to be impacting a lot of people who are otherwise healthy.

A full picture of long COVID is still being drawn. Generally, someone is considered to have long COVID if they experience symptoms lasting longer than 4 weeks after their initial infection. Symptoms can include persistent fatigue, brain fog, headache, loss of smell and taste, dizziness, shortness of breath, fever, depression, and anxiety. And in more severe cases, the function of critical organs like the heart and lungs can be affected. We have heard directly from long-haulers that the continuation of their symptoms as well as management of their care can be more of a battle than the initial onset of the virus, both physically and mentally.

And early studies of long COVID are small in scale but raise alarming trends. One study of about 4,000 found that nearly 15 percent of the patients developed long COVID. The study also suggests that people with multiple symptoms during their initial infection, women, and older individuals are more susceptible to long COVID.

And another recent study in Sweden found that long COVID is prevalent among healthcare workers. They found that 1 in 10 young, healthy adults who initially had mild COVID symptoms continued to struggle with moderate to severe symptoms months later.

So our goal at this hearing is to learn more about long COVID and what is being done to address it. On our first panel, we hear from leaders of two of the world's leading public health agencies, the National Institutes of Health and the Center for Disease Control and Prevention. Both agencies are actively monitoring long COVID and are in the process of expanding their research. And I look forward to hearing from our public health experts on that panel.

Our second panel will include professionals on the ground who are treating and researching long COVID. And these doctors are actively working to seek out answers to many of our questions. And we will be joined by patients also on the second panel who will share their own stories about the impacts that long COVID have on their lives. It is important that we hear directly from patients

as we take a close look at what is needed to make certain that they and other Americans with long COVID reach a full recovery.

So even if a small fraction of COVID–19 patients develop long COVID, hundreds of thousands, if not millions, of people will require ongoing interdisciplinary care and may not be able to maintain their quality of life or their gainful employment. So we think it is our responsibility to ensure that we learn more about this, to prevent it when possible, and to help patients inflicted receive the proper treatment.

I hope this hearing will help us better understand how we can support further research as well, but also how to prevent and treat those who suffer from long COVID.

It is a very important hearing. Thank you, Madam Chairwoman, for doing this. I yield back.

[The prepared statement of Mr. Pallone follows:]

PREPARED STATEMENT OF HON. FRANK PALLONE, JR.

We have been battling COVID–19 for more than a year, and while much has changed in our knowledge and ability to combat this disease, it continues to present these new health challenges.

And over 30 million Americans have tested positive for COVID–19 over the last year, and nearly 600,000 Americans have died as a result of this terrible virus. And we are always mindful of the toll this pandemic is taking on our families, friends and communities.

Over the last year, this subcommittee has played a key role in responding to the ongoing public health crisis. Today, we continue that crucial work as we discuss a consequence of COVID–19 that is perplexing the scientific community. A growing number of individuals are experiencing the lingering effects of COVID–19 weeks and months after their initial infection. These lingering symptoms are being described as long COVID, and it seems to be impacting a lot of people who are otherwise healthy.

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In more severe cases, the function of critical organs like the heart and lungs can be affected. We have heard directly from "long-haulers" that the continuation of their symptoms, as well as management of their care can be more of a battle than the initial onset of the virus—both physically and mentally.

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So even if a small fraction of COVID–19 patients develops long COVID, hundreds of thousands, if not millions, of people will require ongoing, interdisciplinary care and may not be able to maintain their quality of life or their gainful employment. So we think it is our responsibility to ensure that we learn more about long COVID, to prevent it when possible, and to help patients inflicted receive the proper treatment.

I hope this hearing will help us better understand not only how Congress can help support further research but also how best to help those who suffer from long COVID moving forward.

Thank you, and I yield back.

Ms. ESHOO. The gentleman yields back.

The Chair now recognizes the ranking member of the full committee, Representative Cathy McMorris Rodgers, for her opening statement.

OPENING STATEMENT OF HON. CATHY MCMORRIS RODGERS, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF WASHINGTON

Mrs. RODGERS. Thank you, Madam Chair. And thank you to our witnesses for participating and sharing your expertise today.

The long-term effects of COVID–19 that some patients are experiencing is incredibly concerning. As others have stated, many patients have reported long-hauler symptoms like fatigue, brain fog, heart irregularities, chest pain, shortness of breath, impaired memory. Some have even experienced mental illness such as psychosis.

A University of Washington study found that nearly one-third of COVID–19 patients have reported symptoms that can persist for several months. This alarming statistic highlights the sheer scale of the potential next wave of the pandemic. We must have a better understanding about the causes and treatment for long-term COVID–19 symptoms.

I am grateful that because of the success of Operation Warp Speed and the historic public-private partnerships, America has led to develop safe and effective vaccines that are key to beating this pandemic and restoring our way of life. The COVID–19 vaccines and getting them in the arms of every American who wants them are vital for prevention and stopping people from becoming long-haulers in the first place.

The Seattle Times recently shared Joe's story in my district. He was infected with COVID–19 last year and has a preexisting lung disease that subsided with treatment. Inflammation from the virus devastated his lungs, brought his underlying condition back, and caused irreversible damage. He said, quote, "I went from being able to walk a mile quite easily to barely being able to walk to the restroom with oxygen." Now, a lung transplant is his only option.

Unfortunately, there is no diagnostic mechanism for long COVID and there are limited treatment options. While there are still outstanding questions about this phenomenon, health providers and researchers across the country, including many in my State of Washington, are working hard to investigate this poorly understood condition.

Researchers at Seattle's Institute for Systems Biology are collaborating with local healthcare providers to study and detect viral fragments of infection through blood tests. The purpose of this

study is to learn more about the virus, how the body fights it, and the impact of infection on different organs.

Other experts in my State are part of the INSPIRE study, which is a national collaboration conducting applied research to investigate the long-term outcomes of COVID–19.

I am encouraged by this American leadership and ingenuity. And I am hopeful that medical experts will soon be able to deliver hope to patients who so desperately need it.

COVID–19 has had devastating impacts on so many lives, Americans all across this country. As we safely and responsibly reopen and get a vaccine to every American who wants one, we cannot lose sight of the toll COVID–19 has on long-hauler patients. As we work to crush this pandemic, these patients deserve answers and the best care possible.

I look forward to learning more today about what needs to be done to help provide relief for patients experiencing these symptoms.

Thank you, and I yield back.

[The prepared statement of Mrs. Rodgers follows:]

PREPARED STATEMENT OF HON. CATHY MCMORRIS RODGERS

Thank you, Madam Chair, and thank you to our witnesses for participating and sharing your expertise today.

LONG-HAULERS

The long-term effects of COVID–19 that some patients are experiencing is incredibly concerning.

Many patients have reported "long-hauler" symptoms like

- Fatigue
- Brain fog
- Heart palpitations and chest pains
- Shortness of breath and
- Impaired memory

Some have even experienced mental illness, such as psychosis.

A University of Washington study found that nearly one-third of COVID–19 patients have reported symptoms that can persist for several months.

This alarming statistic highlights the sheer scale of the potential next wave of this pandemic.

We must have a better understanding about the causes and treatment for long-term COVID–19 symptoms.

I'm grateful that because of the success of Operation Warp Speed and the historic public-private partnerships ...

... America led to develop safe and effective vaccines that are key to beating this pandemic and restoring our way of life.

The COVID–19 vaccines—and getting them in the arms of every American who wants them—are vital for prevention and stopping people from become long-haulers in the first place.

JOE'S STORY

The Seattle Times recently shared Joe's story in my district.

He was infected with COVID–19 last year and has a pre-existing lung disease that subsided with treatment.

Inflammation from the virus devastated his lungs, brought his underlying condition back, and caused irreversible damage.

He said, "I went from being able to walk a mile quite easily, to barely being able to walk to the restroom with oxygen."

Now, a lung transplant is his only option.

Unfortunately, there is no diagnostic mechanism for long COVID and there are limited treatment options.

While there are still outstanding questions about this phenomenon, health providers and researchers across the country ...

... including, many in my State of Washington.

... are working hard to investigate this poorly understood condition.

WASHINGTON

Researchers at Seattle's Institute for Systems Biology are collaborating with local healthcare providers to study and detect viral fragments of infection through blood tests.

The purpose of the study is to learn more about the virus, how the body fights it, and the impact of infection on different organs.

Other experts in my State are part of the INSPIRE study, which is a national collaboration conducting applied research to investigate the long-term outcomes of COVID–19.

I am encouraged by this American leadership and ingenuity, and I am hopeful that medical experts will soon be able to deliver hope to patients who so desperately need it.

CONCLUSION

COVID–19 has had a devastating impact on the lives of so many Americans.

As we safely and responsibly reopen and get a vaccine to every American who wants one ...

... we cannot lose sight of the toll COVID–19 has on long-hauler patients.

As we work to crush this pandemic, these patients deserve answers and the best care possible.

I am looking to learning more today about what needs to be done to help provide relief for patients experiencing these debilitating symptoms.

Thank you and I yield back.

Ms. ESHOO. The gentlewoman yields back.

The Chair would like to remind Members that, pursuant to committee rules, all Members' written opening statements will be made part of the record.

I now would like to introduce our witnesses for our first panel, a distinguished panel. First—he doesn't need any introduction to us, I don't think to the American people, because his name is synonymous with hope—from the National Institutes of Health, Dr. Francis Collins. He is the Director of the NIH.

We welcome you back to the committee, Dr. Collins, and we are very grateful to you for being with us today.

We are also joined by Dr. John T. Brooks. He is the chief medical officer of the CDC COVID–19 Response.

Welcome, Dr. Brooks, and thank you for joining us.

So, Dr. Collins, you have—you are recognized for your statement. And, again, thank you for the extraordinary work that has taken place at the NIH, especially over this last year that has been so challenging for everyone. And we are very anxious to hear from you because this is an issue that is having great impact, taking a toll on our fellow Americans. And we know that you are going to help guide us with producing an answer. So welcome again to the subcommittee. You are now recognized.

STATEMENTS OF FRANCIS S. COLLINS, M.D., DIRECTOR, NATIONAL INSTITUTES OF HEALTH, DEPARTMENT OF HEALTH AND HUMAN SERVICES, AND JOHN T. BROOKS, M.D., CHIEF MEDICAL OFFICER, CDC COVID–19 RESPONSE, CENTERS FOR DISEASE CONTROL AND PREVENTION, DEPARTMENT OF HEALTH AND HUMAN SERVICES

STATEMENT OF FRANCIS S. COLLINS, M.D.

Dr. COLLINS. Well, thank you.

Good morning, Chair Eshoo and Ranking Member Guthrie, full committee Chair Pallone and Ranking Member McMorris Rodgers, and distinguished subcommittee members. I don't know that I can recall being at a hearing with this much interest and this many Members attending in a long time.

Thank you all for your sustained commitment to the National Institutes of Health, the NIH. I am really grateful for this opportunity to discuss how NIH research is addressing this major public health concern commonly known as long COVID.

We have heard troubling stories—all of us have—of people who are still suffering months after they first came down with COVID–19, some of whom initially had very few symptoms or even none at all. And yet today, these folks are coping with a long list of persistent problems affecting many different parts of the body: fatigue, brain fog, disturbed sleep, shortness of breath, palpitations, persistent loss of taste and smell, muscle and joint pain, depression, and many more.

Late last year, we began to talk with congressional leaders, including many of you, about the substantial research needed both to understand long COVID and to discover ways of treating and preventing it. You immediately grasped the importance of this issue, appropriating more than $1 billion for this work in December. Since then, we have pulled together experts from many scientific fields to design a fast, flexible research initiative. In a moment, I will walk you through our plans. But, first, I would like to speak directly to the patient community.

Some of you have been suffering for more than a year with no answers, no treatment options, not even a forecast of what your future may hold. Some of you have even faced skepticism about whether your symptoms are real. I want to assure you that we at NIH hear you and believe you. If you hear nothing else today, hear that we are working to get answers that will lead to ways to relieve your suffering.

Now on to our research plans. We need to start by understanding the basics. New data arrive every day, but preliminary reports suggest that somewhere between 10 to 30 percent of people infected with SARS–CoV–2 may develop longer-term health issues.

To get a solid measure of the prevalence, severity, and persistence of long COVID, we really need to study tens of thousands of patients. And these folks should be diverse, not just in terms of the severity of their symptoms and type of treatment received, but in age, sex, race, and ethnicity. To do this rapidly, we are launching an unprecedented metacohort.

What is that? Well, an important part of this can be built on existing longitudinal community-based cohorts or also the electronic health records of large healthcare systems. These resources already include tens of thousands of participants who have already contributed years worth of medical data. Many of them will by now suffer from long COVID.

This approach will enable us to hit the ground running, giving researchers access to existing data that can quickly provide valuable insights on who might be most at risk, how frequently individual symptoms occur, and how long they last.

Individuals suffering with long COVID, including those from patient-led collaborative groups, will be invited to take part in intensive investigation of different organ systems to understand the biology of those symptoms. Our goal is to identify promising therapies and then test them in these volunteers.

We also want to learn from following cohorts of patients with COVID who were enrolled in therapeutic trials for their acute illness. Do they get long COVID? Does the therapeutic they were given change that outcome? They are already being meticulously monitored, with researchers recording clinical data and, in many cases, participants providing detailed observations about their own health status.

Finally, we need a cohort for children and adolescents. That is because kids can also suffer from long COVID. And we need to learn more about how that affects their development.

We have already had 273 responses to our call for research proposals. And we expect to make awards in the next 3 weeks. Intensive laboratory and imaging studies should be underway by summer. Patients will have an active role at every level and stage of this research. As we recruit volunteers, we will ask them to share their health information real-time with mobile health apps and wearable devices.

Long COVID and the people living with it can no longer be a hidden toll of the pandemic. We must bring them to the forefront of our fight against COVID–19 and pursue with all the energy that we can muster the answers and the interventions that will help them.

In closing, I would like to emphasize that one critical way to prevent long COVID is to prevent COVID itself. Even for young people who consider their risk of severe COVID to be low, the long-term consequences can be quite serious. So long COVID represents one more reason to encourage everyone age 16 and over to get vaccinated as quickly as possible.

Thank you, and I look forward to your questions.

[The prepared statement of Dr. Collins follows:]

DEPARTMENT OF HEALTH AND HUMAN SERVICES

NATIONAL INSTITUTES OF HEALTH

Testimony before the House Energy and Commerce Health Subcommittee

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

Francis S. Collins, M.D., Ph.D.

Director for, National Institutes of Health

April 28, 2021

Good morning, Chair Eshoo, Ranking Member Guthrie, and distinguished Subcommittee members. Thank you for your sustained commitment to the National Institutes of Health. I'm grateful for this opportunity to discuss with you the best research approach to understanding post-acute sequelae of SARS-CoV-2 infection or PASC. That includes the array of symptoms often referred to as "Long COVID", the recovery process of organs injured during the acute infection, and the question of whether the COVID-19 pandemic will increase the risk of developing common diseases in the future.

We've all heard and read the troubling stories about COVID-19 survivors who are suffering for months after they recover from the acute infection caused by SARS-CoV-2. These people suffer with a wide variety of symptoms that can affect almost every system in the body and last for months. Fatigue, 'brain fog' or difficulty thinking, abnormal sleep patterns, shortness of breath, persistent loss of taste and smell, muscle pain, and the list goes on. Not everyone has the same symptoms or in the same severity. Even those who had an asymptomatic infection can experience these long-term effects. Children can also be affected with long COVID.

Late last year, we outlined the substantial research needed, not just to understand the long-term effects of SARS-CoV-2 infection, but to try to find treatments or prevention strategies. Congress appropriated $1.15 billion for this work in December 2020. Since that time, we've called together experts from the fields of infectious diseases, neuroscience, cardiology, pulmonology, mental health, and more to design a fast, flexible, comprehensive research initiative. Today I'll walk through those plans with you.

Before I do, I want to pause for a moment and speak directly to the patient community. Some of you have been suffering for over a year, with no answers, no treatment options, not even a prediction of what your future may be. Some of you have even faced skepticism about whether your symptoms are real. I want to assure you—I hear you and I believe you. If you hear nothing else today, hear that we are working to get you answers.

First, we have to understand the basics: how frequently do SARS-CoV-2 survivors experience long-term effects? Is there any correlation between the severity of the initial illness and the likelihood of ongoing symptoms?

New data arrives every day, but preliminary reports suggest that up to 30 percent of patients recovered from SARS-CoV-2 infection may have some form of longer-term health impairment. To get a solid measure of the prevalence of PASC in the population, we will need to recruit tens of thousands of patients. For that to provide the answers we need, we must make sure that we are recruiting a diverse set of COVID survivors:

- A good mix of female and male
- People of all races and ethnicities
- Individuals across the lifespan from children to older adults
- Patients who experienced mild, moderate, or severe illness as well as no symptoms at all
- Patients who experienced COVID-19 before there were therapies available and patients who received monoclonal antibodies, remdesivir, dexamethasone, and other interventions
- Patients who were infected by the initial strain of SARS-CoV-2 and those being infected by emerging virus variants.

To do this complex kind of recruitment rapidly, we are launching a meta-cohort: essentially leveraging some existing cohorts (or groups of research participants) as well as forming new ones that we can knit together in ways that make their data comparable and collectively powerful for answering pressing questions about this virus.

We want to leverage existing longitudinal community-based cohorts. Examples include the Framingham Heart Study, the All of Us study, or a cohort based at a health system. These groups already include tens of thousands of participants on whom we have years-worth of clinical data, diagnostic scans, and outcomes before, during, and after SARS-CoV-2 infected some portion of their participants. In addition, they will be well situated to follow persons over long time periods and determine if there will be effects of COVID-19 pandemic on the future health of Americans.

Second, we want to leverage COVID-specific patient cohorts. Tens of thousands of Americans signed up for research trials to test vaccines and therapeutics. They are already being meticulously monitored for COVID-19 with detailed notes on their personal observations of their health and clinical data about treatments and responses.

Finally, we need a special cohort for children and adolescents. We know that, very rarely, some children exposed to SARS-CoV-2 develop a serious disorder known as multisystem inflammatory syndrome in children or MIS-C. But we also are learning that children can suffer from PASC, and we need to know more about those impacts on their physical or neurocognitive development.

We'll need to be flexible so that additional patients can be enrolled as new virus variants emerge and different therapies become the standard of care.

We have already had a robust response from the medical research community to our call for research proposals to better understand, treat, and ultimately prevent PASC. We have received hundreds of research applications that feature the kinds of cohorts I mentioned. They are being evaluated jointly using Other Transactions Authority. This authority provides the ability to engage partners in collaborative innovation and problem solving, and the much-needed flexibility to rapidly evolve our research approach in response to new findings and emerging scientific needs. We expect to make awards in the next few weeks.

Next, we have to bring the cohorts together with common clinical research protocols, ensuring that data are collected in standardized formats from each of the research participants to enable the most powerful comparisons.

Patients will have an active role at every level and stage of this research. We are planning listening sessions to help guide the future of the PASC Initiative. As we recruit patients to take part in research, we will be asking them to share their health information via mobile health apps and wearable devices. Patients will be able to identify new features of PASC, track their symptoms over time, and

provide real world updates. Patients are the experts on what they have experienced, and this will be a way to quickly bring information directly to researchers.

Now, how can we begin to bring all the diverse stories of PASC together into a coherent picture that explains who is at risk and how to prevent and treat it? Coordination, consistency, and cooperation will be key. We will apply these strategies to rapid data sharing, communicating our findings quickly back to the patient and the research community, and engaging the best minds in interpreting the results. By conducting the studies to better understand the clinical spectrum and biology underlying recovery from acute SARS-CoV-2 infection, in parallel with studies of new approaches to treatment and prevention, we can make great strides toward helping those who are suffering now.

Before concluding, I have to emphasize that a critical way to limit the future toll of PASC is to be sure that the number of new cases of COVID-19 is brought down to zero as quickly as possible. Even for young people who consider their risks of acute disease to be low, the long term consequences can be quite serious. So the recognition of PASC is one more reason to seek vaccination of all adults as quickly as possible, and to continue stringent use of public health measures like mask wearing in the meantime.

PASC and the individuals suffering from it can no longer be a hidden toll of the pandemic. We must bring this circumstance to the forefront of our fight against the COVID-19 pandemic. NIH has already initiated this effort and aims to pursue answers with all of the energy and creativity that the scientific community can muster. Thank you for your time today. I look forward to your questions.

Ms. ESHOO. Thank you, Dr. Collins, for your excellent opening statement. And I know that Members are anxious to field their questions to you, but you gave us a great overview.

The Chair now recognizes Dr. Collins for—Dr. Brooks, I am sorry—for 5 minutes.

STATEMENT OF JOHN T. BROOKS, M.D.

Dr. BROOKS. Thank you.

And good morning, Chairwoman Eshoo and Ranking Member Guthrie and all the committee members, for the invitation to talk with you today.

Over the last year, I have had the honor of serving as chief medical officer for CDC's COVID–19 Response. But before I begin, I want to take a moment today to just recognize the nearly 570,000 American lives lost to this virus. I also want to recognize the tens of millions of Americans who have survived COVID–19 but now face serious challenges and uncertainty with post-COVID conditions which are real and concerning.

You are why we are here today. I and my colleagues have heard you. I am here today with others to share what we know about what it is that you are experiencing, because we are committed to helping you.

As a physician myself, I also know how challenging and worrisome these conditions are to the healthcare providers across our Nation who are seeing more and more patients in clinic with ongoing challenges after COVID infection.

I am also grateful for this opportunity to discuss the impact of these conditions and to review CDC's efforts to study them, measure their prevalence and severity, identify persons at increased risk, and develop recommendations for their prevention and treatment.

Although standardized case definitions are still being developed, CDC uses the umbrella term "post-COVID conditions" to describe health issues that persist for more than 4 weeks after a person is first infected with SARS–CoV–2, the virus that causes COVID–19. Based on our studies to date, CDC has distinguished three general types or categories of post-COVID conditions, although I want to caution that the names and classifications may change as we learn more.

The first, called long COVID, involves a range of symptoms that can last for months. The second comprises long-term damage to one or more body systems or an organ. And the third consists of complications from prolonged treatment or hospitalization.

As in all of our work, CDC is committed to addressing post-COVID conditions through a lens of health equity. While we don't yet have clear data on the impact of post-COVID conditions on racial and ethnic minority populations and underresourced communities, we are working to enhance the collection of demographic data to inform our knowledge base and resulting guidance.

As these groups are both more likely to acquire infection and less likely to be able to access healthcare services, we believe they are disproportionately affected by these conditions.

As early as the spring of 2020, CDC initiated studies to understand the nature of these emerging conditions that follow recovery

from infection and to assess their contribution to the burden of disease among survivors. Among these efforts are prospective studies that will follow cohorts of patients for up to 2 years to provide information on the proportion of people who develop post-COVID conditions and assess risk factors for their development.

CDC is also working with multiple partners to conduct online surveys about long-term symptoms and using multiple deidentified electronic health record databases to examine healthcare utilization of patient populations after initial infection. The collection of these data informs our understanding how often post-COVID conditions develop and how long they may be expected to last.

CDC is also working on interim evidence-based guidance, conducting calls to raise awareness among clinicians and educate them and publishing studies with data for action, with a focus on equipping primary care providers with information on diagnosis and management to the extent that is presently available. We regularly solicit feedback from these national clinical organizations to ensure this guidance is informative and up to date.

CDC is also working to identify potential long-term surveillance possibilities, including leveraging existing systems and research.

In closing, CDC is committed to working hand-in-hand with NIH, research partners, healthcare providers, and the affected patients and their advocates across all levels of government to advance the science around post-COVID conditions to more fully understand these conditions and ultimately help the people experiencing them. We will continue to provide guidance on post-COVID conditions that is rooted in science, maintaining transparency about what we know and also what we do not know, and updating our guidance as evidence evolves. And we will keep health equity at the forefront of our efforts to address post-COVID conditions.

While a lot of work has already begun to address post-COVID conditions, we know there is much left to do to create the evidence base needed to help people suffering with these conditions. I really look forward to working together towards that end.

Thank you again for the invitation to testify today, and I welcome your questions.

[The prepared statement of Dr. Brooks follows:]

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TESTIMONY

OF

JOHN T. BROOKS, M.D.
CHIEF MEDICAL OFFICER, CDC COVID-19 RESPONSE

CENTERS FOR DISEASE CONTROL AND PREVENTION
DEPARTMENT OF HEALTH AND HUMAN SERVICES

BEFORE THE

ENERGY AND COMMERCE HEALTH SUBCOMMITTEE
U.S. HOUSE OF REPRESENTATIVES

The Long Haul: Forging a Path through the Lingering Effects of COVID-19.

April 28, 2021

Chairwoman Eshoo, Ranking Member Guthrie, and distinguished members of the Subcommittee, it is an honor to appear before you today. My name is Dr. John Brooks, and I am CDC's Chief Medical Officer for our COVID-19 Response. I am grateful for this opportunity to discuss post-COVID conditions, including what is called long COVID, and to review the Centers for Disease Control and Prevention's (CDC) efforts to define these conditions, characterize their incidence, identify persons at increased risk, and develop and inform recommendations on their treatment and prevention. As we work to bring this pandemic under control over the months to come, we cannot ignore those who may continue to suffer from post-COVID conditions.

CDC's Response to the Coronavirus Pandemic

CDC is America's health protection agency. We work 24/7 to prevent illness, save lives, and protect America from threats to health, safety, and security. Addressing infectious diseases and pandemics, like COVID-19, is central to our mission. CDC's expertise lies in our ability to study emerging pathogens like SARS-CoV-2, to understand how they are transmitted, and to translate that knowledge into timely public health action. By deploying experts on the ground to support our state, Tribal, local, and territorial partners, we translate science into guidance that protects individuals, communities, and populations. In our work with other federal agencies we ensure the safe and appropriate use of medical countermeasures, including vaccines, and collaborate with the academic sector to further our understanding of new diseases.

The scale of this unprecedented public health emergency requires unprecedented action — at CDC, more than 8,500 CDC personnel have been part of our COVID-19 response, both at CDC headquarters and in the field. More than 1,500 staff have taken part in over 3,000 deployments to nearly 300 cities across the U.S. and around the world.

CDC is working to ensure that public health decisions are based on the highest-quality scientific information. Since the start of the pandemic, nearly 250 COVID-19 studies have been published in the *Morbidity and Mortality Weekly Report* (MMWR) and other publications on a broad range of topics, including on post-COVID conditions and health disparities exacerbated during the pandemic.

COVID-19 has highlighted long-standing systemic health and social inequities. Data repeatedly show the disproportionate impact of COVID-19 on racial and ethnic minority populations, as well as other population groups such as people living in rural or frontier areas, people experiencing homelessness, essential and frontline workers, people with disabilities, people with substance use disorders, people who are incarcerated, and non-U.S.-born persons. While we do not yet have clear data on the impact of post-COVID conditions on racial and ethnic minority populations and other disadvantaged communities, we do believe that they are likely to be disproportionately impacted by these conditions as they are more likely to acquire SARS-CoV-2 and less likely to be able to access health care services. As with all our work, CDC is committed to addressing post-COVID conditions through a lens of health equity.

Defining Post-COVID Conditions

CDC uses the term post-COVID conditions to describe health issues that persist more than four weeks after a person is first infected with SARS-CoV-2, the virus that causes COVID-19. While the exact cause of and risk factors for developing post-COVID conditions are not yet fully understood, these health issues are real and concerning for both the people who have them and their loved ones.

Although most people with COVID-19 get better within weeks of illness, some do not. Even people who are not hospitalized and who have mild illness can experience persistent symptoms or long-term effects. Older patients and those with underlying health conditions are at increased risk for severe disease at the time of infection and later long-term effects from critical illness. However, even people who are young and without underlying health conditions have reported long-lasting symptoms and conditions after initial illness, including those with asymptomatic infection. It's also important to note that there is a wide range of post-COVID conditions, with varying health effects. Additionally, some patients with post-COVID conditions may not have a documented SARS-CoV-2 test result, particularly those who developed COVID-19 early in the pandemic when testing was limited.

Post-COVID conditions are currently being referred to by a wide range of names, including post-acute COVID-19, long-term effects of COVID, long COVID, post-acute COVID syndrome, chronic COVID, long-haul COVID, late sequelae, and others; as well as the research term being used by the National Institutes of Health (NIH): post-acute sequelae of SARS-CoV-2

infection (PASC). Although standardized case definitions are still being developed, in the broadest sense, post-COVID conditions are generally characterized by the development and persistence of new or recurrent symptoms that occur after the acute illness has resolved. On our website, CDC has classified three general types of post-COVID conditions, although the names and classifications may change as we learn more. It's also important to note that these categories are not mutually exclusive. People can have multiple types of long-term health effects following infection with SARS-CoV-2.

The first, called long COVID, involves a range of symptoms that can last for months after first being infected with SARS-CoV-2 or can even first appear weeks after the acute phase of infection has resolved. Long COVID can happen to anyone infected with SARS-CoV-2, even if the illness was mild or entirely asymptomatic. People with long COVID report experiencing varied symptoms, including tiredness or fatigue, abnormal sleep patterns difficulty thinking or concentrating (sometimes referred to as "brain fog"), headache, loss of smell or taste, fast-beating or pounding heart (also known as heart palpitations), chest pain, shortness of breath, cough, joint or muscle pain, depression, anxiety, and fever. The causes of long COVID are still unclear, although there are several hypotheses, including damage to blood vessels, autoimmune effects, and ongoing infection.

Multiorgan effects of COVID-19 are the second type of post-COVID condition as described on CDC's website. COVID-19 can affect and cause long-term damage in multiple body systems including those involving the heart, lung, kidney, and brain. These effects can include conditions that occur shortly after the acute phase of SARS-CoV-2 infection, like multisystem inflammatory syndrome (MIS) and autoimmune conditions. MIS is a condition where different body parts can become inflamed. CDC is studying inflammatory symptoms in both children (called MIS-C) and adults (called MIS-A). COVID-19 illness can also precede the development of autoimmune responses which cause the immune system to attack healthy cells by mistake and damage different parts of the body. Multiorgan effects include reports of neurological conditions, kidney damage or failure, diabetes, cardiovascular damage, and skin conditions.

Finally, post-COVID conditions also include the longer-term effects of COVID-19 treatment or hospitalization. Some of these longer-term effects for those who were hospitalized

are similar to those seen in people hospitalized for other reasons, such as severe respiratory infections caused by other viruses or bacteria. Effects of COVID-19 treatment and hospitalization can also include post-intensive care syndrome, which refers to health effects that remain after a critical illness. Post-intensive care syndrome includes severe weakness, brain dysfunction, and mental health problems like stress disorders. Some of these symptoms can overlap with those observed with long COVID.

Early estimates of the prevalence of post-COVID conditions vary. According to one survey from UK's Office for National Statistics, among people who tested positive for SARS-CoV-2, 21percent - or about one in five people - reported one or more symptoms at least five weeks after their estimated date of infection, and 14 percent - or about one in seven people - for up to 12 weeks.[1] Existing estimates may change as we continue to define post-COVID conditions, and refine our understanding of the long-term burden. CDC, other federal partners, and researchers are currently gathering evidence on the longevity and severity of these symptoms. Post-acute COVID care clinics are being established at medical centers across the United States, bringing together multidisciplinary teams to provide a comprehensive and coordinated treatment approach to COVID-19 aftercare. While these clinics are a critical resource for those suffering from post-COVID conditions, many people do not have access to them due to geographic location or insurance status. In addition, survivor support groups have developed and are connecting people, providing support, and sharing resources with survivors and others affected by COVID-19.

CDC, NIH, and experts around the world are working to learn more about short- and long-term health effects associated with COVID-19, identify those people who may be at greater risk for post-COVID conditions, understand why these conditions occur, and determine which interventions may help lessen severity or shorten the period of time people suffer from these symptoms. Infection with SARS-CoV-2 is not unique in terms of causing both an acute illness followed by longer-term conditions; some post-COVID conditions are likely to be similar to those seen after other infectious diseases, but others may be more specific to COVID-19. Post-

[1] UK Office for National Statistics. Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: 1 April 2021.
https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/1april2021

COVID conditions may also overlap with complications not related specifically to SARS-CoV-2 infection, making them hard to differentiate and define. Health complications may persist for several months or lead to new diagnoses of clinical conditions. At this time when we are still early in our understanding of COVID-19 and post-COVID conditions, there is no official U.S. guidance on post-COVID conditions, and the management of these conditions can be difficult and complex.

It is important to note that the best way to prevent all the long-term complications of COVID-19 from occurring in more people is by preventing SARS-CoV-2 infection. We must continue to use every tool we have to fight the spread of this virus, including public health prevention measures such as wearing masks, social distancing, and handwashing. Vaccination is a critical, effective, and safe tool to bring this unprecedented pandemic to an end. As of April 25, over 228 million doses of COVID-19 vaccine have been administered in the United States, and over half of American adults had received at least one dose of vaccine. Although media articles have reported that some people with post-COVID conditions say their symptoms improved after being vaccinated, additional studies are needed to determine the effects of vaccination on these conditions.

Addressing Post-COVID Conditions

CDC is actively studying the epidemiology of post-COVID conditions, including the prevalence, duration, and severity of symptoms following acute SARS-CoV-2 infection, as well as risk factors for developing post-COVID conditions. This work will help to establish a more complete understanding of the natural history of SARS-CoV-2 infection and post-COVID conditions, which can inform healthcare strategies, clinical decision-making, and the public health response to this virus. In alignment with CDC's broader mission to improve data collection, CDC is leveraging surveillance systems to monitor for disparities as we continue to learn more about post-COVID conditions.

Starting in July 2020, CDC established long-term prospective studies with external partners that will be critical in learning more about post-COVID conditions. These ongoing studies will follow patients for up to two years and provide information on the percent of persons who develop post-COVID conditions. This will help researchers better characterize post-COVID conditions and symptoms and assess long-term immunological responses to the infection. These

studies include measures to verify COVID-19 illness either through SARS-CoV-2 PCR testing or other evidence of natural infection from serology tests. Symptoms may be reported by study participants directly or captured through review of electronic medical records. These studies will also gather information on new diagnoses across a range of symptoms including neurological, respiratory, cardiovascular, metabolic, kidney, and liver diseases that may result from infection with the virus that causes COVID-19.

To collect data while the prospective studies are underway, CDC is also using multiple de-identified electronic health record (EHR) databases to better understand post-COVID conditions. These databases include PCORnet®, a national research network with EHR data, and Premier®, a national database of inpatient and hospital-based outpatient discharge data. CDC is also partnering with Kaiser Permanente of Georgia to examine healthcare utilization of their patient population after initial infection with SARS-CoV-2. Using these databases, CDC is examining the persistence of symptoms and incidence of post-COVID conditions. CDC is also partnering with health systems to perform in-depth medical record reviews, which can provide more granular detail than is present in large databases. These reviews provide insight into the patterns of health effects that patients are experiencing and will improve our ability to characterize post-COVID conditions.

CDC is also working with multiple partners to conduct online surveys that ask people directly about symptoms that occur more than a month after they were initially diagnosed with COVID-19. These surveys will help to estimate the prevalence of post-COVID conditions among those who have reported SARS-CoV-2 infection. To allow for comparison, some surveys also ask people without reported SARS-CoV-2 infection about the same types of symptoms, since some symptoms of post-COVID conditions also occur in the general population. Given anecdotal reports that in some people symptoms may have improved after vaccination, some surveys will include questions about changes in symptoms following vaccination.

CDC is also working to raise the awareness of post-COVID conditions among patients, clinicians, and health systems through its website, partnerships and other means. To this end, CDC is working on interim guidance for health care providers on long COVID, with a focus on equipping primary care providers with available information on diagnosis and management. Although evidence is still limited, having guidance for front-line providers is critical, since it's

likely that millions of people have been affected, and many will not be able to seek care in dedicated post-COVID clinics. CDC is working actively with national clinical organizations like the American College of Physicians, the American Academy of Family Physicians, the American Academy of Pediatrics, and the American Academy of Physical Medicine and Rehabilitation to solicit feedback that will help ensure this guidance is as informative and helpful as possible.

CDC frequently communicates and collaborates with partners and key organizations on post-COVID conditions, including NIH, the Centers for Medicare & Medicaid Services, the World Health Organization, providers at post-COVID care clinics, clinical organizations, and patient groups such Body Politic and Survivor Corps. Finally, CDC is disseminating information about post-COVID conditions through multiple other channels, including Clinical Outreach and Communication Activity (COCA) calls targeting healthcare providers, as well as publications on the topic in CDC's *Morbidity and Mortality Weekly Report* (MMWR) and other scientific journals.

Challenges

There are many challenges and unknowns regarding post-COVID conditions. However, CDC understands that patients and the public need information and guidance now. CDC is committed to providing up-to-date and relevant information to address the major long-term health effects from COVID-19 – as the available information and data changes, we will update our guidance to reflect the latest science.

While CDC has established methods of surveillance for MIS-C, surveillance for other post-COVID conditions is not as straightforward given the wide range of non-specific symptoms that can also result from other causes. A key step in establishing surveillance for post-COVID conditions is to better characterize their clinical presentation and develop a standardized case definition. CDC is working to identify potential long-term surveillance possibilities, including leveraging existing systems and research. More data would allow researchers to better determine how common post-COVID conditions are, monitor for disparities, better characterize conditions typical of a case of post-COVID conditions, identify risk factors for developing post-COVID conditions, provide key information to better prevent and treat the condition, and to monitor its impact at a population level.

Other areas where additional targeted studies and further investigation may be beneficial include, but are not necessarily limited to:

- The long-term impact of post-COVID conditions on individuals stratified by age, sex, race or ethnicity, severity of illness, social determinants of health, access to health care and other factors that might indicate who is at greater risk.
- Determining if SARS-CoV-2 variants may cause changes in the epidemiology and severity of post-COVID conditions.
- Determining if vaccination improves or changes severity of post-COVID conditions.
- Determining what proportion of people with post-COVID conditions had similar physical or mental symptoms prior to acquiring SARS-CoV-2.

While CDC and NIH have significant roles to play in this effort, addressing post-COVID conditions is a nationwide effort to be done in partnership with other research organizations, health care providers, patient groups, and across all levels of government.

Conclusion

Given the magnitude of the pandemic, many Americans will continue to suffer from post-COVID conditions, presenting a tremendous burden on the individuals themselves and the health care system. Even after the average number of new cases declines, CDC will continue monitoring and addressing the impact of post-COVID conditions.

CDC is committed to advancing the science around post-COVID conditions and providing corresponding guidance rooted in that science. Additionally, we are committed to improving health equity, including as it relates to post-COVID conditions. CDC efforts to address post-COVID conditions will maintain health equity as a key goal, and CDC is working to collect data on these conditions by race and ethnicity and other demographic features to inform decision-making.

We look forward to working together to address both the immediate challenges of this pandemic and the long-term challenges associated with post-COVID conditions. Thank you again for the invitation to testify today and I look forward to answering your questions.

Ms. ESHOO. Thank you very much, Dr. Brooks. And we are so pleased to have you with us today as a witness.

We are now going to move to Member questions. And I recognize myself for 5 minutes to do so.

To Dr. Collins and Dr. Brooks: 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, the COVID Health Equity Task Force, but I don't think there has yet been a similarly public coordinated and comprehensive effort to address, you know, this multifaceted issue that we are having the hearing on today. Because it is—as you both noted, it is a crisis for patients, has an effect on our healthcare system, and there are so many issues that are attached to this.

What I would like to know is, who is in charge of leading this effort? In listening to your testimonies, you are both in the same lane. But is there one person or one outfit or one task force in charge of this? Maybe it is a yes-or-no answer, I don't know.

Dr. COLLINS. It is a very appropriate question. I think we have excellent relationships between NIH and CDC. Dr. Brooks works intensively with Dr. Lerner and my staff. We are working with FDA also in this space and also with CMS. But you are right, there is no sort of supervisory, top-level oversight like there is——

Ms. ESHOO. Do you think, Dr. Collins, we need one?

Dr. COLLINS. You know, I have to think hard about it, because sometimes——

Ms. ESHOO. OK.

Dr. COLLINS [continuing]. It can be a good thing or sometimes it can kind of get in the way of a more organic approach.

Dr. Brooks, go ahead.

Dr. BROOKS. Yes. I just wanted to add that I would say that, first of all, we are collaborating intensively. And this is sort of standard for how we often address these emerging problems, you know, 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, you know, we would have to think about whether a coordinating body is necessary. I think we are working very well right now together.

We also—you had asked about sort of other government engagement. I just would say a couple of things to that. While we are 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 Social Security Administration.

Ms. ESHOO. OK. Well, Dr. Collins—well, thank you, Dr. Brooks, for that.

I think that there are a lot—we have patients with us today. And thank you, Dr. Collins, for in your opening, in your testimony, you spoke directly to patients across the country.

Now, you also spoke about metacohort undertakings. When do you expect that to conclude? How long is that going to take? And in the meantime, what can NIH, CDC, FDA, the administration, the Congress, what do we tell our constituents that are undergoing what is attached to this condition?

Dr. COLLINS. So the timetable we are moving forward with is pretty unprecedented for such a large-scale study, but it needs to be. The funding you all provided was made available in December. By February, we put out a notice to all of the organizations and academic centers and other entities that we thought could help with this. And we got a response of that 273 applications that are currently going through an intense review. We aim to make those awards within the next 3 weeks and to stand up this metacohort in a series of core facilities so that we can immediately begin the process of collecting the data. And doing a deeper dive into trying to understand really what is the mechanism that is causing this illness.

And one thing, I guess, we will be depending on the patient groups is participation in those research studies. And I think I am hearing a lot of motivation for that, so I think we are going to have wonderful partnerships. And we want them at the table for every decision we make. This is not supposed to be a top-down, but more of a bottom-up effort to get answers——

Ms. ESHOO. Thank you very much. Oh, I think my time has been used.

And so the Chair will now recognize Mr. Guthrie, the ranking member of our subcommittee. You are recognized for your 5 minutes of questions.

Mr. GUTHRIE. Thanks, Chair Eshoo. And thanks to our witnesses here today.

And, Dr. Collins, first off, I heard your message a few Sundays ago on "CBS Sunday Morning," and in here, and all times I have dealt with you. And, Dr. Brooks, I haven't dealt with you as much, so I am sure this is appropriate as well. But, you know, the tone in which you speak about testing is important. We have a lot of information, but we don't need to come off like we think we are smarter than everybody else, even though we have more information than people have. And so as we share that, I think the way we speak to people is how they listen to us. And I think your tone on that message you put on that Sunday morning about being vaccinated was just absolutely the right way we need to speak to people. So thank you for that.

Speaking of vaccinations, Dr. Collins, I have heard through anecdotal reports that people who have long-term COVID are experiencing improvement after they are vaccinated in their conditions. Can you speak more to this, and what do you think is causing this reaction?

Dr. COLLINS. It is a great question. There have been anecdotal reports of people who suffered for months sometimes with long COVID, and after getting the COVID vaccine [inaudible]—a bit of a background there. Well, I guess I will just keep talking —have reported benefit, in some instances, fairly dramatic benefit within a few days.

It is hard to get really good data. The largest study that has actually been published in a preprint was only 44 individuals who had in fact had long COVID, got vaccinated, and there was overall a tendency towards improvement. Something like 23 percent of them said they were better after a month, whereas those who didn't get the vaccine, it was 15 percent. So it is a small difference. We need to understand that.

One of the questions is, how would that work anyway? Does that say that there is still lingering infection by the SARS–CoV–2 virus in people with long COVID? Even though we have not been able to recover the virus from those folks, does the vaccine giving this response say that there is some sort of reservoir there? That is a clue. So it is one of the more interesting things that has come along recently. It might be a possible way to go forward.

This is one of the reasons we really need to have this much larger-scale metacohort to try to get an answer to whether this is a real signal or not. So we are all over it.

Mr. GUTHRIE. Well, thank you very much. That is great to hear.

And, Dr. Brooks, a recent study of COVID patients found that nearly 13 percent received their COVID–19 diagnosis for the first time were presenting with long-COVID symptoms. Presumably, these people first had COVID either when testing was not prevalent or had asymptomatic or mild cases.

How can we diagnose more of these long-COVID cases earlier? And is there a role for serology testing? And what other diagnostics are needed to better identify long COVID?

Dr. BROOKS. Thank you very much for asking that question. You raise a really important point, which is, not only are there persons who develop post-COVID symptoms who we later through serology or testing recognize as having had COVID, but there are also people who develop these post-COVID conditions who have no record of testing and we can't determine if they had COVID. So we have got to think carefully about what that—how to manage that when we are coming up with a definition for what a post-COVID condition is.

But more to the point of your question, the most important thing as I think was first laid out is to just get vaccinated and avoid getting the infection in the first place. If, however, you experience the infection and develop post-COVID conditions, one of the most important things is to make sure that this condition is recognized. We need to make sure that folks know what they are looking at.

As you have heard, it is sort of protean, there are all sorts of different ways, and maybe we will talk about this later, but the symptoms and ways that people present are very varied. And people need to be thinking, could this be post-COVID, and also taking patients at their word. You know, we have heard many times that patients have been ignored or their symptoms minimized, possibly because they didn't recognize they had COVID previously.

Mr. GUTHRIE. OK. Thank you.

And then, Dr. Collins, how is NIH leveraging existing longitudinal community-based cohorts such as the All of Us Study to examine and study long COVID? And what more can be done to study these individuals?

Dr. COLLINS. That is a great question. All of Us, you may know, is this large-scale study, very diverse in those who have enrolled in it, aiming to have a million Americans that we can follow over time for all kinds of questions that could be asked at length about how to prevent illness or how to manage chronic disease.

We are already up to over 300,000 participants. I think some of you are participants. Thank you, if you are. And this is a golden opportunity because these are individuals who have consented to be part of research. They are enthusiastic about it. They are our partners. And with 300,000-plus of them, there have been lots of people who have had COVID and quite a few who are now suffering from long COVID. And we have this historical information about them prior to their being exposed to this virus. So we can really look at the sweep of their experience and perhaps identify what were the predisposing factors that caused those people who get the acute illness to go on to long COVID and not just get better the way most respiratory viruses ought to do.

So that is part of our metacohort, a very exciting part or our metacohort. We are going to build on that as well by enrolling other folks with other backgrounds, but I am glad you raised that one.

Mr. GUTHRIE. Thank you very much.

And thanks, Chair. I yield back.

Ms. ESHOO. The gentleman yields back.

It is a pleasure to recognize the chairman of the full committee, Mr. Pallone, for his 5 minutes of questions.

Mr. PALLONE. Thank you, Madam Chair.

And let me say how pleased I am to have Dr. Collins and Dr. Brooks here today to discuss the long-COVID issue.

I think that you have touched a little bit on some of my questions, so maybe we can just ask you to develop some more details.

Let me start with Dr. Brooks. I know you touched upon the strides that the CDC has been making in addressing the pandemic in the short and long term, and you talked about the incidence and prevalence of long COVID so far. But just share with me a little more details about what you have been able to understand about the incidence and prevalence of long COVID so far, if you will.

He may be on mute. Maybe I am on mute.

Dr. BROOKS. My apologies. My Christmas card is going to be "I am on mute."

OK. Thank you. I am happy to share with you what we know about this. As I mentioned, we have been doing some cohort studies since early last spring. These and some of our analyses of electronic health records have given us some insight into the potential incidence of post-COVID conditions. That together with also external research that others have cited already lead us to believe that, one, it is common. It could be as common as two out of every three patients.

A study we recently published in our flagship journal, the Morbidity and Mortality Weekly Report, suggested two out of three patients made a clinical visit within 1 to 6 months after their COVID diagnosis. So that is unprecedented. People who recover from the flu or a cold don't typically make a scheduled visit a month later. It does seem that for some people the condition gets better, but

there are definitely a substantial fraction of persons in whom this is going on for months.

The value of the study that Dr. Collins spoke to is that with the large numbers it will really help us hone in more closely on what the precise numbers look like.

Mr. PALLONE. Well, thank you. And I know you, both of you, have mentioned this metacohort study, which maybe you can explain what metacohort means, and then, you know, how that is going to help us get a more reliable measure of how widespread this long COVID might be, Dr. Collins.

Dr. COLLINS. Yes. Let me give a try at that. Yes, maybe that is not such a familiar word. Even for people who do epidemiology, we haven't had a lot of metacohorts, so let me explain.

Basically, what we did was to think of all of the ways in which we could try to get answers to this condition by studying people, both those who already have self-identified as having long COVID as well as people who just went through the experience of having the acute illness, to see what is the frequency with which they ended up with these persistent symptoms. And if you look around sort of what would be the places where you would find such large-scale studies, one would be, like we were just talking about a minute ago with Mr. Guthrie, the idea of these long-standing cohort studies, Framingham being another one, where you have lots of people who have been followed for a long time, see if you can learn from them who got long COVID and what might have been a predisposing factor. That is part of the metacohort.

You could also look at people who have been in our treatment trials, because there are thousands of them that have enrolled in these clinical trials, and they got a particular treatment applied, like a monoclonal antibody, for instance. It would be really interesting to see if that had an effect on how many people ended up with long COVID. Did you prevent it if you treated somebody acutely with a monoclonal antibody?

And then there are all these patient support groups, and you will be hearing more from them in the second panel, were highly motivated, already have collected a lot of data themselves as citizen scientists. We want to tap into that experience and that wise advice about how to design and go through the appropriate testing of all this.

So you put those all together and that is a metacohort, where you have different kinds of populations that are all put together in a highly organized way, with a shared database and a shared set of common data elements, so we can learn as quickly as possible. Theoretically, we can just do one of those, but this is such an urgent crisis, and you the Congress have given us enough resources. We are trying to do all of them but in a seamless, integrated, synergistic way.

Mr. PALLONE. Thank you.

Could you just quickly, Dr. Brooks, tell us about how CDC is planning to keep providers informed on how to diagnose and treat patients with long COVID? There is only like 20 seconds left, if you could quickly.

Dr. BROOKS. Yes. First, we do webinars and regular calls, updating them on what we know, publishing interim guidance that we

regularly update. And that guidance is informed, not only by clinical providers, but also by patient groups with whom we share the information.

Mr. PALLONE. All right. Thanks a lot.

Thank you, Madam Chair.

Ms. ESHOO. The chairman yields back.

And the Chair now recognizes the ranking member of the full committee, Congresswoman Cathy McMorris Rodgers, for her 5 minutes of questions.

Mrs. RODGERS. Thank you, Madam Chair. Thank you. Thank you, everyone.

I wanted to start with a question to Dr. Collins. And really appreciate both Dr. Collins and Dr. Brooks being with us today. This is extremely helpful. I wanted to take a moment just to ask a question about a letter that Congressman Morgan Griffith and Congressman Brett Guthrie and I had sent to NIH back in March, March 18, that was really about understanding the origins of the pandemic. And I understand that NIH is working on a response. And I want to thank you for your attention.

The question is, do you believe that it is in the public interest to have a comprehensive, scientific investigation into the pandemic origins? And do you agree with the Director-General of the World Health Organization that further investigation into COVID origins is needed, including reviewing possible links to the potential laboratory leak?

Dr. COLLINS. Yes, I do believe that an investigation following on the original WHO investigation is needed. You may have seen The Wall Street Journal report just yesterday indicating that there is a serious effort now within the U.S. Government, between the State Department, the Department of Health and Human Services, the Department of Agriculture, and five other Federal agencies to put forward to WHO what we believe ought to be the components of such a followup investigation. It should be science based. It should be looking at evidence. It should be rigorous. It should try to get answers to the questions that the first investigation was not able to derive. And NIH will undoubtedly play some role in that, although it obviously is occurring at the Department level.

So yes. To answer your question directly, we do believe that a followup investigation is appropriate. And we are working on answers to your letter with 29 questions and 40 footnotes and 11 pages. It is taking us a little longer than a few days.

Mrs. RODGERS. Yes, I understand that. It is very comprehensive. I appreciate your attention to those questions.

I also wanted to ask about children. And I think we are learning that children are better protected from some of the most severe symptoms of COVID–19. However, it is becoming increasingly apparent that some children who have contracted COVID–19 are having long-term effects. And would you just speak to what we know about long COVID in children? And can you tell us about the special cohort that the NIH is developing for children and adolescents?

Dr. COLLINS. Yes. And I really appreciate that question, because this is another critical part of the metacohort that I failed to mention a minute ago and should have.

We do know that children can get long COVID. In fact, the harder you look, it seems, at least in the study that I think that has done the most thorough job so far, that somewhere around 11 to 15 percent of kids who have had the COVID infection, and they are not immune to it, can end up with this long-term consequence, which can be pretty devastating in terms of things like school performance. So we need to understand that as well.

Just to clarify: There is a separate problem that children who have had COVID–19 can have, which is something called MIS–C, multisystem inflammatory syndrome of children, which is an autoimmune, a rather dramatic condition which can put kids in the ICU, which we do know how to treat. And that is a critical one as well, but I think it is a different pathogenesis than the long COVID.

The long COVID cases look kind of like the adult cases, except they are in younger individuals. So as part of studying this we need to include children in a very significant way and collect all the data that we can and try to understand the cause.

Mrs. RODGERS. Thank you very much. And I appreciate your attention to that.

Dr. Brooks, you say that COVID infection is not unique in terms of causing both an acute illness followed by longer-term conditions and that some post-COVID conditions may be similar to those in other diseases. Would you just speak to what post-COVID conditions are similar to those seen in other infectious diseases? And can we learn anything from those diseases that would help our understanding of long COVID?

Dr. BROOKS. Yes, happy to. So I think the complications that are seen in the post-COVID conditions to which the parallel is often most rapidly drawn is to myalgic encephalitis, or chronic fatigue syndrome. Let me be very cautious there and say that that is usually—we often jump to framing something, when it is new, to frame it with something we already know. And I want to stress that we now also know that what we are seeing with post-COVID differs from that set of conditions.

What it shares in common, particularly in people who have this for months, are extreme fatigue. I mean fatigue, as you probably heard, so bad you can't get out of bed, it makes it impossible for you to work and limits your social life. Anxiety and depression lingering, chronic difficulty breathing, with either cough or shortness of breath. The loss of smell persists for a very long time, which, incidentally, is particularly unique to this infection, the best I know.

What I would like to stress is that what we are doing now to understand post-COVID conditions may well have benefits for other conditions like it. It is a leading hypothesis, I think, that myalgic encephalitis is caused by an infectious disease insult, but we don't really know the timing and how it occurs.

The cohorts that Dr. Collins described, where we are following people in real time already and that we can see them when they get COVID and follow them forward, we have a unique opportunity to really begin to understand what the interplay may be between this insult, if you will, from an infection and how that results in these conditions later. And then use that to identify people at risk, predict who may get it, and better understand how to treat it.

Mrs. RODGERS. Super. Thank you very much. Thank you both.

I yield back.

Ms. ESHOO. The gentlewoman yields back.

It is a pleasure to recognize the gentleman from North Carolina, Mr. Butterfield, for your 5 minutes of questions.

Mr. BUTTERFIELD. Thank you very much, Madam Chair. And good to see all of you today and hope you are doing well.

Let me first start with Dr. Brooks. Dr. Brooks, thank you for your testimony. The evidence from the past year clearly shows that COVID is disproportionately harming African Americans, Latinos, and Native communities. In your testimony, you note that because of the higher rate of COVID cases in these communities, it is likely that these communities will also experience post-COVID conditions at a higher rate.

And so my question is, data can be a powerful tool. Is the CDC tracking race and ethnicity in its long-term studies, long-term studies that have worked utilizing data from electronic health records and online surveys? And if not, let me ask you, why? And how can those challenges be fixed?

Dr. BROOKS. Well, thank you for raising that question. I think this may be a short answer, which is, absolutely, we are following race, ethnicity, as well as often income, educational attainment, and other social determinants of health in the studies that we are doing related to COVID.

I would like to point out that one of the cohort studies we are doing is particularly focused on American Indians and Alaska Natives. Others are oversampling racial or ethnic minority populations or those who are underresourced to ensure that we get information about these communities.

One point I would like to make is electronic health records can be a little tricky, because it depends on what the clinician entered as the race or ethnicity. And in some of our studies, we have the opportunity to ask people themselves, tell us how you want us to represent you in this study. And it is nice when we are able do that.

Mr. BUTTERFIELD. Thank you. Thank you for that response.

And now I will go to my good friend Dr. Collins. It is good to see you, Dr. Collins. And thank you for your incredible work.

In your testimony, Dr. Collins, you describe taking advantage of existing cohort and clinical studies to create a megacohort to compare post-COVID conditions data. You note that for this effort to be effective, the data must be standardized.

My question is about standardization. Can you explain how the NIH is planning to address the standardization issue and whether you see any other barriers that would prevent megacohort data from being used effectively?

Dr. COLLINS. That is a great question, Congressman. Yes, it is both a metacohort and, as you have said, it is a megacohort as well. We can use the T or the G and they would both be correct.

So the idea of trying to assemble such a large-scale effort from multiple different kinds of populations of patients is our idea about how to do this quickly and as vigorously and accurately as possible. But it won't work if we can't actually compare across studies and figure out what we are looking at.

So part of this is the ability to define what we call common data elements, where the individuals who are going to be enrolled in these trials from various sources have the same data collected, using the same format, so that you can actually say if somebody had shortness of breath, how did you define that? If somebody had some abnormality in a lab test, what were the units of the lab test that everybody will agree so you can do apples-to-apples comparisons? That is already underway.

Part of this metacohort is also to have three core facilities. One of those is a clinical sciences core, which will basically come up with what are the clinical measures that we want to be sure we do accurately on everybody who is available for those to be done.

Another is a data sciences core, which will work intensively on these common data elements and how to build a data set that is both preserving the privacy and confidentiality of the participants, because these are people who are human subject participants in a trial, and also making sure that researchers have access to information that they can quickly learn from.

Then there is a third core, which is a bio repository, where we are going to be obtaining blood samples and other kinds of samples, and we want to be sure those are accurately and safely stored so they can be utilized for follow-up research. All of that has to fold into this.

And so I am glad you asked the question. That is the mechanism by which we aim to make the whole greater than the sum of the parts here. Even though the parts are pretty impressive, the whole is going it to be pretty amazing.

Mr. BUTTERFIELD. Thank you. Thank you very much, Dr. Collins. And we are going to continue to support your work on this committee. And, again, thank you. And thank you to all of your colleagues at the agency. You are doing incredible work. And let's hope the President tonight will also recognize your great work. Thank you.

I yield back.

Ms. ESHOO. I think he recognized Dr. Collins' great work because he was one of the first individuals that he called and said, "We need you to stay." So thank you.

The gentleman yields back.

A pleasure to recognize a former chairman of the full committee, a great friend to all of us, Mr. Upton from Michigan.

Mr. UPTON. Well, thanks, Madam Chair. It is a little bit of a cold, rainy day back here in Michigan, but I am delighted to be here with all of you, and certainly my very good friend Dr. Collins, a University of Michigan former professor before he moved forward and has done great work. And I have got a Bo Shembechler bobblehead right behind me if you look carefully.

But let me just—I want to focus on a couple of things with you as we move forward. You know, you and I talked a lot last year about the RADx program, which was part of the first COVID package that we adopted on a very strong bipartisan vote, over 400 votes. It speeds up the innovation and the development to commercialization and implementation of testing for COVID.

So what has NIH learned literally in a year since the launch of that program where you put it together, I want to say, over a week-

end. But what did you learn that can help us as we move forward, particularly as we have now made real progress with the vaccines, but we have a long way to go still in the years ahead?

Dr. COLLINS. Well, thank you for that question, and, yes, for your support of RADx. Yes, it is interesting you ask the question, because tomorrow is the 1-year anniversary of the launch of RADx, Rapid Acceleration and Diagnostics, another program made possible by the Congress by providing us with some additional funds to be able to build new platforms for technology to detect the presence of that SARS–CoV–2 virus, increasingly being able to do those now as point of care instead of having to send your sample off to a central laboratory and even now doing home testing, which has now just in the last month or so become a reality, and that is RADx that developed those platforms.

It was a pretty amazing experience, actually. We basically built what we called a shark tank. We became venture capitalists. And we invited all of those people who had really interesting technology ideas to bring them forward. And the ones that looked most promising got into the shark tank and got checked out by business people, engineers, various other kinds of technology experts, people who knew about supply chains and manufacturing and all of that to make sure that we put the funds into the ones that were most promising.

And right now today, Congressman, there's about 2 million tests being done today as a result of RADx that otherwise would not have been. Two million a day. Thirty-four different technologies that we put through this innovation funnel. And that has opened up a lot of possibilities for things like getting people back to school, where you have testing capacity that we didn't have before.

What did we learn about that that applies to long COVID? Well, one thing I learned was we can do things at NIH in really novel ways that move very quickly when we are faced with a crisis like COVID–19 pandemic. We are applying that same mentality to this effort on long COVID.

Normally, it would have taken us more than a year to set up this kind of metacohort. We are doing it in a couple of months because we need to. Utilizing some of those same mechanisms that you gave us in the 21st Century Cures bill, which has been a critical part of our ability to move swiftly through something called Other Transactions Authority. So, yes, we have learned that.

And by the way, I have to put a little plug here, if you saw in the President's budget proposal for fiscal year 2022 something called ARPA–H, which is basically bringing the DARPA attitude to health. That also builds on these experiences and will give us, if approved by the Congress, the ability to do even more of these very rapid, very ambitious, yes, high-risk but high-reward efforts as we have learned to do in the face of COVID and want to continue to do for other things, like Alzheimer's disease or cancer or diabetes, because there's lots of opportunities there too.

Mr. UPTON. Well, even though I will be in Michigan tonight and not on the House floor, I know that work on ARPA–H, but Chairwoman Eshoo and myself and Diana DeGette were meeting with the President a little bit more than a month ago, and we talked about ARPA–H. I acknowledge and support the promise that this

may really provide as we go to the next level. And I would suspect, I would hope, that the President will talk about it this evening and that we, in fact, can come back—as you know, we are looking at a CARES 2.0 bill, and this would be an element of that that we pledge to work with the President on that. And I think it can be very, very positive and constructive, not only for us but for the entire world. And I appreciate your leadership on that and your good work and look forward to working with you in the months ahead.

And, with that, my time is expired.

I yield back.

Ms. ESHOO. The gentleman yields back.

And I appreciate what you just said about ARPA–H. That meeting with the President was bipartisan, obviously, it was bicameral, and I think shoulder-to-shoulder that this effort can really move the needle in very important and overarching ways for people in our country and for the world.

So it really was uplifting and is to be a part of that effort. And the gentleman has a history of leading on these issues. So thank you.

The Chair now recognizes the gentlewoman from California, Ms. Matsui, for her 5 minutes of questions. Great to see you, Doris.

Ms. MATSUI. You too.

Thank you very much, Madam Chair. And thank you for this hearing, and I want to welcome Dr. Collins and Dr. Brooks for joining us this morning on this very important hearing.

While primarily it was a respiratory disease, we know that COVID–19 can also lead to neurological problems. To investigate these problems, researchers at NIH National Institutes of Neurological Disorders conducted the first indepth examinations of human brain tissue samples from people who died after contracting COVID–19.

Now, Dr. Collins—and it is great to see you—can you talk a bit about the findings from this NIH study, and what did it suggest about the likely explanation for COVID–19's many neurological symptoms?

Dr. COLLINS. Thanks for the question, Congresswoman Matsui.

This was work done by our investigator in our intramural program, Dr. Avindra Nath, and he was looking at brain samples from individuals who had died, many of them suddenly and unexpectedly. These weren't necessarily people who had been in the hospital a long time. Some of them never were hospitalized and then had sudden death.

And he looked very carefully to see what was happening and found that there was evidence not actually that the virus itself was present in the brain. It was not possible to find the actual viral proteins or the viral RNA, but instead a lot of damage seemed to have been done to blood vessels as if they had started to leak. Now maybe that was because the virus had been there and done a hit-and-run and caused that leakage, or maybe it was a consequence of an overactive immune system response that had done damage to those small blood vessels, but that was the finding.

Now, that is very intriguing. That is not what most people would have expected. I got to be careful, though, not to leap to the conclusion that the much more common neurological consequences that

people with long COVID are describing in terms of the fatigue, the depression, anxiety. It would also have the same findings because obviously what Dr. Nath looked at were the most dramatic and most tragic circumstances. And it could be that what is going on in the brain in the more common circumstances has got a different mechanism. That is one of the things we need to find out by studying very large numbers of individuals with the most sophisticated kind of imaging that we now have at our disposal, and we would aim to do that.

Ms. MATSUI. OK. So I follow along what you are saying. What steps are you planning, has NIH taken or planning to take to advance research on COVID–19-related neurological symptoms, complications, or outcomes?

Dr. COLLINS. Well, first, we need to collect as much information we can about those presentations, about what the symptoms are and carefully record those and make sure we use this common data element so we are talking about the same thing between different studies, but then I think imaging is going to be critical here, and we will invite the participants in this metacohort who have neurologic symptoms—some of them; we can't afford to probably scan all of them—to look in the most sophisticated way to see what has happened in the brain. Is there clear evidence of something in the way of a circulatory problem? Is there some kind of swelling going on? Is there a blood-clotting issue? All that information we just don't have, and that is what we need to find.

Ms. MATSUI. All right. Thank you very much, Dr. Collins.

Dr. Brooks, adverse mental health consequences of COVID–19, including anxiety and depression, have been widely predicted but are challenging to measure accurately. I am interested in the role that electronic health records can play in efficiently providing some of the central information needed to understand and control the mental health consequences of this pandemic and plan for the future ones.

Dr. Brooks, you mentioned EHRs can be tricky for mining accurate race and ethnicity data. Are there similar challenges to using electronic health records for monitoring the mental health of long COVID–19——

Dr. BROOKS. Sure. There sure are. You know, it requires a person enter the data and recognize that there is a mental health problem present, but—so many clinicians are trained and good at doing that, but as you may have heard, in our business in medicine, chance favors the prepared mind. And one of our jobs is to get people trained up to recognize when that is present and get them to enter it. But there are other ways electronic medical records can help us, particularly with disorders like these.

We can look at the prescription drugs they were prescribed, drugs they may have been prescribed to treat anxiety, depression, pain, fatigue, and that can be another indirect way of assessing what is going on. But all of these are, unfortunately, still an indirect indicator of what the person's illness journey was actually like. And this is where some other studies where we follow patients, as Dr. Collins has mentioned, really can make a big difference.

We can do surveys to measure quality of life, social functioning, and physical functioning, to actually measure and quantify what is

going on and then correlate that with the imaging, for instance, that he mentioned before.

Ms. MATSUI. OK. Well, thank you very much for your testimony, both you and Dr. Collins.

And, Madam Chair, I yield back. Thank you.

Ms. ESHOO. The gentlewoman yields back.

It is a pleasure to recognize one of the doctors on our subcommittee, the gentleman from Texas, Dr. Burgess, for your 5 minutes of questions.

Mr. BURGESS. Well, I thank the chair, and I thank our witnesses for being here today.

Dr. Collins, the observational data that both the vaccine will help ease some of the symptoms of long COVID is certainly intriguing, but I think you referenced in your testimony and certainly we heard on the prehearing chatter across the board that perhaps the best offense is a good defense, and preventing the illness in the first place may be our best bet for preventing patients from getting the symptoms of long COVID.

So is there an opportunity here for that teachable moment where people who are on the fence as far as to whether or not they get the vaccine, can we perhaps provide them some additional information with, like, what we are doing with this hearing today?

Dr. COLLINS. Well, Dr. Burgess, it is a great question, and let me say I just saw yesterday the effort that the Doctors Caucus has made to get the information out there about the importance of vaccination.

Thank you for putting on your white coats and making very compelling statements from the perspective of yourselves as medical professionals about why this is something everybody should take advantage of.

I do think that the risks of long COVID has not been appreciated mostly by the public unless they happen to know somebody who has been going through this. I think they have particularly not been appreciated by young people who may continue to view this as an illness that they don't have to worry about too much because they heard that young people generally don't have very severe acute illness, although we can all say there's plenty of exceptions to that too.

And so I have started talking about it when I am raising the issue about the importance of vaccination. I worry a little bit that it sort of feels like, OK, here goes that government guy shaking his finger at people again, saying these are all bad things that are going to happen to you if you don't get that vaccination, which we know is safe and effective.

So I am trying to moderate that a bit by also saying and think of all the things you can do when you get vaccinated, like, you know, meet with your friends with your masks off inside because you have all been vaccinated and you can hug each other again, which is something we have all kind of missed for the last year.

Mr. BURGESS. That is a perfect segue to, actually, one of the things I wanted to talk about. Look, we are having a joint session of Congress tonight. The President for the first time is going to be present in the Capitol since his inauguration. I won't be there. This is the first joint session of Congress that I will have missed in al-

most 20 years, and the reason I won't be there is not because I am boycotting but because we were limited to the number of invitations that could go out. And, presumably, it has something to do with the continuing, lingering effects of the pandemic.

But here is the deal. We all got vaccinated very early, as soon as the emergency use authorization came forward. I can't say we all got vaccinated, but a great number of us did. Another number of us have already had the coronavirus itself. It just seems to me that we are sending the wrong message because here we were one of the first groups as a body to avail ourselves of the vaccine, yet we are still behaving like we did a year ago, like it didn't help us at all. It didn't help us get over the effects of the pandemic.

So I know that it has been correctly pointed out that there are others who were responsible for these decisions, but I would just ask you in your conversations with House leadership to encourage us as much as is practical to get back to normal voting patterns, normal hearing patterns, normal visits in the office. And because of the protection provided by the vaccine, this is something now we can do and perhaps make that message more prevalent because there is no question about it, we are missing something with getting people—getting to all the people who could be vaccinated, and yet some are holding back.

But I feel like we are sending the wrong message as a body. So you referenced the Doctors Caucus. We also sent a letter to the Speaker urging the Speaker to get back to a more normal activity level in the House because, again, show the power of having had the vaccine. So, to the extent that you have the availability of making that which is known to the Speaker, I would ask that you do so.

And let me also give a plug for, in Cures, we did the interoperability title in the electronic health records. I am glad to see that you and Dr. Brooks are using the metacohort data and the electronic health record data to a good end.

Dr. COLLINS. That is right. It would make a great statement, Dr. Burgess—and the Doctors Caucus I know is trying to push this—if every single Member of the U.S. Congress, all 535 would get vaccinated, even those that have had COVID. You are better protected to get the vaccine even after you have had the natural infection, like President Trump did. That would state to the whole country just how crucial this is for our future. And I suspect even the Capitol Physician, if everybody was fully immunized, would say, "OK, you guys can get back together again." I am not going to speak for that physician, but I suspect that is the principles that he is looking at right now.

Ms. ESHOO. The gentleman's time has expired.

I thank the gentleman for raising the points that he made. I think the Doctors Caucus needs to meet with the Capitol Physician because the lay persons, whether in leadership or not, are going with what the determinations are that he has made. And I think in both caucuses on each side of the aisle, we really need to urge our colleagues—and I said this as we were beginning much earlier today—that every Member of Congress should be vaccinated, and they are not, and that is holding us back. So I just wanted to add that. But I think if the doctors meet with the doctor, we might

make some better headway on this because there is no excuse for 535 not being fully vaccinated. You are absolutely right about that.

So the Chair now has the pleasure of recognizing the chairwoman from Florida, Ms. Castor, for your 5 minutes of questions.

Ms. CASTOR. Well, thank you, Chair Eshoo. This is a very important hearing, and I am grateful for your leadership in bringing us together. And Dr. Collins, Dr. Brooks, thank you so much. Thank you for starting your testimony recognizing this very difficult year for all Americans. It is just staggering that we have lost over 570,000 Americans and so many more have been suffering through with illness or loss. But there is hope here. I love the conversation on vaccinations. My office, right outside my door here is the health unit, and when I came in this morning there was a long line. Remember, yes, it is the 535 Members of Congress, but it takes all of our professional staff, Capitol Police, the custodians, everyone getting vaccinated, and I know the Speaker is very eager to get back to normal because I have raised this with her, and she has said it is time to move that way. So we all have to do our part here and back home.

So thanks [inaudible]. Dr. Collins, when you brought—when long COVID kind of entered into the consciousness last year and you came with Dr. Fauci and others and said we are going to need some long-term studies on the long-term effects of the coronavirus, I was—I think that was very timely. Thank you for being thoughtful about doing that early on, and I am glad that Congress responded in a bipartisan way to get those funds, and here we are. You have—you said 273 proposals already. You are going to make some decisions next week. I wonder, you know, when we first started trying to understand what COVID–19 is, it was most analogous for people to the flu, but when you talk about flu you don't really think about long-term impacts, health impacts to people, but there have to be other infections where we have had long-term studies in place, and we have learned something about treatments and eventual cures.

Could you provide maybe some analogies on how important it is to have those long-term studies and look at other infections, and what we have learned over time?

Dr. COLLINS. Sure. Obviously, a particularly dramatic historical example of that [inaudible] is HIV/AIDS, where we know that somebody infected with that virus can then have lifelong consequences, which we can suppress with appropriate antiretroviral therapy. So I would love to be where we are with HIV for long COVID in terms of understanding the mechanism and having a treatment, not that I would want anybody to have HIV long term either.

But we aren't there yet. We don't understand the mechanism of what it is that is causing this prolonged set of symptoms for long COVID. It is true that there are two other coronaviruses that preceded SARS–CoV–2 that got us worried, didn't spread in the same way and that being SARS—remember SARS back almost 20 years ago, and then MERS in mostly Middle East area, and those also were coronaviruses where people were acutely very sick and then they seemed to get better, but they didn't get all the way better. So there was a prolonged kind of potential there of trouble, but

there was a sufficiently small number of infected individuals in that situation to learn very much about it.

Frankly, I think it is pretty unprecedented for a respiratory virus like SARS–CoV–2 to do this. Influenza, yes. If you were in the ICU and you almost died and you had terrible pneumonia, you would potentially have a long recovery for sure just getting over that organ damage, but to have a disease that is a respiratory virus where people, many of them, don't end up in the hospital but then still 6 months later have serious symptoms is kind of unprecedented. So we are kind of in new territory.

Ms. CASTOR. Dr. Brooks, do you have anything to add?

Dr. BROOKS. Yes. First, I want to echo exactly what Dr. Collins said, particularly, the analogy with HIV. Also, that the number of people seeking care after recovering from COVID is really unprecedented. It is not just people who had severe COVID. It may include people who had very mild COVID. In fact, we know there is a number of people who never had symptomatic COVID who then get these long symptoms. And just historically, the other disease I can think of that may have a little analogy to this is polio. It was a more devastating sequelae that people lived with the rest of their lives, but it was thanks to the enrollment of some early cohorts that these patients followed over the course of their life that when post-polio syndrome later came up in the population, we had the wherewithal to begin to understand it. And it happens with that condition in many ways sharing some characteristics of this post-COVID condition.

Ms. CASTOR. Well, thank you both so much for all of your work. Madam Chair, I yield back.

Ms. ESHOO. The gentlewoman yields back.

The Chair is pleased to recognize the gentleman from Virginia, wonderful member of our subcommittee, Mr. Griffith, for your 5 minutes of questions.

Mr. GRIFFITH. Thank you very much, Madam Chair. I appreciate it.

And I appreciate the suggestion that maybe the Doc Caucus get together with the Attending Physician's Office because, while I was one of those who was lagging, I lagged because I had—in getting the vaccine—I lagged because I had had the disease and felt like others should go first because we do need to get our staff and other folks who are here in the Capitol vaccinated as well.

And so I have now had my first shot and will soon have my second shot, but also had the disease last year. And so we have got to be getting close, of the 435 of us in the House, we got to be close to herd immunity if we aren't already there.

That being said, Dr. Collins, if I could ask you a couple questions.

I have a friend who has long-term COVID. He has been in the hospital four times with breathing difficulties and just can't seem to shake it. From a public health perspective, does the fact that a patient has had COVID–19 change the approach that you would recommend to the doctors who are treating or taking care of that individual?

Dr. COLLINS. That is a great question, and we are learning as we go. You may know there are now more than 60 clinics that have

set up specifically to try to understand how best to provide medical care to long COVID sufferers, and you are going to hear from two of those clinic leads in the next panel from UCSF and from Yale.

And I think they are trying to see what kinds of things are going to be most beneficial. It does seem that some sort of pulmonary rehabilitation and cardiac rehabilitation, if the symptoms are there, as well as some of the things that are being done to help with the brain fog, many of which are built upon experiences we have had helping people who had traumatic brain injury or concussion.

Those do seem to help, but at the moment it is really kind of learn as you go. So, yes, I would certainly think somebody who has got long COVID ought to explain to the physician that that was their history because the way in which they are going to be understood and managed is going to be very much related to that background.

Mr. GRIFFITH. And even if they go in reporting for the first time and maybe haven't been diagnosed with long COVID yet, it may be helpful for them to say, "I had COVID 4 weeks ago. You might want to be on the lookout for other issues."

Dr. COLLINS. Absolutely.

Mr. GRIFFITH. Now, you mentioned the layers of current research being done on the effects of long COVID. Is there research being done on the relationship between COVID–19 vaccinations and long COVID?

Dr. COLLINS. So we do know that there are reports, and we mentioned this a bit earlier, of people who have long COVID where the vaccination seems to have provided some relief of symptoms, but it is not universal, and it can be pretty mild.

Otherwise, just flipping it around the other way in terms of whether vaccinations prevent you from long COVID, yes, we believe so in that they prevent you from getting COVID in the first place, 95 percent efficacy for the Pfizer and the Moderna vaccine.

So, as all of us have been saying, if you don't want long COVID, then you don't want COVID, then get a vaccination because that is the best prevention we have got.

Mr. GRIFFITH. My friend got the COVID and the long COVID before the vaccination was available to him.

Dr. COLLINS. Of course.

Mr. GRIFFITH. Yes. So let me ask this and let me give you a chance for a little advertisement. If somebody would like to participate in an NIH study, who should they contact or what is your website that they should go to?

Dr. COLLINS. That is a great question. Thank you for the opportunity for the advertisement. It is very easy. You go to clinicaltrials.gov—clinicaltrials, one word, dot gov—and I looked the last day or so, there are at least 30 clinical trials up there right now that are enrolling participants that are interested in trying to understand long COVID, and that is even before we make this whole bunch of new awards in the next 3 weeks or so, which is going to greatly expand that. But people who want to get started now, clinicaltrials.gov.

Mr. GRIFFITH. And, of course, you need as many people as possible in order to get all the data that you can get?

Dr. COLLINS. Absolutely.

Mr. GRIFFITH. You don't have just 44 people involved in long-term study?

Dr. COLLINS. No. We want thousands. Tens of thousands.

Mr. GRIFFITH. Thanks. I just have a minute left.

Dr. Brooks, vaccines are not currently recommended for those who have tested positive for COVID–19 within 90 days. Is that based on concerns about the vaccine interacting with the virus, or is it an attempt to reserve doses for those without antibodies?

Dr. BROOKS. Right. The recommendation is that persons do not have to get vaccinated within those 90 days. They could opt to wait 90 days, but we do recommend that if people want to get vaccinated, they can.

The concern, though, is that having had the infection, the residual immune response to the infection may blunt the benefit that you would get from the vaccine. So we want to give time that the immune system has basically kind of rested, again, so that when you give them that vaccine, they have the best chance of having a good response.

Mr. GRIFFITH. All right. I do appreciate that and encourage anybody who wants to be in an NIH study to please do so. And I have told the committee several times I am doing—I think I might even be in two. But I always go to the same place, and they take good care of me.

With that being said, I yield back.

Ms. ESHOO. The gentleman yields back, and the entire committee thanks you for that public service announcement. Really, everyone has a smile on their face. I saw Dr. Brooks, thumbs up. So thank you very much for that.

The Chair is now pleased to recognize the gentleman from Maryland, wonderful member of our subcommittee and full committee, Mr. Sarbanes, 5 minutes.

Mr. SARBANES. Yes. Thank you very much, Madam Chair.

I want to thank the witnesses for their testimony today.

Dr. Collins, can you speak a little bit to what the intersection is of some of these long-COVID cases in terms of the conditions you are starting to see—and obviously there is a lot more analysis to be done—the intersection of those kinds of conditions with chronic conditions that can impact people's ability to work. And I am thinking about the Social Security disability categories that result from chronic conditions.

Do you see an overlap there, and what do you think those implications could be in terms of the workplace and employment generally?

Dr. COLLINS. It is a good question. You know, at the beginning, Dr. Brooks outlined this sort of categorization of things that are post-COVID syndromes, something we at NIH are calling PASC, Post-Acute Sequelae of COVID–19. Long COVID is one of them, and that is what we have been talking about primarily at this hearing, but there are individuals who suffer really significant organ damage during the acute illness as, for instance, somebody who had very severe lung disease ended up on a ventilator, and that is just going to take a long time to get back.

And then there are people who have the consequences of having been extremely ill in the ICU for weeks and the whole consequence

that has in terms of what you have lost in terms of your metabolism and many things.

So I am setting those in the same context because we need to worry about how to manage those individuals as well, and the post-ICU syndrome certainly overlaps with people who have been in the ICU for other reasons, and we can learn from that. I think the one, though, particularly people bring up—and they should—is this particular condition called chronic fatigue syndrome, or sometimes called MECSF, which was mentioned earlier by Dr. Brooks, where these individuals do have profound fatigue, oftentimes after an acute illness of uncertain nature, which seems like it was probably a virus but generally you don't know what it was. And then they just don't recover from that and may end up being bedridden for months or even years.

These are heartbreaking circumstances. We are studying that at NIH with a program that has been ongoing to try to figure out what the cause is there. I think the overlap here is notable in terms of the symptoms, but with the COVID–19 situation, we have the advantage of actually knowing what the infectious agent was. It is SARS–CoV–2, and we are hoping what we can learn from that will then map across to things that we can do to help people with chronic fatigue syndrome who are suffering many of the same consequences. At least that would be my hope.

I feel a great deal of sympathy for people who have suffered from chronic fatigue syndrome over many years and oftentimes are not being treated by the medical care system the way they should be, many times sort of frustrating their physicians and the physicians tending not to take their complaints seriously. And these folks need our help too.

Mr. SARBANES. I appreciate that. I mean, I can see what may be coming is that we will be seeing more cases of permanent disability coming forward related to long COVID potentially, so it will be interesting to begin to build those models in terms of what that impact might be.

Dr. Brooks, I would be curious to hear from you about the implications of long COVID when it comes to the workload of healthcare providers across the country. We know we have some shortages already in certain disciplines in the medical field in terms of responding generally to the demand for care out there.

Can you talk about the implications of long COVID against that backdrop and particularly how it might affect certain specialties and the need to make sure that the pipeline for those specialties in the medical field is strong and robust?

Dr. BROOKS. Thank you. That is an excellent question. You know, as Dr. Collins alluded, there are 60 clinics roughly, maybe more and hopefully continuing to grow, that have stood up to begin to address this. And what is characteristic of many of these—and I am sure you will hear this later this afternoon—is there is no post-COVID specialist yet. Maybe there will be, but it pulls people from multiple specialties together to address the problems we are seeing, predominantly pulmonary disease, rheumatology, neurology, neuropsychology. So those are areas where we are going to have demand for clinical care with these sorts of patients.

The burden could be large. I mean, consider that today we have had almost 33 million infections in this country, and even if a very small percentage of them go on to have problems, that is a really large burden. So getting ahead of this with proper training is important.

Our agency is—part of our agency's mission is to ensure people recognize the condition and know what they can do to direct treatment. Ultimately, clinician organizations will pick up writing the guidelines in the long term, but in the short term we are pulling that together and helping with that process. I think——

Mr. SARBANES. Thanks very much.

Dr. BROOKS. Yep.

Mr. SARBANES. Thank you very much. I appreciate it.

I yield back.

Ms. ESHOO. The gentleman yields back.

And it is a pleasure to recognize the other great American on our subcommittee, Mr. Bilirakis, for his 5 minutes of questions.

Mr. BILIRAKIS. Thank you, Madam Chair. I appreciate it very much. Before I get into the questions—actually, Morgan beat me to it, but I wanted to volunteer my services as well, clinical trial, whatever cohort group because I did—I tested positive in early January, and I do have underlying conditions. So, if I can be useful, please don't ever hesitate. Please reach out.

I have a question for the panel before I [inaudible]. How long would you say, is there a general consensus as to how long a person is immune once they have had COVID–19 prior to the vaccine? And I had to wait the 90 days as well because I received therapeutics once I was treated. I was treated for COVID. And I did have the first vaccine and plan to get the second shot next week, and I encourage others to do it as well. So, if somebody could respond to my first question, I would appreciate it.

Dr. COLLINS. Sure. I will do my best, and it is not a question that I think we have as rigorous an answer to as I wish we did in part because the virus has been evolving. So one question is, how long will you be immune to the same virus that infected you the first time? And we think that is probably quite a few months.

But then are you immune to a variant of that virus that emerges, like the one called B.1.1.7, which now is almost 60 percent of the isolates we are seeing in the United States after it ran through the U.K. and then came to us. That degree of immunity will be somewhat lower.

The good news here, though, is—and this may surprise people—the vaccine actually provides you with better broad immunity than the natural infection. You don't quite expect that to be the case. Usually you would think natural infection is going to be the way that revs your immune system to the max and the vaccine is like the second best. It is flipped around the other way in this case, and I think that is because the vaccine really gets your immune system completely awake, whereas the natural infection might just be in your nose or your respiratory tree and didn't get to the rest of your body.

With the vaccine, we think the immunity has at least 6 months, but is it longer than that? We don't know yet because this disease hasn't been around long enough to find that out. And, so far, the

vaccines—the Pfizer, the Moderna—do seem to be capable of protecting against the variants that are now emerging in the U.S., like this B.1.1.7.

Mr. BILIRAKIS. Well, thank you very much. I appreciate it, Dr. Collins. That was a great answer.

Dr. Brooks, can you discuss the study CDC has already set up to follow cohorts of patients post-infection? What analysis has CDC conducted or recently published using already available data? Do these long COVID [inaudible].

Dr. BROOKS. I can't hear.

Ms. ESHOO. I think Mr. Bilirakis' connection has somehow failed.

Dr. BROOKS. Madam Chairwoman, would you like me to try and answer, or should I wait?

Ms. ESHOO. Sure. Go ahead. Can you hear us, Gus? Are you back on?

No, he isn't, but—maybe he can hear. Why don't you take his question, please.

Dr. BROOKS. Yes. I would be happy to, and hopefully it is recorded so he can get the response if he is not hearing it now. So, as I mentioned, we have eight prospective cohort studies that are collecting information on people during the post-COVID period and also doing electronic health record analyses. And actually the data that we have published most recently has been the study I think you referred to in your opening remarks, the study with Kaiser Permanente Georgia published in our MMWR, and this is telling us and is consistent with what others are reporting as well that it is a common problem after COVID for people to continue to have some residual symptoms or complaints that they seek care for.

They do begin to go down over time for some people, but they can persist very long for others. I am sorry I didn't catch the rest of his question. If you did, maybe you could share it. I would really be happy to try and answer.

Ms. ESHOO. I didn't. Did Dr. Collins? I don't know. Dr. Collins, did you catch——

Dr. COLLINS. I am afraid I didn't. I think Congressman Bilirakis' link locked at the same moment for all of us.

Ms. ESHOO. OK. All right. Well, maybe we can when he has reconnected, maybe we can circle back with him, and he certainly can re-ask the question in the printed questions that we—every Member can submit to witnesses. So I believe that the gentleman yields back.

And now, wonderful Member from Vermont, colleague Peter Welch, you are recognized for 5 minutes of your questions.

Mr. WELCH. Thank you very much, and thank you very much to the witnesses, the extraordinary work that you and your institutions are doing. First question is this: With respect to the long haul and the necessity to come to some consensus about what that is, what the symptoms are, how you differentiate between a complaint that is related and a complaint that is not? What is the best methodology by which we can come to a medical consensus on that, because I would regard that as essential to coming to a consensus on how to treat it. I will start with you, Dr. Collins, and go to you, Dr. Brooks.

Dr. COLLINS. That is a wonderful question, and it is a really serious challenge for all of us with such heterogeneity in the symptoms that individuals are experiencing. I think with a large collection of a very large number of people who are suffering these symptoms and enable assists from some machine learning efforts to try to identify what is the clustering of symptoms that makes the most sense as far as some kind of uniform view, that should get us closer than we are right now to saying what is the case definition. But I should turn this over to Dr. Brooks because CDC's very much engaged in this issue of trying to come up with case definitions.

Mr. WELCH. Thank you.

Dr. BROOKS. Thank you. And, Dr. Collins, that is right. A lot of it is—this machine learning you pointed out is a new tool we have had in the last 10 years or so that is very useful. We also pull in information by scanning data sets, looking for what people are doing in terms of what visits they are making to doctors, to see the specialists they are going to, the drugs that are being prescribed. We also interview groups of doctors caring for patients to try and get a smell test as we are arriving at some definition, does this really fit what we are seeing? And we also bounce that off of patients and patient advocates, again, to make sure that we are homing in on something that comports to what their experience has been.

What really makes this a challenge is the broad heterogeneity. And so we have got a lot of work to do. People around the world are working on this.

Mr. WELCH. Well, thank you. And the followup on that and this whole question of data collection that is so critical to diagnosis and then treatment. There is a challenge with our BIPOC community and with our lower-income communities that are spread throughout the United States of getting this accurate data as we need.

In fact, what you were just describing, Dr. Brooks, is the more data, the better. So, if there are certain communities that, for a variety of reasons, we don't get the information, that compromises your ability to come to conclusions.

So my question is, first of all, do you agree that there has to be additional efforts to get data from communities where we don't have all the data that we need, and what can we do to allow that to happen?

Dr. BROOKS. I absolutely agree that we have to get these data—these are the most affected communities by COVID to begin with and therefore where we expect the greatest burden of post-COVID illness to be. So that is a critical part of what we are doing. The methods that we use, a typical one is to over-enroll people from these minority communities, whether it be minority by race, ethnicity, by income, and other groups.

We also want to make sure we focus on groups that are often affected very heavily by COVID but may not be in the spotlight. People who are challenged by housing or justice involved. People in incarceration are going to experience this too, and they deserve to understand what is going on to be offered the best care that is available.

Mr. WELCH. Well, I appreciate you saying that. We all deserve it, wherever the person is, but we all need it. We need that data

in order for you to do their job, and my hope is that—and I am sure you are doing this, both the NIH and CDC, the lessons learned after analysis, because I think a lot of us are now aware that this may not be a one-time event. We have got to be prepared for this happening again.

So thank you very much.

Madam Chair, I yield back.

Ms. ESHOO. The gentleman yields back.

Our subcommittee is really blessed to have physicians, doctors, and I want to recognize now the doctor from Indiana, Dr. Bucshon, for your 5 minutes of questions.

Great to see you.

Mr. BUCSHON. Good to see you, Madam Chairwoman, and thank you for the time.

Dr. Brooks, I have a daughter who has had COVID and has persistent problems with her smell and not as much her taste. Do we know specifically exactly what COVID did to the person's neurologic system or whatever to cause that? And based on historical problems with that system, the neurologic system, the chance for recovery?

Dr. BROOKS. That is an excellent question. In particular, because anosmia, or the loss of smell or change in smell, is an often overlooked but surprisingly common problem among people.

Mr. BUCSHON. Yes.

Dr. BROOKS. But this disease really seems to target that and cause it. I can say this: I have had a particular interest in this topic. The reading that I have been doing seems to suggest that the virus isn't necessarily targeting the olfactory nerves, the nerves that transmit smell, but more of the nerves that are sort of around and supporting those nerve cells, and it is the swelling and the inflammation around those cells that seems to be leading to some kind of neurologic injury.

I will say the good news is that many people will eventually recover their sense of smell or taste, but there are others in whom this is going to be a permanent change.

In terms of treatment, smell training—interesting therapy, but it really works. And I really want to raise people's awareness around that because the earlier you can begin smell training, the better the chances that you will recover your sense of smell.

Mr. BUCSHON. Yes. She had COVID in late November, and she is still having issues with her smell. So I will tell her what your recommendations are.

Dr. Collins, in your testimony, you mentioned that the funding the NIH receives from Congress to help examine and research long COVID—and I am constantly a supporter of enhancing your funding, by the way, and remain committed to doing so, especially for research like this. I realize this may be a little bit premature based on what we have been talking about, but what percentage of the NIH funding is going to be directed towards potential therapies for long COVID in the coming months?

Dr. COLLINS. It is not premature at all, Dr. Bucshon, and I appreciate your asking it. And I think patients who are listening to this hearing probably are really interested in knowing what is this

metacohort all about, and is it basically just collecting information? Are you all about trying to find answers?

We are all about trying to find answers. So we would aim to initiate therapeutic interventions as soon as we have this cohort together and begin to imagine what might potentially work.

In a way, you could say we have already started that in one instance because we are running a lot of clinical trials on acute COVID, and at least one instance, we have now enrolled participants who are over their acute phase in anticoagulants because we think maybe the ongoing hypercoagulable state where you have small blood clots affecting various organs may be part of long COVID. So that one is already underway, but there will be other opportunities to do this. We will have to think about what exactly would be the safe kind of interventions that have a decent chance of success, and we would design those as randomized trials so we will really know if they worked or not.

But I want to say, yes, very much to everybody who is listening: This is not just admiring the problem. This is actually getting the data we need to initiate the interventions that we hope will help.

Mr. BUCSHON. Yes. And I want to make sure that we provide you the resources to do that. And you mentioned, I think, anticoagulants. Do you have any other possible treatments that you are already looking at other than the anticoagulants for long COVID?

Dr. COLLINS. Well, certainly, people are contemplating whether this would be an instance where steroids or other immune suppressants might be helpful because there is some possibility here that this is an autoimmune condition, and we know in other autoimmune conditions, that can help, or even such things as giving intravenous immunoglobulin, which we know can also sometimes help in an autoimmune situation.

All the things that are currently on that list are chosen because they are known to be relatively safe. I don't think we are ready to start giving toxic substances until we know things a little better.

Frankly, you are an experienced physician. It is always easier to know what to treat the patient with when you understand their condition.

Mr. BUCSHON. Yes.

Dr. COLLINS. And here we are. We don't know whether long COVID is because there is a persistence of the actual virus in the system, in which case maybe that is why immunization is working, or maybe it is an autoimmune response, or maybe it is a consequence of blood clotting that has left damage in various organs, or maybe it is something we haven't thought of yet. And the most critical thing is to get all of that clinical data, develop those biomarkers, and then we will be able to target the therapy in a more rational well.

Mr. BUCSHON. Well, thank you for that, Dr. Collins and Dr. Brooks. I appreciate that.

And, Madam Chairwoman, I yield back.

Ms. ESHOO. The gentleman yields back.

Important questions and observations in that exchange.

With the permission of Members, I want to circle back with Mr. Bilirakis and allow him 1 minute to ask the question that none of us heard. We are dying to hear it.

You need to unmute, Gus.

Mr. BILIRAKIS. Here we go.

Ms. ESHOO. There you are. OK. You have a minute.

Mr. BILIRAKIS. I am so sorry. OK. I have a minute, so I will be quick.

Dr. Brooks, can you discuss the study CDC has already set up to follow cohorts of patients post-infection, what analysis has CDC conducted or recently published using already available [inaudible]? Do these long-COVID symptoms eventually resolve, and is there any data, anecdotal or otherwise, that suggests this COVID vaccine may help reduce symptoms for long-haulers?

Now, I know you covered this, but you may want to elaborate a little bit on this.

Dr. BROOKS. Pardon me. I am going to try to do it in a minute or less. So we have large cohort studies. They are underway. We have published data most recently that the chairwoman mentioned during her opening from the Morbidity Mortality Report in collaboration with Kaiser Permanente Georgia showed that there was remarkable incidence of people seeking care after recovery, unheard of with most illnesses of this kind like flu.

So that is a warning sign. We also were using electronic health data combined with cohort studies to look at all of these kinds of questions. We have a number of publications in the pipeline that you should be seeing shortly in journals, as well as the MMWR. And I will also point out there is some excellent studies—we are not—we don't hold all the information. They are fantastic studies also by some of our colleagues out there, in particular, one from a group in St. Louis at the Veterans Administration Hospital, a place that I have worked for many years and love.

Lastly, to your question about does vaccine help with long COVID: It has been mentioned a couple of times there are these well-reported anecdotal instances and even some early research data that suggests they may, but we really need more robust data to say that with a surety and to know how to use vaccination, if we can, to ameliorate the post-COVID conditions.

Mr. BILIRAKIS. Thank you very much.

And I want to yield back, but I want—Dr. Collins, my dad, Congressman Bilirakis, says hello. Take care.

Dr. COLLINS. Thank you. Please tell him hello back.

Ms. ESHOO. And the gentleman yields back.

We all remember and have great affection and respect for your father, who was the chairman of this subcommittee during his service in the Congress.

The Chair now is pleased to recognize the gentleman from Oregon, Mr. Schrader, for your 5 minutes of questions.

Mr. SCHRADER. Thank you very much, Madam Chairwoman. Good hearing today. Very interesting. Learning a lot.

Dr. Collins, given the fact that the symptoms of long COVID mimic the symptoms of a lot of other diseases, I guess a very basic question is, how are we just ruling out these other diseases coincidentally showing up in these patients?

Dr. COLLINS. Another great question. The easiest way to be sure in a given individual that this is a consequence of the COVID infection is to have absolutely clear definition that they had the acute illness with the positive viral test. If that is not available, then an antibody test to show that they previously had it.

Having said that, going back a year where tests were not so readily available and the antibodies may have waned by now, we have a lot of people, and you will hear in the second panel what this has been like for folks who have the symptoms of long COVID but don't have this clear laboratory evidence of having had the acute infection. And we need to take care of those folks as well.

But more recently now that I think we have widespread testing that is available, and we talked about RADx a bit earlier, which has contributed to that, I think we are in a circumstance to be able to have that part of the diagnosis.

But I think maybe your question is also suggesting maybe there are people who had acute COVID infection and now they are having something else that isn't really related to that but was going to happen anyway. Somebody who has the onset of a new illness like rheumatoid arthritis, and so they are having a lot of joint pains. You might assume, therefore, oh, this must be long COVID, but it might be something else. So the people who are running the clinics, and you will hear from two of them in the next panel, have to watch closely that we don't end up merging together conditions that don't belong there and maybe things that really aren't long COVID but deserve a different kind of treatment need to be recognized and appropriately managed.

Mr. SCHRADER. On one of those diseases, I have got, unfortunately, some constituents who suffer from chronic fatigue syndrome, ME, and, you know, very concerned, you know, about that and wondered, you know, that is an entity, as I understand it, unto itself, but one of the main symptoms that folks with long COVID talk about is this chronic fatigue. And as I understand it, with some of the studies on chronic fatigue, they think it might be virally induced. Could it be that other viruses, other things have caused this, and are there studies going on right now with long COVID causing or increasing the frequency of chronic fatigue syndrome?

Dr. COLLINS. There is certainly a lot of overlap in the symptoms, and I think we need to learn from that. People with chronic fatigue syndrome many times report an acute illness that sounded like it was a viral infection of some sort, a fever, maybe being in bed for a day or two, but then they don't get better. And that has a lot of overlaps now with what we are seeing with long COVID.

With chronic fatigue, though, we almost never actually catch the original infection in the act, so we don't know what it was, but it could be that this is a pathway that other infections can also induce occasionally in individuals. My hope would be that, as we study long COVID and look at those comparisons with chronic fatigue syndrome, we will learn a lot about both of them. We will figure out how they are similar, how they are different, and how, if we can identify interventions, they might work for both of those groups because there is lots and lots of people with chronic fatigue

syndrome who are still waiting for something that is going to help them.

Mr. SCHRADER. Right. Right. Yes. Might be some overlap. I guess, lastly, my team and I have been reading a little bit about high levels of cytokine secretions that occur sometimes in relationship to the disease and wonder if that is a biomarker for long COVID potentially, and are you looking at other biomarkers to, again, help us get a handle on cause and effect?

Dr. COLLINS. Well, you are right on the place we need to go, and certainly we see cytokine elevations, even cytokine storms in people with acute illness, particularly those that are very sick in the hospital, but it hasn't been so obvious in people months later who are still suffering from long COVID. There is a very interesting paper just came out about a few days ago in the journal called Nature where they studied 73,000 veterans and followed them 6 months after they had an acute COVID infection and looked to see were there any kind of markers there. There is nothing that jumps out at you, like, oh, wow, that is it, but there are laboratory abnormalities that do seem to occur more frequently in people with long COVID than in the people who didn't end up with that consequence.

So that is kind of a start. We want to take that kind of a study and expand it even more rigorously to more and more groups, but that was a really important one.

Mr. SCHRADER. Very good. Very good. Well, thank you, Dr. Collins, for all your work and thank goodness we have NIH, and you are doing wonderful things and look for more great things in the future.

And I yield back, Madam Chair.

Dr. COLLINS. Thank you.

Ms. ESHOO. The gentleman yields back.

The Chair is very pleased to recognize another one of our doctors, Dr. Neal Dunn from Florida.

And he will be followed by Congressman Cárdenas from California. So I think I will announce that so Members will know who's next in the lineup.

So you are recognized for 5 minutes for your questions.

Mr. DUNN. Thank you very much, Madam Chair. I am pleased the committee is holding this hearing today about the long-term health complications that can follow COVID–19 infections. I had the opportunity to meet with a group of COVID long-haulers from Florida last week, and hearing from these patients confirmed my impression about the mysterious and lingering medical conditions that affect a number of COVID survivors, even long after the infection has past.

The group I spoke with had teamed with an advocacy group for myalgic encephalitis and chronic fatigue syndrome as my colleague, Representative Schrader, just mentioned, diseases that also affect and debilitate multiple body systems often following a viral infection. And their hope was, of course, that existing research on MECSF can shed some light on why COVID patients are facing an array of symptoms that are often similar.

So I commend our witnesses and our researchers from other academic institutions for their rapid response to this problem. One

question they had that really stuck with me from that conversation with one of my long-haul constituent patients was, how do I get my doctor to believe me? And this came from a constituent who had—a doctor—who had some, quite frankly, perplexing symptoms and had never tested positive. So—and this was just mentioned also. To that problem determining who has, indeed, been infected with SARS–CoV–2, don't you think we need to immediately scale up our ability to test for patients for humoral immunity to COVID, not just antibodies but testing for T cell immunity, which we know is a much more reliable test for prior infections no matter how far in the remote past?

Dr. Collins, I am unaware of a shark tank actually addressing that problem.

Dr. COLLINS. This would be a great shark tank opportunity for sure. Dr. Dunn, you ask a great question. One of my other jobs in COVID is cochairing the effort between industry and NIH and CDC and FDA on everything we are doing about COVID therapeutic trials.

We had a big discussion just this morning about T cell testing and why we are not doing more of that in terms of the ability to assess response to vaccines as well as to natural infection. And there was, shall we say, a vigorous disagreement amongst the experts about exactly how to do it. And that was the problem. People hadn't quite arrived at a consensus about what is a reliable way to assess T cell response, whereas measuring antibodies, everybody kind of agrees how you do that.

Mr. DUNN. Well, we have the tests, though, that we use for T cell immunity, and I have read papers on how to scale it up. So I am hoping—you know, nobody is better qualified to scale this up than you. So I am not going to charge you with this, I guess, the responsibility, but I would encourage you to look into it vigorously.

And by the way, I want to be the first to say that I don't think every single primary care physician or urologist, like myself, to be up to date on the latest research of long COVID, but I do hope that we are empowering all the physicians with the information they need to best serve their long-haul patients or direct those patients to the proper specialists.

So, you know, to that question, I would ask both Dr. Brooks and Dr. Collins, what educational resources can you direct physicians like me for patients who present with these curious long-term symptoms following COVID? And have we developed a sense of recommendation regarding which specialists are best equipped to assist these patients?

Dr. BROOKS. I am happy to answer that question. I mean, this is something we have been working on since—very early when we recognized long COVID. We hold regular webinars and calls for clinicians they can call into. These are often attended by thousands of providers. We use these as an opportunity to raise awareness. Because I think you made a really critical point that patients feel like their doctors don't recognize their problem or they don't accept that it is possible they have this condition.

We use those calls in webinars to raise awareness that this is a real entity. We also then publish papers and put out guidelines

that illustrate how to diagnose and begin to pull together what we know about management.

We have completed a first draft of interim guidelines that are in the clearance process, we call it, here at CDC. They should be coming out very shortly. They were drafted in collaboration with multiple physicians groups, also passed by a number of advocates with the patient population. And we will continue to do that. They will be updated regularly.

They emphasize a couple of points to what you said, particularly the multidisciplinary nature of what you need to do to manage these folks and how important it is to recognize that you may have this disorder and direct them to care——

Mr. DUNN. Dr. Brooks, we are going to get cut off here in just a second. But if you could just either put me on a list that gets that information.

Dr. BROOKS. You bet.

Mr. DUNN. I am easy to find. Or you can tell us right now and I will write it down.

Dr. BROOKS. Sure.

Mr. DUNN. Where do I go?

Dr. BROOKS. You go to cdc.gov and look for COCA calls. Those are Clinician Outreach and Community ... something. I am—a bad acronym, I am very sorry. Community something. I will get it to you.

Mr. DUNN. All right.

Dr. BROOKS. Look for our guidelines. They will be advertised heavily to clinicians because we want to ensure people like yourself get them.

Mr. DUNN. Thank you so very much.

Thank you, Madam Chair. Thank you for your indulgence. I yield back.

Ms. ESHOO. Thank you, Doctor. It is great to get that information out, because our constituents need to know if their doctors know. So it is really elemental.

It is a pleasure to recognize our patient colleague from California, Mr. Cárdenas, for his 5 minutes of questions.

Mr. CÁRDENAS. Thank you very much. I am glad we got that glitch out this morning so we could continue this amazing hearing.

Ms. ESHOO. Yes.

Mr. CÁRDENAS. And I just wanted to take the opportunity to thank Dr. Brooks and Dr. Collins for committing themselves to public service. This is critical that we are able to pursue what you are doing and your respective duties because it truly, truly, truly is lifesaving en masse, actually. So thank you so much for making yourself available for this hearing.

And I just want to remind the public that this really is what Congress is about. You have people from all over the country, from all walks of life, learning from these two experts and then from the next panel so that we can make decisions and we can actually legislate for the people of this country. And fortunately enough, we are the leaders in the world when we do it right. So I just wanted to thank the public for tuning in to this important discussion.

Social determinants of health are the conditions in the environments where people are born, live, learn, work, play, and worship,

and have a major impact on people's health, well-being, and quality of life. Examples of social determinants of health include things like access to nutritious foods and green space, clean air and water, safe housing, and transportation options.

Dr. Collins and Dr. Brooks, could you discuss the relationship between social determinants of health and COVID–19, as well as on long COVID? And what are some of the ways we can respond to these things?

Dr. COLLINS. Well, that is a profoundly important question. Certainly, we have seen it is unmistakable that social determinants have played a major role in who is most likely to have been affected by this terrible pandemic. This has hit particularly hard in those same communities that already suffered from health disparities: African Americans, Latinos, Native Americans. And that is not because they have some different genetics. Even though I am the geneticist, let me say I don't think that has anything to do with it. It has to do with their access to care, with their ability to be able, if faced with a pandemic of this sort, to isolate at home, like I have been doing for the last year, or whether they have to be out there going to work in order to put food on the table.

So if you needed any more evidence that our healthcare system does not give equal treatment to everybody, look at COVID–19, because the consequences are quite obvious. And a lot of that is the social determinants and the way in which our society does not provide those kinds of opportunities for health equitably to everybody. And that will play out and already is in terms of long COVID, because the gateway to long COVID—a terrible gateway that it is—is getting COVID in the first place and knowing, therefore, that these underserved communities have been hit twice as hard or, in some cases, three times as hard with the original infection. You know that is going to also play out in terms of what happens next.

And we also know that people with long COVID who come from underserved populations are less likely to get the kind of medical care that they now are looking for, just because of the way our system is set up. So there is all kinds of aspects about this that is shining a bright light upon the way in which our system in this country needs a lot of work. If we are going to take what we have learned about social determinants in health and the inequities that are attached to various other aspects of our society and try to implement those in a way that would be more equitable and just and fair—and that is a long, hard problem that we have lived with for far too long, but I hope this is one of those moments where we can look at it collectively and try to see what we can do about it.

Mr. CÁRDENAS. Thank you.

Dr. BROOKS. I would just like to add that this COVID–19—this pandemic has been unprecedented in terms of really revealing longstanding social inequities, sometimes even embodied in what we call structural racism that are driving the disparities that we are now measuring. It is not pleasant to watch these numbers coming in and see how this is playing out.

However, as Dr. Collins noted, this is also an opportunity to start making changes that will help rectify some of those inequalities. And we do it not only by addressing differences by race and eth-

nicity, but also imbalance in terms of rural or urban or by educational attainment or by income inequity.

I think a critical thing to do first, though, is to listen to these communities. We have learned in our agency that before you go offer help to somebody, find out what they want so that you could learn what is the help that they need and it is going to resonate with them. And we spend a lot of time doing that as we introduce studies into communities, understanding sort of how that might play out, how we can help address the problems that they are facing.

Mr. CÁRDENAS. Thank you. And with the few seconds I have left, I just want to encourage, of the 27 institutes and centers within the National Institutes of Health is the National Center for Complementary and Integrative Health. I am hoping that they are as involved as any other portion of your research to make sure that we get those answers and the solutions we need for all of our constituents.

With that, I yield back.

Dr. BROOKS. And they are.

Ms. ESHOO. Unmute. The gentleman yields back.

It is a pleasure to recognize the gentleman from Utah, Mr. Curtis, for your 5 minutes of questions.

You need to unmute. Can't hear you.

There you are.

Mr. CURTIS. [Inaudible.]

Ms. ESHOO. Mr. Curtis, there is something wrong with the transmission and——

Mr. CURTIS. Is that better?

Ms. ESHOO. Oh, that is much better.

Mr. CURTIS. All right. I was using a remote mike and I just unplugged it. Thank you. Thank you for your patience.

Ms. ESHOO. Now we can hear you loud and clear. You may proceed.

Mr. CURTIS. Thank you very much.

I wanted to join my colleagues in their appreciation for our witnesses and for this hearing.

And let me start with you, Dr. Collins. I believe that NIH recently started granting resources to research institutions like Harvard to study long-COVID patients. And I am curious if you are seeing trends among the patient population that you are studying that you have observed. For example, do patients with underlying health conditions, are they more likely to have long COVID? I am curious what you are seeing there.

Dr. COLLINS. Well, yes. When one looks at the resurgence already going on, there is a lot happening, not quite yet on the scale that we think we are going to need to really understand this with a level of intensity that it deserves. But it certainly does seem that the risk of developing long COVID goes up.

It is fairly clear that the initial seriousness of the initial illness is somewhat of a predictor. Certainly, people who are in the hospital have a higher likelihood of long COVID than people who stayed out of the hospital. But people who weren't hospitalized can still get it. It is just at a somewhat lower rate. It is even possible, if you look at the symptoms that somebody suffers in their first 7

days of the acute illness, to do a pretty good prediction now about whether they are likely to end up with long COVID. That is a paper that has just recently come out that looks fairly compelling but needs to be replicated.

The risk factors: older-age people, higher likelihood. Women have a slightly higher chance of developing long COVID than men. BMI, obesity also seems to be a risk for the likelihood of long COVID. Beyond that, we are not seeing a whole lot of things that are predictive. And there must be things we don't know about yet that would give you a chance to understand who is most vulnerable to not be able to just get this virus out of there and be completely better. But we don't know the answers just yet.

Mr. CURTIS. I think we are all looking forward to answers.

Let me build off of that question and also refer back to something a couple of my colleagues have asked about. And Dr. Dunn was very good about asking this from a physician's perspective.

I would like you to put a patient's hat on for just a minute and go back to the same theme of, like, how do we know? And hypothetically, during this last year, every time I get a runny nose, a cough, or a headache, I would run down to be tested, thinking, oh, my goodness, I have COVID. And, for instance, a seasonal allergy could give me a headache or drowsiness. From a patient's perspective, how do they know to seek out treatment? And, two, where do they go for that treatment?

We have heard today that can be very confusing, from a doctor's perspective, even more so imagine from the patient's perspective. So what advice to those people listening to this hearing today who think that they may have some long-term symptoms do you have?

Dr. COLLINS. Dr. Brooks, I think CDC is right in the middle of that.

Dr. BROOKS. Yes. Thank you. That is an excellent question. And I would advise patients a couple of different ways. First of all, if you are having symptoms that you haven't had before, something new following your COVID—chest pain, difficulty breathing, you can't get your thinking clear, you are just not getting better the way that you thought you should—have a low threshold to seek care. Your primary care physician can help determine if it is something else that is causing those symptoms, or maybe it is long COVID. But one of the first steps is to make sure it isn't something else that we can treat and take care of.

Also, documenting that there was a COVID infection can be very helpful. However, as Dr. Collins pointed out, we have an awful lot of people who never had the opportunity to be diagnosed but developed these symptoms, so we don't have that clue.

And then lastly, the temporal association, that is the timing of what happened. You felt sick with a disease that looked a lot like COVID, and then weeks or months later you are still having this cough, your fatigue is just getting worse, I can't think clearly, and my sense of smell is not coming back the way that it was supposed to. That should bring people to medical care.

I hope that—you know, sometimes we worry a lot about driving people to care who were worried but really generally doing OK. But in this case, while we are learning more about this, that may be

all right for the short term until we really can discriminate more clearly what defines this. We are in that stage of learning.

Mr. CURTIS. And just with a couple seconds left, where do they go? Do they go to their primary care physician? Do they need to go to a specialist? Where would you send them?

Dr. BROOKS. I would urge they start first with a primary care clinician. And if they are concerned about potentially having post-COVID, they could try to seek out a post-COVID clinic in their area, if there is one there. They tend to be right now affiliated with academic centers and hospitals that tend to be in large cities. That may not be available to everyone. But one of our duties, our mission at CDC is to raise awareness among frontline providers to recognize this syndrome.

Mr. CURTIS. I am sorry to cut you off.

Madam Chair, thank you for the few extra seconds. I yield my time.

Ms. ESHOO. Absolutely, Mr. Curtis. And we restored the 30 seconds that were lost because of a bad mike. So thank you.

And the gentleman yields back.

A pleasure to recognize another one of our physicians on the subcommittee, Dr. Ruiz, of California. You are recognized for 5 minutes.

Mr. RUIZ. Thank you, Chair. And thanks to both of our witnesses today.

We have clearly not even scratched the surface of what there is to learn about long COVID, how it affects individuals physically, mentally, and even economically. And as a doctor, I am very concerned about the initial research that I have seen.

As someone who grew up and then practiced medicine in a farmworker community with low health access, I am worried as we learn more that our historically underserved communities will once again be left behind, just as they were with testing and now with vaccination rates. I applaud the actions the Biden administration has taken to address these issues. And moving forward, we must be vigilant to make sure our underserved populations do not get left behind as we study, identify, and treat long COVID.

Dr. Brooks, I was pleased that your testimony made multiple references to equity and disparities. It is clear that you recognize the importance of the issues and that it will be at the forefront of your work. In your testimony, you acknowledged that there are barriers to accessing post-acute COVID care clinics such as transportation or insurance coverage. What is the CDC going to do, and what can Congress do, to address these barriers and increase access for all populations to get the post-acute care that they need?

Dr. BROOKS. Thank you, Congressman, for that question. It is really a critical one, because you have pointed out some of the important disproportionalities that have been occurring in this country around COVID. And in some ways they are baked in a bit, and we want to fix that.

One of the first things we are doing is we have put about $3 million, if I am not—$3 billion, rather, into building vaccine confidence, focusing on underserved communities in particular.

In addition, we have created $2.2 billion worth of funding opportunities for people to help address these disparities and bring the

care and the knowledge necessary to the communities like the one you were describing so they can get the access that they need.

And then I think a really important aspect that I particularly like is building this core of community health workers. We have invested about $300 million into community health workers who ideally are from the communities that are infected and can be trusted messengers with that constituency.

Mr. RUIZ. I am a big fan of the community health worker model ever since my medical school days with Partners in Health program. And in the Hispanic communities they are called promotoras, and they have been integral in doing the outreach to the hardest hit, hardest to reach communities in my district and throughout our Nation.

I am just concerned because disproportionately Hispanics, African Americans, Native Americans have been infected at a higher rate, dying at a higher rate. They will have the long COVID at a higher rate. And we need to make sure that as we build a system of post-acute care for long COVID, that we don't use traditional systems of just tertiary care, affluent hospitals being the locations of these treatment centers. We need to make sure that we take them down into the communities.

So you also in your testimony talked about efforts to raise awareness of post-COVID conditions among patients and providers. What efforts are being made to target the underserved communities?

Dr. BROOKS. Right. That is an excellent question. So we work very closely with a number of types of groups of people to try and bring these messages that we are sharing with clinicians right now also to providers that are not just—necessarily have all the access in the world to the internet, like we hope everybody has, but also some people who may not have that kind of access. We work with community-based organizations, community health workforces that may be in the field, our allied partners and pharmacies. And then we also tap into the wealth of the colleagues that we have, who have specialized knowledge and relationships with these communities, like the Hispanic Medical Association and the National Medical Association, as well as other national organizations that are empowered as being trusted messengers, like the Urban League.

You know, this is an area that we are going to be hopefully paying a lot of attention to as we begin to develop more——

Mr. RUIZ. Well, I can assure you that the Congressional Hispanic Caucus will be paying a lot of attention——

Dr. BROOKS. Good.

Mr. RUIZ [continuing]. And will be insuring that you all pay close attention to these issues, because equity needs to be part of the design, not an afterthought of policy.

Let me ask you another question while I have you and Dr. Collins here. Multisystem inflammatory syndrome in children has disproportionately affected African Americans and Hispanic and Native American kids. Up to three out of four children who suffer from this illness are minorities. One, have we found long—what is the rate of long COVID in these children? And, two, what is NIH and CDC doing to address multisystem inflammatory syndrome in children?

Dr. BROOKS. Well, I will use the acronym MIS–C, multiinflammatory syndrome in children. The good news here is that when recognized early, almost every child does well and gets better. To the best of my knowledge, we really haven't seen a lot of long COVID, if you will, the way we are describing it in these children. Early recognition is key here.

We have also developed case definitions, provider information, aiming at providers who treat populations of children who come from racial and minority communities to raise the flags when they get early recognition of these, of the possibility of this condition.

I just want to also add that we see this in adults. And the demography is similar that it tends to be in the populations most heavily affected by COVID, those that are racial or ethnic minority or underresourced, and we are trying to raise awareness in the same fashion among those communities.

Mr. RUIZ. Thank you. My time is up.

Ms. ESHOO. The gentleman yields back.

The Chair now has the pleasure of recognizing another one of our important doctors on our subcommittee, Dr. Joyce of Pennsylvania. And he will be followed by Congresswoman Debbie Dingell of Michigan.

So you are now recognized for 5 minutes, Doctor, for your questions.

Mr. JOYCE. Thank you, Chair Eshoo and Ranking Member Guthrie, for holding this important hearing.

As we listen to the approach that we need to be taking for post-COVID condition, it brings to mind another medical situation which many of us will recognize: Acute strep throat, strep pharyngitis, when treated early, diagnosed, prescribed penicillin, has a rapid recovery with very little sequela. But if undiagnosed or untreated with penicillin, can go on to develop rheumatic fever, a disorder which can affect the heart, the brain, the joints, and the skin. Early diagnosis and treatment is the key, but having that treatment is so essential.

As we look to prevent COVID conditions, the post-COVID conditions that we are discussing here today, how important is it that, A, we look at those who have had treatment with monoclonal antibodies to see whether or not they have gone on to develop post-COVID syndrome? And do you see a role in continuing to develop the necessary therapeutics so that we can prevent post-COVID conditions?

And, Dr. Collins, I will ask you to address this first.

Dr. COLLINS. And that is just a great set of questions, and very much on my mind. Yes. As part of this metacohort that we are putting together to try to understand the causes and the ability to prevent long COVID, we are enrolling those who have taken part in our therapeutic trials, and many of those are on monoclonal antibodies. We want to find out whether monoclonal antibody treatment reduced the likelihood of that individual going on to long COVID.

But monoclonal antibodies are not universally successful. People still can develop symptoms from that, but we hope that if this is actually going to provide some benefit, we could see that.

But your point about the need ongoing for treatments and particularly for oral agents that could be given to anybody as soon as they get a positive viral test is very much front and center of everything that we at NIH are trying to do right now in collaboration with our pharmaceutical partners. In a partnership called ACTIV, which stands for Accelerating COVID–19 Therapeutic Interventions and Vaccines, we are running a total of six master protocols right now on therapeutic agents that we hope will have this benefit.

It has been frustrating. Most of the things we all had hoped for didn't turn out to work, but there is plenty more in the pipeline, including now some very more sophisticated designer drugs that really interfere with the viral lifecycle, which is what we most would like to have. So we are going to push very hard on that, because as much as we think we would like to drive this virus away with vaccination—and we will do a pretty good job of that in this country—it will still be in the world, and it will still be popping up in hotspots in our country as well. We need to have effective therapies that keep people out of the hospital and maybe keep them out of long COVID downstream. It is a great point.

Mr. JOYCE. Dr. Brooks, would you address this as well?

Dr. BROOKS. Sure. I want to say first, the epidemiology also gives us a clue here, which is that a paper that we both referred to previously showed very nicely that the more severe, the more significant the illness the person had, the greater likelihood it was that they were going to develop long COVID. What that means is, not only preventing long COVID—excuse me, preventing COVID infection in the first place, but treating it early to ameliorate the severity of that infection, if diagnosed, really makes a difference. This is a place where these drugs like the monoclonal antibodies have some opportunity, and we hope that there will be other therapies coming along soon.

Another area of research would be looking for preexposure prophylaxis or some kind of medication you could take if you are in a jurisdiction where the virus was circulating or had known you had been exposed to it that you might be able to use to prevent developing the infection if you were exposed. A nasal spray, a single pill, all of these are things that are out there being looked at.

So I really think whatever we can do to not only prevent infection but treat it as early as possible and continue to develop excellent therapeutics that lessen the severity of the disease or prevent it from happening are going to be the way to impact these—the number of people who develop long COVID.

Mr. JOYCE. And, Dr. Brooks, I think it is so important that you bring that into the discussion, that we need to have that nasal spray. We need to have that ability to take an oral medication. This is going to be the multipronged approach, our pathway through this pandemic.

In the few seconds I have remaining, Dr. Collins, could you please comment on—you said 273 proposals that you are looking at at the NIH. Do any of those include HLA and preexisting parameters that an individual might have that would predispose them to post-COVID condition?

Dr. COLLINS. Another great question. Those most definitely will be included in this metacohort. The applicants are coming forward with particular cohorts that they already are offering up as a means of figuring out how we can get as many possible people involved in this study as possible. And then there is this clinical sciences core, which is going to look at all of the cohorts and say "What lab tests should we do?" And I can't imagine that HLA won't be one of them, because of what we know about how that plays a role in so many autoimmune diseases.

Mr. JOYCE. Again, my time has expired. But, Madam Chair, this has been an important meeting. Thank you and Ranking Member Guthrie for arranging this.

Ms. ESHOO. The gentleman yields back. And I appreciate those comments, and we appreciate you.

The Chair now recognizes the gentlewoman from Michigan, Representative Dingell, for her 5 minutes of questions.

Mrs. DINGELL. Thank you, Madam Chair. And thank you, Ranking Member Guthrie. And thank you both, Dr. Brooks and Dr. Collins, for sitting here this long. And there are a lot more after me in the second panel. You are angels for being here.

I am going to go back to the very beginning of this hearing and just make that a public service ad for those that want to get us back together and they think, you know, most people have been vaccinated. I come from Michigan, which both Dr. Brooks and Dr. Collins know, and almost 50 percent of the people in Michigan have had at least one vaccination. We still, I am told, have close to 100 people in our institution that haven't been.

Our hospitals have been full. Our children are filling the intensive care units. Our nurses are stressed to the limit. I had to find the money to bury a frontline worker on Sunday who committed suicide over COVID. So anybody who thinks that this is over, these two can attest to what it has been like in Michigan. And it isn't over, and we can't let down our guard. So COVID fatigue is what leads to some of this happening. So thank you to both of you.

A lot of us have brought this up, and I just want to build on it. I think all of us also have heard from a lot constituents too who had chronic fatigue. Because I can tell a number of us have met with them. And they are worried about the amount of money that is being put into research to have the resources needed. I met with a group of doctors. I have met with several groups of doctors, both at Michigan University, feel more connected to you than single practicing primary care doctors. And I think this is really a major issue for us right now. The next panel is going to include patients who have shared their written testimony, their various experiences in going or seeking care in the primary care setting.

So, Dr. Brooks, can you expand upon what you have been talking about? How has COVID impacted primary care physicians? And how do we make sure—because a lot of them don't feel they have got what they need. How do we make sure they have the tools they need to diagnose this condition? And then, where do they refer patients?

Dr. BROOKS. Right. You know, thank you so much for also paying attention to the healthcare workforce, because they have been really slammed basically by this pandemic. And with long COVID it is

possible that, if large numbers of people experience this, we are going to have another problem where we need to help providers learn what it is, how to recognize it, and how to refer people properly if they themselves aren't equipped to care for it.

So first we need to build the recognition. There is nothing more frustrating, I can say from my personal experience, of taking care of someone and you don't know what is happening, you can't figure it out. And one of our jobs at our agency is to try and build that frame where you can begin to fit that person's symptoms and signs into something that can bring at you, "I think I know what may help you. You need referral to this kind of a specialist."

It also means building those specialties. And I think we are going to see a lot of subspecialties, some of the ones I mentioned before, rheumatology, neurology, pulmonary medicine, physical and rehabilitation medicine, you know, really growing around this.

And from my experience in HIV, I can also share something, which is maybe we focus a lot on this condition, but its benefits echo with other conditions. What we learned around the HIV virus benefited our knowledge around many opportunistic infections. It benefited infectious diseases in all sorts of different areas. Here, too, what we may learn about managing and treating this condition will benefit those patients with chronic fatigue and ME.

Mrs. DINGELL. I just want to ask both of you in my minute left, you are talking about the programs you have. Dr. Collins, you have got 200-and-some proposals. Do you have the resources you need? How do we—we know this is important. The numbers we are seeing here we haven't seen in any other disease. By the way, it is really real that people say, people don't believe me. Dr. Dunn said that, people have said that to me in the meetings I have had over the last few weeks. How do we make sure you have what you need? And what do we as a committee need to do to support you?

Dr. COLLINS. Well, I always appreciate hearing you ask that question. I think that $1.15 billion that Congress provided in December for us to build this very intense, large-scale study is what we need right now. But I don't know exactly what we are going to encounter if this goes forward.

As we have talked about in the course of this hearing, we are going to want to institute as many clinical trials as possible for interventions. We don't know yet exactly what those agents will be or how large those trials will need to be. And I can imagine if we get into that in a significant way, we may need to find more resources and we may need to come back to you and explain why that is.

But I have to be very grateful for what you have done for us back in December to enable us to take this on in a very ambitious, large-scale way, which is what the seriousness of the problem deserves.

Dr. BROOKS. If I may?

Ms. ESHOO. The gentlewoman's time has expired, I think.

Mrs. DINGELL. Thank you.

Ms. ESHOO. Did Dr. Brooks—just very quickly, because we still have plenty Members for your panel.

Dr. BROOKS. All I wanted to say was that having this hearing today is probably one of the most important first steps in raising the awareness that we need in America. And I encourage people to

take seriously when they have someone they know talk about this syndrome. It is real.

Ms. ESHOO. Thank you, Dr. Brooks. Exactly my intent in identifying the issue is one that really needed to be raised up to a congressional hearing by our subcommittee. So thank you.

Now, is the gentleman from Georgia still driving around, Mr. Carter, our favorite pharmacist? Not with us? Going, going, gone.

All right. Then I will recognize the gentlewoman from New Hampshire, Ms. Kuster, for your 5 minutes of questions. Great to see you.

Ms. KUSTER. Great to see you. And thank you so much, Madam Chair. I am so grateful for this hearing.

This past year has been an incredible challenge for Americans all across this country. But for those who have had COVID–19 and suffered from the lingering effects of this disease, this past year has been even more painful. And this discussion hits close to home for me and my family.

My wonderful niece, Laurel, who is an extraordinary athlete—she was literally on the United States Ski Team and was an amazing ski racer—had COVID just over a year ago today. And she continues to have trouble with everything, even the simplest activities of daily living. She has to choose between taking a shower or making dinner. Otherwise, she was a 34-year-old and previously very healthy, very competent young woman. And I am so proud of her for hanging in there.

Everything you have talked about today, including doctors who didn't take her seriously, has happened in her life. She has seen countless doctors and taken endless tests, adding up to literally thousands of dollars in out-of-pocket expenses. Despite the tests and the preliminary research being done on long COVID, her doctors cannot identify exactly what she is suffering from.

As we have heard today, she is not alone. According to NIH, more than 50 percent of COVID–19 patients experience lingering symptoms longer than 50 days after recovering from their initial infection. And the long-term effects are profound. So it is critical that we have a coordinated effort here at the Federal level. And I really appreciate, Chairwoman Eshoo, for you hosting this important hearing.

Dr. Collins, in December 2020, Congress, we, appropriated $1.15 billion in funding to expand research on long-term COVID and potential therapeutics. And you have talked a lot about the research and the metacohort. I am very curious if you have seen any effective treatments.

I would love to put into the record a recent article from The Atlantic about exploring what these treatments might entail. And how will you communicate and get the word out to the medical community so that we can alleviate the suffering of these patients with long COVID?

Dr. COLLINS. Yes, it is a very appropriate question. And I do hope everybody understands this is not just putting together a cohort to study their symptoms and watch from a distance. We want to initiate, as soon as possible, interventions. And the clinical science's core of this is going to be the best experts, including tapping a lot into the people who are currently running these long-

COVID clinics that you are going to hear about in the next panel to see what ideas are out there.

We will, however, want to ensure that, if we are going to test a therapeutic, that we do it in a fashion that is rigorous, that is well powered, that is placebo-controlled so we really will know whether it works or not, because you have so much variability in the course of long COVID. Some people seem to spontaneously get better over a few months, some people don't. And if the only way you are going to really know if your intervention work is if you design the trial accordingly, we will be doing that.

I mentioned earlier we are already running a trial about whether anticoagulants in the convalescent period might be beneficial and certainly some ideas about immunosuppressants that could be tried as well. Beyond that, I haven't see the article you mentioned in The Atlantic. There are ideas floating around, but we are going to need to prioritize them about which are the most promising, make sure we have the appropriate clinical trials and master protocols put together, and then we are going to go and see what works as soon as possible to try to come up with things that we can advertise to the clinicians around the country as here is new information you might want to know. CDC will help us a lot with that because of their connections with the clinical community out there.

Ms. KUSTER. And I am curious, as well, not just interventions with therapeutics or medication but also treatment. This article related to breathing techniques that might be helpful. Have you heard about any other types of treatments that don't entail intervention but just entail helping the person live with the situation?

Dr. COLLINS. Yes. Certainly, this kind of pulmonary rehabilitation, which has been used for other conditions, does seem to provide some benefit to patients, cardiac rehabilitation for people who are primarily suffering from things like palpitations and fatigue. And also interventions to help with the brain fog, similar to what has been done for people with concussions, do seem to provide benefit.

Again, I think you are going to hear from the people running the post-COVID clinic in the next panel about things that they have tried. But it is still kind of early days. We are all just trying to see what could we try and did it work. And you want the most rigorous, large-scale data as soon as possible. That is what I think we can contribute with this metacohort.

Ms. KUSTER. Well, my time is up. But I thank you all for everything you are doing to get to the bottom of this.

And I yield back.

Ms. ESHOO. The gentlewoman yields back.

I am always struck by the term "novel coronavirus." We keep learning. There is a reason it is called novel; we keep learning every day. And hopefully, today's hearing advances that learning and how we can apply it best.

I just want to say, we don't have any more Republican members of our committee in the lineup, so I don't want anyone to think that I am skipping over them. But we will continue on and it will just be from our side of the aisle, unless someone shows up that didn't have the opportunity to question.

So it is a pleasure to recognize the gentlewoman from Illinois, Ms. Kelly, for her 5 minutes of questions.

Ms. KELLY. Thank you so much, Madam Chair.

Dr. Collins, when we talk about long COVID our constituents are saying that they are no longer able to work due to fatigue. How do we help employers understand the plight of their employees' experience in long COVID to ensure they are not discriminated against in the workforce and are able to remain productive citizens if they chose to do so? And thank you for being here.

Dr. COLLINS. Thank you for the question. It is really important that we figure out ways to support people who are going through this prolonged period of fatigue that makes it impossible for them to work full time or maybe even to work at all. And we know that does happen to a substantial number of individuals with long COVID. And that means we need to figure out how to get this information into the hands of Social Security, for instance, in terms of disability claims.

By the way, it also means we need to be sure we have a good connection with CMS so that the coverage for medical expenses doesn't end up bankrupting individuals who are already going to be in a tough place because of this illness. Both CDC and NIH have been working closely with CMS on that issue aiming to try to come up with the usual thing you need, which is an ICD–10 code so that these kinds of reimbursements will begin to take place more readily.

Again, I think employers generally are not going to be very sympathetic unless they are totally convinced that this is something that is medically established. So the docs are going to have a lot to do with that, which is why what we have been talking about a minute ago in terms of getting information to clinicians so that they don't brush these symptoms off as if it was something not so serious is going to be critical.

But I should ask Dr. Brooks also to address your question, because I think the connection CDC has in here is really important with employers, with Social Security.

Dr. BROOKS. Thanks, Dr. Collins. And thanks, Representative. That is a really insightful question. We spend a lot of time, first of all, working with the employment community to show that people who may be disabled—and I am not going to say that people with this condition are disabled—but people who are challenged by medical illness are still able to work and to work with them to find ways to help them work.

We have got a year of experience living on Zoom—as we are doing right this minute—and we are finding ways to help people do their job and be gainfully and meaningfully employed outside of the standard workplace.

And then, as Dr. Collins was mentioning, for people who are down for the count, we have got to make sure that we can clarify for people this is a real condition that people are living with and to take the symptoms seriously. This is one of the driving forces for us to get these interim guidelines together so we can begin to provide clinicians with a way to describe what is going on.

I hope you will hear this afternoon from our colleagues at UCSF and Yale some of the challenges they may have faced in terms of

filling out disability claims or off-work claims and the ways that they are working to address that. But it is critical that people who have been affected by this disease are able to be taken care of and, if that means they are unable to work for a period of time, that we are able to support them then.

Ms. KELLY. Thank you so much. And I know my other colleagues have been waiting a long time, so I will just ask one question. Thank you so much.

Ms. ESHOO. The gentlewoman yields back. That is so generous of you.

I am going to go back to the gentleman in the car. I called you our favorite pharmacist, the gentleman from Georgia, Mr. Carter, for your 5 minutes of questions.

Mr. CARTER. Thank you, Madam Chair. I appreciate this. And thank you for bearing with me.

Dr. Collins and Dr. Brooks, I thank both of you for being here. This is extremely important.

I have got a staffer who has been diagnosed with long COVID. And that staffer has been—that individual has suffered from severe anxiety, fatigue, long-lasting loss of smell and taste, and these are very serious issues, and I am very concerned. And concerned, obviously, because it is someone close to me.

I wanted to ask you—the staffer in my office, she says that many of her long-COVID symptoms dissipated after she received the vaccine. Is the CDC or the NIH aware of any reason the vaccine may help with long-COVID symptoms? Dr. Brooks?

Dr. BROOKS. That is a great question. Thank you. And I will say these were fascinating reports when they began to come out. We have talked a little bit about this, so I don't want to go over all of that territory, other than to say there are some emerging research data that suggests there may be something there. But we have really got to look at it more closely.

The mechanisms are—there are multiple things that could be going on. I think the ones that I like the most are the idea that the vaccine is bringing benefit in terms of either controlling this, if it is an ongoing active infection that we are not recognizing, or doing something to get the immune system back on track to where it should have been.

Also, this is a great reason for people who are having post-COVID to get vaccinated, if they haven't been vaccinated already. We can't guarantee that this positive experience some people have reported is one that everyone will have, but I certainly hope it would bring people off the sidelines to get vaccinated if they are hesitant.

Mr. CARTER. That is great.

Dr. Collins, are you aware of any studies that are being done about this?

Dr. COLLINS. Yes. There is one small study that has been published as a peer review, but it is 44 individuals where there was overall a small improvement in those who got vaccinated versus those who didn't. But also, there is a patient support group called Survivor Corps, and they did a survey, I think of more than 500 individuals who had had long COVID, got vaccinated. Forty percent of them reported some improvement, which was encouraging to

hear. And relatively few reported the opposite, of having a worsening of their symptoms.

What exactly that means as far as the mechanism, I am sure you are wondering about that too because we all are. Does that mean that those individuals with long COVID still have a low-level viral infection that we haven't been able to quite discover and that the vaccine basically gives their immune system the kick it needs in order to take care of that residual virus? Or is it that they have an autoimmune condition already because of that COVID infection and the vaccine interrupts with that? We don't know. Those are theories.

Mr. CARTER. I am going to kind of go off script here, because this is something that—and I never try to get personal in any of these hearings, but I have got a dear friend who is suffering right now with psychological, mental problems as a result of COVID. What is going on with that? Dr. Collins, do you know? I mean, he has had to be admitted, and I am just worried to death about him.

Dr. COLLINS. I am very worried about that because we are seeing instances—first of all, let me say anxiety and depression is a very common feature of long COVID. But there are instances of actual induction of new psychoses in individuals who previously were normally functioning, who actually fall really into a much more serious psychiatric illness. We assume this must be some way in which this virus has interfered with the function of the brain, maybe by affecting a vascular system or some other means of altering the way in which the brain normally works. But we have so little information right now about what that actual anatomic mechanism might be. And that is something we have to study intensively.

But you are so right, this is a big part of long COVID, is the mental health consequences. We shouldn't just talk about shortness of breath and palpitations. We have got to talk about the mental health issues.

Mr. CARTER. Dr. Brooks, any comment on that?

Dr. BROOKS. I completely agree that mental health is often the last breath and a discussion of what we need to address when often in a condition like this it needs to be the first thing we bring to the front. I hope your friend gets the care they need. And I am very, very sorry to hear how ill they are.

Mr. CARTER. I tell you, it is just obvious—I am very, very concerned. And I just—has the vaccine—to be quite honest with you, I don't know whether he has gotten the vaccine or not. Is this another instant if he was to get the vaccine? Has it shown improvement for these people?

Dr. BROOKS. I think from what Dr. Collins described, there is a possibility it will help, and there is not a lot of indication that it is going to do harm. And we know that in the long run it will protect him against the possibility of reinfection. I would do it.

Dr. COLLINS. Yes, I am with you.

Mr. CARTER. Good.

OK. Madam Chair, thank you very much. I appreciate it. And I yield back.

Ms. ESHOO. The gentleman yields back.

It is a pleasure to recognize the gentlewoman from California, Ms. Barragán, followed by Representative Craig from Minnesota.

Ms. BARRAGÁN. Thank you, Madam Chairwoman.

The USC school—the Keck Medicine is reporting that 1 out of every 10 COVID–19 patients at Keck Medicine of USC is a long-hauler. And for them, they say that this statistic is pretty nationwide, about 10 percent of COVID–19 patients have these long-haul symptoms. At Keck, they say most of the long-haulers are between the ages of 20 and 40 years old, which is quite remarkable when you think these are young people, many of them maybe healthy.

Is there any data or information that we have about why maybe in southern California, I don't know how common it is, that it is impacting younger people between 20 and 40 more than others?

Dr. BROOKS. If you want, I can start with that, Dr. Collins.

Dr. COLLINS. Sure.

Dr. BROOKS. And, Congresswoman, thank you much for that important question. Let me point out one thing that is important to have in the back of your mind, is that among the persons affected by COVID in this country, the largest numbers of new infections are among people in that age group, 18 to 39. So it is not a surprise necessarily that they would be overrepresented in the persons who are experiencing post COVID as well.

Having said that, I still think it merits close attention, because it is an unusual signal. And I hope folks are, you know, going to begin focusing more on the age differences as well as some of the others that we have raised before.

Dr. COLLINS. Yes, I agree with that. When you look at what is the likelihood that somebody who was just diagnosed with COVID–19 is going to go on to long COVID, it looks as if it is a bit higher for older people. But on the other hand, there are more young people getting infected. So if you go through the mathematics, you can see why it is that long COVID seems to be particularly prominent now in younger people, who may not have been very sick at all with the acute infection. Some of them had minimal symptoms but now are turning up with this.

That 10 percent number that USC is reporting, that is pretty typical for what a lot of the studies are showing, although there is quite a lot of variability, some as high as 30 percent, some lower than 10. One of the things we really need to get a better fix on is what is that percentage when you have a very large study and you can control for all of the other correlates that might play a role there.

But, you know, here we are having this hearing about is this really an important issue. Think about this for a minute: We have got 32 million people who have been diagnosed with the acute infection of SARS–CoV–2, COVID–19. Let's say 10 percent is right. That means there are 3 million people who are going to be affected with this or already are and whose long-term course is uncertain and may very well end up being people with chronic illnesses. That is why this is such a serious issue.

That is why I am grateful to you all on this subcommittee and in the Congress for taking this so seriously and giving us the opportunity to throw everything we have got at it to try to understand this and try to interfere with the diabolical nature of this virus to not only get you once in an acute illness but also get you again as you think you are getting better and maybe don't. So

thank you for the recognition of that. I can't overstate how serious this situation is for the health of our Nation.

Dr. BROOKS. Let me add, if I may, just one thing. This is a great opportunity to remind young people they are not immune to this, right? This is really the audience you want to reach with "vaccination is something you should strongly consider, yhis affects people like you."

Ms. BARRAGÁN. Right. And that is a good reminder, gentlemen, about what we are hearing and read about these days, that more and more Americans are not going to get their second dose because they are worried about any side effects that may last a day or two on, you know, a headache or aches and pains. And so this sounds like the alternative of a possible long-term impact is going to be a lot worse. And so I am encouraging those in our community to go get that second shot if they have not yet.

You know, I represent a district that is almost 90 percent Latino, African American. We have been hit super hard by COVID–19. Many are low income, many don't have access to services they need, maybe they don't have full access to healthcare.

Dr. Brooks, you have already touched on how the social determinants of health affect people in underserved communities who have long COVID. And I know that the CDC is very interested in addressing social determinants, not only regarding COVID but also more broadly. Dr. Brooks, do you believe that Congress should be doing more to address social determinants of health, including fully funding the CDC's social determinants of health program as a strategy to help those most impacted by the pandemic?

Dr. BROOKS. I agree with you completely. The social determinants of health are critical underlying causes for what may be driving some of the things that we are seeing. Unfortunately, that is an area, the funding part, that is a little out of my expertise. But what I want to do is I will take that back to our folks and get an answer for you. I want to make sure we address the question you are answer—you are raising, rather.

Ms. BARRAGÁN. Fantastic. Thank you.

With that, Madam Chairwoman, I yield back.

Ms. ESHOO. The gentlewoman yields back.

A pleasure to recognize the gentlewoman from Minnesota, Congresswoman Craig, followed by another one of our outstanding doctors from the State of Washington, Congresswoman Schrier.

So, Angie, take it away. You have 5 minutes.

Ms. CRAIG. Thank you so much, Chairwoman.

It is really an honor to be here to talk to both you, Dr. Collins, and Dr. Brooks.

We have heard you both share that long COVID is such a complex disease that we don't know so much about it at this point. So many different symptoms that involve many different organ systems, from the lungs, to the heart, to the brain. We know that these complex conditions often require advanced and multidisciplinary care that might only be available at some larger institutions.

In my home State of Minnesota, of course, we are fortunate to have world-class facilities that help people suffering from long COVID return to—to help them try to return to that pre-COVID

life. Programs such as the COVID Activity Rehabilitation Program at the Mayo Clinic provide comprehensive rehabilitation services and mental health support.

Dr. Brooks, with such complexities, with such multidisciplinary medical care needed, where should my constituents start in terms of the setting that they are looking for to receive, generally seeking care for long COVID?

Dr. BROOKS. You know, you raise a really important question, because in an evolving disease like this, we really want to get people to the right place as soon as we can so they get the appropriate care.

As before, I would recommend that people first seek care with their primary care physician. It is our duty to raise awareness in the frontline provider community that this is a real condition, that it exists, it may be misunderstood, but to recognize that there is something there, and to use that as a cue to seek referral to a specialty center.

Now, for the time being, we may have to work in that system, but I hope one day we are able to move to a system like we used for HIV now, another complex disease, but where we were able to diffuse the knowledge and actually bring it to people further away from the centers of academia.

Ms. CRAIG. Dr. Brooks, just stay with me for one more minute, what is the CDC doing to help inform those primary care providers on long COVID and to ensure that those appropriate services are available?

Dr. BROOKS. So we have regular webinars and phone calls to which we invite clinicians and care providers, and actually pretty much anyone is welcome, but it is intended for that audience to bring them up to speed about the latest knowledge around COVID–19, but also in this case long COVID.

In addition, we have drafted interim guidelines to assist in the early diagnosis, recognition, management, and referral to services and how to do that and also how to help patients engage with support groups that may be out there and can offer some other options for them.

Ms. CRAIG. Thank you so much.

I want to ask Dr. Collins the next question. It is nice to see you again, and thank you for the great tour of NIH before COVID.

The majority of NIH funding flows through academic medical centers who are often, obviously, leading the way in addressing long COVID.What is happening at NIH or other Federal agencies to learn from these academic medical centers to assist you in the development of care models for long COVID?

Dr. COLLINS. Well, they are most certainly critical partners for us, and you will hear from a couple of representatives in the next panel about how academic centers have tried to pull together the kind of multidisciplinary care that is necessary for long COVID. One of the things I worry about, relative to your earlier question, is if people start bouncing around from specialist to specialist and nobodyis actually coordinating the big picture, then long COVID is not going to be well taken care of because almost nobody with long COVID has one symptom or one organ that needs to be attended to. It is multicomponent. And that is where the academic centers

trying to put together these long-COVID clinics that have access to multiple expertise is going to be really important.

Those 273 applications I mentioned that we are reviewing right now, a very large number of them are from academic centers that do in fact bring their expertise and their hopes and dreams of helping with this situation as they have been our partners in many other situations. They are going to be that here as well, although they have to show what they can do. We won't be able to fund all of them, not with that number, but we are going to build on that expertise as well as bringing in other kinds of insights from small businesses and from other government agencies like CDC and FDA and really try to bring, as we have done in therapeutics and vaccines, all of the players around the same table to solve a really hard problem.

Ms. CRAIG. Well, I just want to say thank you to both of you, Dr. Collins and Brooks, for a grateful American public. I know it has been incredibly difficult. Thank you for your leadership during these difficult times.

With that, Madam Chair, I will yield back.

Ms. ESHOO. The gentlewoman yields back.

The Chair is very pleased to recognize another one of our outstanding doctors on the committee, such value added since she has come on: Dr. Schrier, from the State of Washington. You are recognized for 5 minutes.

Ms. SCHRIER. Thank you for that kind introduction, Madam Chair.

And thank you, Dr. Collins and Dr. Brooks, for joining us today and giving your insights about what we know about long COVID and what we don't. It will not surprise my colleagues that, as a pediatrician and a mom, I am going to focus on children today. Because we have talked for over a year about how we are so fortunate that children are only minimally affected by COVID–19, that it is changing a bit with the B.1.1.7 variant, the fact that adults with no symptoms or very mild symptoms can still have pretty devastating and life-altering COVID symptoms really begs the question about children's risks for long COVID and whether we are a bit too complacent about how we are managing their risk. And I am thinking about schools and camps.

So my first question is for Dr. Brooks. Could you just quickly list, just based on what you know so far—and I know it is limited—what are some of the ways that long COVID seems to present in children, just so we have our radar up?

Dr. BROOKS. Right. Right. So the data that I am aware of, for some of the symptoms are the ones you see in adults as you would expect in, particularly, pulmonary conditions, persistent shortness of breath, maybe cough, as well as persistent fatigue. There is also some evidence that the experience—what is called a brain fog, but it is probably some issue—probably neurocognitive in nature, and it is important for kids when they are growing and developing that we understand what is happening there because we don't want that to impair their ability to learn and grow properly.

Those would be the main symptoms that I am most aware of to look for.

Ms. SCHRIER. And those are so interesting because we do see symptoms like that frequently, and I will get back to this, but it may raise the question of whether part of the workup now becomes titers in those kids. Now, both of you—I will start with Dr. Collins, you have said many times and we doctors on the call have said that the best way to prevent long COVID is to get vaccinated. And I have to note that Pfizer submitted a request for emergency use authorization for children 12 to 15 years old several weeks ago.

Do you have any idea why we are not moving as quickly with that approval as we did for adults? Because we had that, you know, out to the public, I think, within a week or so. And I, as a mom of a 12-year-old, and I know moms everywhere are wondering, especially with long COVID, when can our kids get vaccinated?

Dr. COLLINS. Very good question, Dr. Schrier. And I, as a grandfather of a 14-year-old, am wondering the same question. So, yes, I know Pfizer did submit their data and is seeking EUA for kids 12 to 15. FDA has been looking at it. I think, to be fair, it took FDA 2 weeks with the adult data before they convened their advisory committee and had the public discussion, but it has been a little longer than that.

I don't have insight into what is happening in the internal workings of the FDA. I am sure they have been a little busy with this J&J circumstance, but I am hopeful, as you are, that they will come forward pretty soon with a rendering of a judgment here, and they will have to convene their public committee so that everybody gets to look at this. Obviously, everybody wants to be sure, if we are talking about kids, that there's no new safety concerns there. But, yes, wouldn't it be great if we could do that and not have to wait till the fall when school starts up, to get started now this summer immunizing those high school kids and middle school kids, too? I would love it.

Ms. SCHRIER. It sure would be nice. Summer camp is coming up. So I have another question for you because we are doing our own research here. Israel is a country that has medical records on everybody from the day they are born. They had high rates of COVID like we did. They also now have astounding rates of immunization. I am just wondering if we are kind of collaborating with Israel on the question of long COVID.

Dr. Brooks, sorry. Dr. Brooks.

Dr. BROOKS. Sure, yes. We certainly follow the Israeli literature closely because the benefit that you just described are allowing them to pour out new information to share with people is very valuable. We also work with the World Health Organization on the long COVID effort, and it is probably primarily through that relationship with WHO, who are also very vested in this because this is a problem seen everywhere in the world. I just want to mention that this is not unique to America. It makes common sense, but it is being seen in every country pretty much.

So we—I have spoken to Israeli colleagues through that relationship and also a panel that is convened regularly by the European CDC where they bring leading CDCs from other countries together. Israel is always in that group. You remind me that I am going to want to talk about long COVID in our meeting coming up shortly.

Ms. SCHRIER. Well, thank you. Thank you both for this really important meeting and your attention to it. Thank you.

I yield back.

Ms. ESHOO. The gentlewoman yields back.

The next two Members that I will recognize, first, the gentlewoman from Massachusetts—again, high value added, new member of our subcommittee, we are thrilled to have her—Congressman Trahan. You are recognized for 5 minutes.

Can you hear me?

Mrs. TRAHAN. Thank you, Chairwoman Eshoo. Yes, can you hear me?

Ms. ESHOO. I can.

Mrs. TRAHAN. OK. Terrific. Well, thank you, Chairwoman Eshoo, for holding this illuminating and important hearing. And my thanks to Drs. Collins and Brooks. You know, I want to just spend a minute elevating the story of one of my constituents, Lauren Nichols. She is a 33-year-old former athlete——

Ms. ESHOO. Can I—excuse me for interrupting. We can't see you. I don't know if it is just my screen, or is it everyone else's? We can hear you, though.

Oh, there you are. Good.

Dr. COLLINS. I think it is a weak signal.

Mrs. TRAHAN. All right. OK. Sorry about that. So Lauren is a 33-year-old former athlete, runner, and hiker from Massachusetts who has been suffering from long COVID since March of last year. She first developed the symptoms on March 10 of 2020, and her initial symptoms were severe neurological and gastrointestinal issues, which then escalated to severe shortness of breath a few days later. When Lauren tried to get a COVID test through her primary care doctor, the answer she received was not at all encouraging. In fact, I, quote: "You are young, and you will be just fine if you contract COVID."

And she was denied a test. But as her symptoms worsened, Lauren sought a second medical opinion where she, again, was met with skepticism from a physician who did not believe the severity of her gastrointestinal issues or that they were even related to COVID. But due to her own advocacy, Lauren eventually received a COVID test and was diagnosed with the virus.

But in the weeks that followed, Lauren developed pneumonia, painful colitis, and due to the lack of support from those she sought medical help from, she developed depression and became suicidal. Months later, she developed eye shingles and is now visually impaired. She started to have seizures and even a stroke, all due to the lingering effects of COVID–19. Although, she is insured, Lauren has spent more than $12,000 out of pocket for her [inaudible]. Long-COVID patient developed fatigue or MECSF, which has been raised by [inaudible]. Dr. Anthony Fauci last summer stated that many COVID–19 [inaudible] patients [inaudible] significantly increasing the number of those patients across our country.

So, Dr. Collins, historically research into clinical trials and treatments for MECSF have gone underfunded at NIH, leaving many patients to suffer physically [inaudible].

Ms. ESHOO. Your voice is—Lori, can you restate your question?

Mrs. TRAHAN. [inaudible] Congress appropriated $1.15 million for research for the agency, but heading to DC.

So, Dr. Collins, this question is for you. As NIH leverages its research on MECSF to better understand the intersection of MECSF and COVID–19 syndrome [inaudible]. When can patients like Lauren and so many others expect developed from COVID? Did that not come through? That question not come through?

Ms. ESHOO. We are having a problem with your audio. It is really breaking up in the car.

Dr. Collins, did you get the gist of the question?

Dr. COLLINS. I think I got the general gist, particularly asking about a CSF or MECSF and the relationship to long COVID and the need for research on both of them, and I agree with that. I have been very concerned for several years about the lack of understanding of MECSF and what the mechanism is that causes individuals to suffer from this oftentimes years of fatigue that are sufficiently severe to keep people almost bedridden.

We do have a lot more research going on on that. We funded no less than four centers of excellence to work on CSF. Our own intramural program at NIH has a big program bringing patients to our clinical center for intense study with CSF, and the same investigators are now studying long COVID with the same mindset.

So, if there is an overlap between this, I think we are going to discover what that might be. And my hope would be that the fact that we are now able to put a lot of resources into studying the long COVID circumstance where we know what the inciting agent was—we know what the virus was—we should learn something that will spill over in a useful way into our understanding of CSF, and we will be able to offer something more successful to those individuals who have suffered a lot for much too long.

Mrs. TRAHAN. Thank you, Dr. Collins, and I appreciate the committee's patience. I apologize for the in and out and the weak signal. I will submit my question for Dr. Brooks—I will submit it for the record. Thank you.

I yield back.

Ms. ESHOO. Wonderful. Thank you. We certainly understand, you know, all of the glitches that are possible and sometimes probable out there, but we want to make sure that we got your question in and submit—all Members can obviously submit their written questions to our witnesses.

Pleasure to recognize the gentlewoman from Texas, Mrs. Fletcher, for your 5 minutes of questions. Great to see you. Thanks for your patience.

Mrs. FLETCHER. Great to see you, and thank you so much for holding this hearing, Chairwoman Eshoo. This is really critical, as so many of my colleagues have said before me today, and I am looking forward to our next panel as well. But I think that our witnesses in this first panel have really been excellent in making it abundantly clear that long-term COVID, long COVID, is real. It can be debilitating. I really appreciate it. The answers just now about comparisons with CSF, that is certainly something that we have experienced here in our community, a lot of folks and those challenges, but, you know, I am very concerned, as I think has been made clear today, that once we get past, you know, this pan-

demic or get to the next phase of this pandemic and the majority of people are vaccinated, we are still going to have a health crisis on our hands. Certainly that has been made clear, also my colleague Debbie Dingell mentioning the status of things in Michigan, certainly we still have our challenges down here in Houston and in Texas.

So I wanted to just use the time that I have to see about—to follow up on sort of two things. Dr. Collins, in your testimony today, both written and in response to questions from some other colleagues, you talk about individuals facing skepticism about what they are experiencing. And I think, as some other people have mentioned, there are also real challenges to identifying as a patient, you know, whether these are symptoms, what to expect, how to properly categorize what you are experiencing.

So I am wondering, actually, if both of you could just touch on a little bit more anything you haven't had a chance to say about how we educate the public about how to recognize symptoms and how to access care. And, obviously, I am particularly worried about those areas where there may not be a COVID–19 long-hauler clinic.

So really understanding what patients can do and how they can evaluate and get access to care and also how health workers are equipped with the resources and training to deal with those? So I would love your thoughts on those issues.

Dr. COLLINS. Well, first, I would say this hearing is a good step in the right direction, and so thanks to the leadership for putting this together, and I hope, because the press tends to listen to these things, that this will provide another opportunity for people to be informed about long COVID. It is a real and serious condition.

And let me just turn, though, now to Dr. Brooks because CDC is in such a critical place in terms of trying to both do the public education and the provider education so that people aren't faced with this terrible circumstance of not only having a terrible condition but not being believed that you have anything wrong with you.

Dr. BROOKS. Yes. Thanks, Dr. Collins, and especially, Congresswoman, for the question, the insight here. You know, one of the things we are doing first is trying to make sure that clinicians are aware that this exists and that it is real and how to recognize it. And we are doing that through a variety of different means of webinars, phone calls, and developing interim guidance. At the same time, we want to make sure patients are aware that, if they have something, to seek care.

We want them to seek primary care first to make sure that it isn't something else. There are a lot of things that may look like some of these early symptoms, and those can be taken care of, but if it is not and they are concerned that it could be long COVID, then to refer them to the proper place to get that kind of care. Although it is primarily centered in urban and academic centers presently, as we learn more I fully expect that it will be basic care for people with long COVID. We will be moving out into community health centers, secondary and tertiary hospital centers so that people will have access to the services that they need, but the burden question is a burning one: 32 million Americans so far have been infected, as Dr. Collins referenced. Even if a small percentage of them, 10 percent, have this, that is lots of people. That is millions

of people. So we need to be prepared that this will be with us for a long time. It could be substantial.

Mrs. FLETCHER. Well, thank you so much for your insights and for your testimony here today. I really appreciate the emphasis that you are placing on this and on communicating with our communities, and certainly we here in Houston and Harris County are very interested in being a part of the research and the work that you are doing. And I know there is a lot of collaboration going on from folks here in the Texas Medical Center and beyond, you know, working hard to try to address these issues.

And, you know, the one other thing that I would love to just hear you touch on if either of you have additional thoughts, Dr. Collins, you mentioned earlier about the ARPA–H proposal and, in the short time we have left, if you have any additional thoughts you haven't shared on that. I think it is really exciting.

Dr. COLLINS. Well, I do, too, as you might have guessed from my earlier comment. This is an opportunity to take some of the lessons that we have learned, particularly with COVID–19, but going back to other things we have done that have been out of the order in terms of really rapid progress in areas that require a lot of different disciplines to get together and move forward in a fashion that has been pioneered by DARPA and the Defense Department, of which we could bring to the health arena with great benefit.

So I am very excited if this is, in fact, embraced by the Congress and the appropriations process that we are getting into for fiscal year 2022, if we could stand up this new unit at NIH, that would be doing some pretty breathtaking things across the board in many different areas—not just infectious diseases, but other things as well. So thanks for asking.

Mrs. FLETCHER. Well, thank you so much. I see I have gone over my time. It is very exciting. I look forward to working with you and Chairwoman Eshoo on these matters.

Chairwoman, thank you so much for allowing me this time and for holding this hearing.

Ms. ESHOO. Absolutely. It is a pleasure. We have two Members that are waiving on to our subcommittee, and we always welcome them and any Member that wants to join us from the full committee to waive on, and they will be the last two that I know of to question this panel. So, Drs. Collins and Brooks, you are going to have your late lunch shortly.

So, at this time, I would like to recognize the gentlewoman from Illinois, Ms. Schakowsky, who very often waives on, and we are always happy to have her. You have 5 minutes.

Ms. SCHAKOWSKY. Thank you so much, Madam Chair, for allowing me to be here.

I am—first of all, just want to thank both Dr. Brooks and Dr. Collins. Makes me so proud that within our government and our public health system and our scientists are doing so much. I really appreciated that when Dr. Fauci got his vaccine, he called it the NIH vaccine, underscoring what we do together as a country to support your wonderful work. So thank you for that.

But I have to tell you that I am very worried. You know, we have right now vaccines and therapeutics that are affordable because we are doing that during what we call the COVID crisis, but after

that, for the long COVID, are people going to be able to afford it? Are people going to be able to get the help they need?

I know you have talked about just proving that they are sick in the first place is a challenge, but let's say that they are. We have seen through COVID the disparities, communities of color, individuals who are more infected, people in lower-income communities. We have already seen Pfizer report to their stockholders and investors that, oh, this is going to be a good year because we are going to have these vaccines boosters every year for people, and we are going to—so once this designated timeframe, it has passed, are people who have long COVID going to be able to not only access the doctors and get the treatment but be able to afford this?

I am very worried about this and Big Pharma's proclivity to profit on what is happening right now.

Dr. COLLINS. So I wish I could get my crystal ball to be a little less cloudy here as we try to look forward where we might be in 6 or 9 months. I think in 6 or 9 months, we will have a better understanding of what the actual mechanism is of long COVID. Maybe that is a little early to be really, really clear, but I think we will have some pretty good clues, and that will lead us in the direction of treatments, but then we will have to figure out do they actually work in rigorous trials.

So let's say a year from now, we might begin to really get a sense of what is optimum medical management of people suffering from long COVID and who is going to pay for it. We have already started that conversation with CMS because, as you know, a lot of what happens with third-party payment follows CMS's guidelines for both Medicare and Medicaid, and I think that is going to be critical going forward. Because you can imagine the tragedy that will ensue if we come up with a way to treat long COVID, but it happens to be a fairly expensive agent and it is not covered by third parties, then we are hitting people with one more terrible outcome. We can't let that happen.

I know CDC has worked closely also with CMS in this space, and this is a place where our three agencies plus FDA are going to need to be in lockstep to make sure we don't stumble with the ability to find things that are going to help people that are affordable.

Ms. SCHAKOWSKY. Well, I think what you can do to help us is to identify the symptoms that are almost certainly connected to COVID, because I think that there may be some resistance to even identify something as COVID-related.

Dr. COLLINS. Yes. I think that is right, and I think CDC is very much trying to push into that space of saying what really is our case definition here that ought to be reimbursed.

Dr. BROOKS. I have to agree. Establishing case definition is fundamental to the issues that you are talking about, Congresswoman.

Ms. SCHAKOWSKY. And that is what you folks do, right?

Dr. BROOKS. Yes.

Ms. SCHAKOWSKY. OK. Well, I am just so grateful for all of the work that has been done in the public sector by people like you who are so dedicated, and I just appreciate it, but, you know, women, by the way—and we are going to hear some testimony and we have had testimony at this committee—are often also underlistened to——

Dr. BROOKS. Oh, yes.

Ms. SCHAKOWSKY [continuing]. When it comes to health issues. So it is an issue for women as well to make sure that we are accepted for the treatments that we need and that they are available and affordable. So thank you once again.

And I yield back.

Ms. ESHOO. The gentlewoman yields back. And I would say back to the gentlewoman, how about just across the board relative to women and speaking and really being paid attention to? We push forward. We are changing that every day.

It is now a pleasure to recognize the gentleman from Pennsylvania, a great friend, chairman of one of our—another very important subcommittees at Energy and Commerce, Communications and Technology, and he has been with us since the gavel went down this morning. So thank you, Mr. Doyle, and you have 5 full minutes. I won't hammer the way you do. How is that?

Mr. DOYLE. Madam Chair, I want to thank you so much for holding this hearing and for allowing me to waive on, and it is great to see Dr. Collins and Dr. Brooks here and the great work that they do.

Peter Welch brought up a good point about being able to diagnose and having tools to diagnose long hauler. I have—one of my sons is a long-hauler going on his fourth month since he was infected. Young, athletic type, wrestler, body weightlifter, I mean, just in perfect physical condition, and to see how debilitated he has become. He just took disability from his job, and he works in pharma, and he has got a great job and two of our grandkids, and it has been tough to watch.

But because he is a COVID long-hauler, I have been in touch with a long-COVID researcher in California, Dr. Bruce Patterson, who is the former medical director of the Diagnostic Virology at Stanford, and Dr. Patterson has a database of long-COVID patients and blood samples of some 4,500 now. Here is an article entitled "Immune-Based Prediction of COVID–19 Severity and Chronicity Decoded Using Machine Learning," which was just accepted by peer review, and it is going to be published in one of the immunology journals soon.

And with his model, he has been able to accurately predict long-haulers through the 14 cytokines related to COVID using a simple blood sample from a patient. I hope this is something that NIH is interested in, and I guess my question is, how do we make sure that when we have researchers that have, you know, breakthroughs like this that it is widely disseminated and that NIH, you know, and the rest of the medical community is aware of it?

Dr. COLLINS. Well, Congressman, it does sound like a very interesting study, and I would hope, yes—the way in which the information gets disseminated is exactly what Dr. Patterson is getting ready to do, is to publish this in the peer-reviewed literature. All of us who are concerned about COVID and especially long COVID are avidly reading the journals daily. If you could see my desk, you would see a pile of published manuscripts that is about 2 feet high that I am kind of constantly looking at for what is the new idea. Yes, tell Dr. Patterson, if he is listening, send me a preprint. I want to see what this is with the cytokine that might be a bio-

marker indicating who is at the greatest risk in something about mechanism. That is the kind of thing we are looking for.

Mr. DOYLE. I mentioned that I did introduce Dr. Patterson to Dr. Gary Gibbons. We put him in touch with him, and I just wanted to draw attention to it because he has been doing a lot of good work in this field.

I got to ask you, my colleague Dr. Joyce I thought brought up a great point on, you know, an ounce of prevention being worth a pound of cure, and that is some of these therapeutics that we can use. Not everyone is going to take this vaccine. We know we have people out there that just aren't going to get the vaccine, but they may get COVID. And one of the ways to make sure they are not long-haulers is to get them some sort of therapeutic treatment the minute they get the disease. I have heard from a lot of doctors in my district and patients about a therapy that is not a novel therapy but one that has been around for quite some time and has an excellent safety profile, and that is ivermectin.

What is the NIH and CDC's position on ivermectin? And I have a lot of doctors who have contacted me and sent data from various randomized control trials showing benefit with this drug, and I have been reading that a lot of other countries are starting to use ivermectin as a treatment for people that aren't vaccinated. Maybe they don't have access to vaccines, and it is cheap, and it is safe. So what is the position on that?

Dr. COLLINS. That is another great question. Yes, there are a number of studies on ivermectin. They don't all agree. There are certainly people who are very enthusiastic about this, and others who are quite skeptical. There is a recent pretty large study published in Colombia, South America, where ivermectin has been used a lot. It was quite disappointing and didn't show benefit for people right after they got diagnosed to keep them out of the hospital, but we are really intensely interested.

We just announced last week a new trial which is called ACTIV–6, which means it is the sixth one of this partnership we have with industry that is specifically aimed to test oral agents that you can give to people right after their test turns positive with exactly the goals that you just outlined.

Ivermectin is a very high-level candidate to get into that trial in the very near future. So we are interested in getting a really rigorous look at this. Unfortunately, there have been other disappointments. We need to really find out exactly what the answer is before we begin to advocate for it, but it is a potentially promising lead.

Mr. DOYLE. Great. Thank you.

Madam Chair, thank you so much. I appreciate your indulgence.

Ms. ESHOO. Absolutely, Mr. Doyle. And it is wonderful to hear that you are working with my constituent at Stanford.

And, Dr. Collins, I am worried about what is buried in that big pile that you have to read. I hope that you have some assistance with that because, if there are real kernels of gold in there, we want you to get to them sooner rather than later.

We have Congresswoman Kathleen Rice. She is the last to question this panel, and she has been with us since before we gaveled in the hearing this morning. New member of the committee, an-

other Member that is value added, and you are recognized for 5 minutes. You may be last, but you are not the least.

Miss RICE. Thank you so much, Madam Chairwoman.

And thank you too for allowing me to waive on for this hearing. I would like to thank Dr. Collins and Dr. Brooks for all the work that you have done leading our public health agencies throughout this pandemic and for your ongoing, clearly, your Herculean efforts to understand this disease and its long-term effects.

Dr. Brooks, I have some questions about the MMWR regarding the study of long-COVID care that CDC conducted with Kaiser Permanente in Georgia. Can you share with us what—and forgive me, I had to mute a couple of times so I didn't hear if this question was asked, but can you share with us what CDC learned from the partnership with Kaiser and what might be some of the limitations of the study and what are some of the limitations, in general, regarding long-COVID research?

Dr. BROOKS. Thank you so much for that question. Yes, actually, no one did actually address exactly that question before, so I am really happy to share with you and appreciate the opportunity.

This is a study that CDC conducted with Kaiser Permanente Georgia. If folks aren't aware, that is a big HMO here in the State of Georgia. The main findings from the study were this: Following people who are outpatients only, never admitted to the hospital, right—so these were people who probably had COVID they could manage outside of the medical care of a hospital or an ICU—of these persons, during the 1 month to 6 months after their COVID diagnosis, about 68 percent sought care for some condition.

Now that alone is sort of a striking figure because imagine how many people after a head cold, pneumonia, influenza seek additional care a month later. I can tell you from my clinical experience, this is quite unusual. So that is a high burden. In addition, among all of those people out of that total that began, about 38 percent sought care with a specialist that might be working on a body system that has been affected by COVID. So someone like a cardiologist, a pulmonologist or rehabilitation doctor, a doctor who deals with joint pain or body pain.

That was the first important finding. The second was that there wasn't a—that it was evenly distributed pretty much across different groups. One of the nice things about the study, though, is we were able to enroll a pretty hefty number of African Americans and Hispanics, representative of their prevalence here in the State of Georgia, and that is probably because this HMO is one that is accessible to so many of our citizens here.

Some of the limitations here are very important. First, when you are using electronic medical records, you are having to make a lot of inference about the data that you are finding because you are not able to speak to the people that sought care or talk to the doctors about, "Why did I record that finding in the paper?" So understanding the patient's journey is something that is not able to be gathered from this kind of research, but what it does tell us is that we are seeing patterns that are worrisome that a number of—a large number of people who, after they recover from outpatient COVID, so not needing to be in the hospital, are seeking care, and that is not like other infectious diseases of the same kind.

Miss RICE. Wow. So I think I have time for one more question, Dr. Brooks. As the data from the research hospitals in your own MMWR seem to suggest a higher prevalence of long COVID among women and non-Hispanic/Black individuals who were not hospitalized, that group who were never hospitalized for COVID. I mean, while it is obviously still early in the total understanding of the disease, can you speak to how the data we had is informing your guidance to clinicians as well as patients?

Dr. BROOKS. Right. One of the first lessons is, when a woman tells you she has a problem, listen.

Miss RICE. That is a novel theory.

Dr. BROOKS. I mean, I know some of the people on this panel have probably and in Washington today had the experience of not having their complaint taken seriously. It happens to men too, it happens to everyone. But I think this is something that we need as a clinical and public health community to pay attention to.

Second, it is a little hard for us to disentangle this time whether the excess burden, if you will, of what we are calling long COVID per that paper is something that is driven by gender or race/ethnicity or if it is driven by the inequity in who is getting COVID to begin with. And so——

Miss RICE. Can I ask you, Dr. Brooks, how is the CDC ensuring that the research takes into account health equity?

Dr. BROOKS. Right. That is one of the ways we do it is, in this study, we can only look at the records of patients who sought care. So there wasn't much—what we do in many of our other studies, particularly cohort studies where we can control sort of who is enrolled, is we try to overenroll underrepresented groups to ensure that they are present in enough numbers that we can make valid research findings from that important population.

And, in fact, some of our cohort studies now of the eight we have running, there is one focused on the Alaskan Natives and American Indians. Others are overenrolling African Americans and Hispanics, and we look forward to being able to continue doing that.

Miss RICE. Thank you, Doctor.

And thank you, Madam Chair.

Ms. ESHOO. The gentlewoman yields back.

Well, I can't—on behalf of all of the members of the subcommittee and the Members that have waived on from the full committee, all of our thanks to you, Dr. Collins and Dr. Brooks. This has been 3½ hours of testimony and answering questions. I think that we have all learned a great deal from you. We also—I think it has deepened and broadened our knowledge that we have a long pathway in order to fully address long COVID.

I also want to highlight the intense interest of the members of the subcommittee participating in this hearing. We have outstanding Members on both sides of the aisle who care deeply about this, and this is a nonpartisan issue. So it calls for bipartisan approaches. We will continue to work with you. We ask you to reach out to us when you see bumps in the road where we can assist, but for sure we know, according to the statistics, with 32 million infected by the virus and roughly 10 percent having long COVID, we have a population in the country that we need to put our arms

around and make sure—and make sure—that we bring answers and care to them that is designed for exactly what this is.

So we all thank you very, very much. You are absolutely terrific. You are a source of pride to all of us, as more than one Member has said, the American people listening in and hearing and understanding your extraordinary commitment to the people of our country. I can't think of anything that is as beautiful as that. So we are lastingly grateful to you. And just think, you are finished with us for today.

So you get to stretch your legs and hopefully have a good late lunch.

Now, we are going to move on to our second panel of witnesses, all distinguished—thank you, Dr. Brooks. I am so glad that you participated. Thank you, dear Francis.

Dr. COLLINS. Thank you so much, Madam Chair.

Dr. BROOKS. Thanks for your attention.

Ms. ESHOO. Absolutely. Absolutely.

So now we are going to start with our second panel. The first three witnesses that I want to introduce are all long-COVID patients. So they are not going to get into studies, they are going to tell us about their day-to-day experiences.

First, Natalie—is it "Ha-KAH-la" or "HAH-ka-la"?

Ms. HAKALA. It's "HAH-ka-la."

Ms. ESHOO. Beautiful name. Natalie is a long-COVID patient from Eugene, Oregon. She was a collegiate track star, and her struggle with long COVID has been covered by HBO's "Real Sports with Bryant Gumbel."

Thank you, Natalie, for joining us and making yourself available to the committee.

The next patient, Chimere Smith, she also is a long-COVID patient and a consultant for urban communities from Baltimore, Maryland. Welcome to you, and thank you for responding to our invitation to be a witness today.

And Ms. Lisa McCorkell, also a long-COVID patient and a contributor to the Patient-Led Research Collaborative. Thank you to you for accepting our invitation to testify today.

And two really distinguished physicians. Dr. Jennifer Possick, she is the director of the post-COVID recovery program at the Winchester Center for Lung Disease at the Yale-New Haven Hospital. Welcome to you. And thank you.

And, last but certainly not least, Dr. Steven Deeks. He is the professor of medicine at the University of California, San Francisco, one of the great research institutions in our Nation, and he is the lead scientist for the Long-term Impact of Infection with Novel Coronavirus study, and that is referred to as LIINC, I believe. So, welcome to each one of you.

Ms. Hakala, I am going to call on you first. You are recognized for 5 minutes for your testimony. And, again, we are very grateful to you and also for your patience, because this has been and continues to be a long day, but so worthwhile for all of us. So thank you, and you are on.

STATEMENTS OF NATALIE HAKALA, COLLEGIATE MIDDLE-DISTANCE RUNNER AND LONG COVID PATIENT, EUGENE, OR; CHIMERE L. SMITH, LONG COVID PATIENT, BALTIMORE, MD; LISA MCCORKELL, TEAM LEAD AND RESEARCHER, PATIENT-LED RESEARCH COLLABORATIVE, OAKLAND, CA; JENNIFER D. POSSICK, M.D., ASSOCIATE PROFESSOR, PULMONARY, CRITICAL CARE AND SLEEP MEDICINE, AND MEDICAL DIRECTOR, WINCHESTER CENTER FOR LUNG DISEASE, YALE–NEW HAVEN HOSPITAL; AND STEVEN DEEKS, M.D., PROFESSOR OF MEDICINE, UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

STATEMENT OF NATALIE HAKALA

Ms. HAKALA. OK. Thank you.

So, as was stated, I was a collegiate runner at a D2 College. I got COVID July 4, 2020, and the first 2 weeks were very, very mild. I just lost my taste and smell. I had a fever for a couple days. My fever broke, and I was feeling, I thought, normal immediately following my 2 weeks of quarantine.

Then, following my 2 weeks of quarantine, I began developing chest pain, shortness of breath, difficulty breathing. I had to take—I had severe fatigue building up. Each week got worse and worse. By the end of July, I discovered that I had pneumonia because I went to my primary care provider, and it was shown that I had some slight indications that it may be pneumonia in my lungs.

So they put me on an inhaler, some other medications to help with that, some as-needed pain medications to help with the chest pain I was having. During this time, I was still trying to work, only half days. Going into August, I went to urgent care once. Everything came back completely normal, so I was sent home.

A couple weeks later, I went back, again, with severe chest pain, unable to breathe, could not get comfortable. Went into urgent care, and this time my oxygen saturation dropped to low 80s. You are typically supposed to have 95, so this was concerning to them. So they admitted me to the hospital, and I stayed there for a few days. They ran a bunch of tests.

I had a cardiologist look at me, a pulmonologist, an internal medicine specialist. I think those were all the doctors that looked at me, and most of my tests came back completely normal. Nothing was really showing anything abnormal, but because my oxygen saturation came back up, they sent me home, and they had placed me on a couple of different meds to kind of help with pain. And, hopefully, you lower some of the inflammation factors that were happening throughout my body. They were just assuming what was occurring.

And the rest of August I did not work. I stayed home on the couch completely bedridden. I was unable to make breakfast. My big activity for the day was taking a shower.

Throughout September, it was very, very similar if not worse. I would not be able to have a conversation like I am right now. I would be stopping every other word to catch my breath. And in September is when I got my cardiac MRI, which showed inflammation around my heart, and when I was diagnosed with pericarditis. I had pleurisy, costochondritis, and just overall inflammation they

were assuming was happening, especially around my chest wall because it was difficult to take deep breaths. I started cardiac rehab in October, and that was—I was only able to go for like 8 minutes, I believe, on a treadmill at a very, very slow pace. I still—I barely started watching TV because tracking things on a screen was too difficult. It gave me severe headaches, and I was just too exhausted.

By November, I was watching TV again. By December, I was able to read a book. I couldn't remember a lot of what happened in books. So I had to reread stuff multiple times just to grasp what was going on. In January, by the end of January, is when I got my vaccine. That first week was very uncomfortable for me. I felt like I was back in September, and I did my very first jogging in January as well. I jogged for 2 minutes, and that was the farthest I could go at a very slow pace.

Then in February is when I got my second dose of my vaccine. Same reaction as the first one, a whole week of discomfort, difficulty breathing again, increased chest pains, more headaches, more fatigue. And I was still very uncomfortable following that. About 2 weeks after my vaccine is when I started to notice that I felt like I was going back to how I was in mid-January, and I was able to start jogging again in February. I actually started help coaching. So I am coaching a track and field team. So I am able to stand for a couple hours a day now, and currently I am able to jog for 15 minutes is the most I can go at like about a 10-minute-mile pace, which compared to my previous self, I would normally run an easy run at 8-minute pace. So I am still a little ways off, but definitely improving.

My energy has improved a little bit. I am definitely able to focus for a lot longer amounts of time now, but I am still unable to work my full job that I previously was working before I got sick. So that is kind of where I am at now, and I think that is everything.

[The prepared statement of Ms. Hakalah follows:]

Testimony of Natalie Hakala
Collegiate Middle Distance Runner and Long COVID Patient
House Committee on Energy & Commerce- Subcommittee on Health
April 28, 2021

On July 4th, 2020, I was diagnosed with Covid-19 after spending a weekend camping with my friends. The day I got tested, I had a slight headache and a tingling feeling on my skin when it would touch things. It was aggravated by activities such as leaning back in my chair or the brush of my T-shirt. The following day I had a more intense headache directly behind my eyes, making it difficult to focus.

Not only were there these intense physical symptoms, but the emotional toll was one I was not prepared for. There was the initial fear of being a Covid patient and how my community would view me. I was mainly scared about what that would mean for my family. I was terrified of infecting them. The entire two weeks, I was sick; I was outside and far away from my family. I used one bathroom that I cleaned after and was only in my bedroom to sleep. I had gloves and a mask on at all times inside, and I did not touch anything. My whole goal was to limit the exposure to my family. I had an air mattress outdoors where I would take naps and a small table to eat on apart from my family. I used paper plates and plastic utensils so nobody had to touch what I had touched. Outside and far away was the only place I felt comfortable enough to relax without the fear of accidentally infecting my family. I was so worried because my younger brother and mom have ulcerative colitis, and my parents are both over 50. I knew I would be okay because all I had heard was that you are sick for two weeks, and it does not affect the young and healthy as negatively as it does the older and those with comorbidities.

As the first week continued, I lost my sense of smell, and my taste shortly followed. I still had a very consistent headache and weird tingly feelings on my skin. By the end of the first week, I began having body aches, and a day later, my fever began. This fever did not feel like a usual fever from the flu would feel; it was all-encompassing it felt like my veins were on fire. This is when I truly began to understand how deadly Covid could truly be, especially if it was someone who was not as young, healthy, and in shape as I was. I remember clearly thinking, "thank goodness this happened to me and not my parents or brothers or grandparents," because I was the one who had no health issues. My fever continued to melt me from the inside out as I was hot and cold all at once. It lasted for four days, and on the last night with a fever, it was so challenging to sleep comfortably. Once it was broken, I only had a few days left of quarantine, and my taste and smell were returning, so I thought the worst of my trials were over.

To understand how disabled I become, you need to know where I was. One year prior, I started my senior year of college in the best shape of my life. That cross country season, I got a personal record (pr) in the 5k and 6k races and finished in the top 5 for my team—something I had never accomplished in all my years of college due to various hip injuries. I was running 40 miles a week with 5-10 hours of cross-training (biking or swimming) to help take the impact of mileage off my body. Starting my track season in the spring, I consistently got prs in practice for

the 200 and 400 meters. I was the fastest 800 middle distance runner my D2 college had. I had goals to finish at the top of my Conference and qualify for Nationals. When my season was canceled, I continued training and continued to work out. I dropped my mileage from 40 miles to around 25-30 miles a week once I started working in the summer following my virtual graduation. I got a job at a local orthopedic center where I was a cast technician. I would run 4 miles before work and then help with casting patients until around 5 pm. My casting job required me to hold up legs while a team member placed the casting material, or I did the wrapping of the cast material. I would remove casts and splits and sometimes place splints. I would go up and downstairs to get to the different casting rooms and make the beds for patients. Once I was diagnosed with Covid, I took time off from work and received Covid pay for the two weeks I had off.

After I was out of quarantine, I was very excited to leave my house and go for an easy jog around my neighborhood. I had planned to do an easy two miles; I made it 200 meters before I was gasping for air and felt my heart beating out of my chest. I knew something was wrong, so I walked home and tried to get my breath back and my heart rate under control. I brushed it off as just not having moved for the last two weeks and being overly tired.

As the week went on, I tried to return to work and could only do half days because I was so exhausted. I found myself getting out of breath more and more frequently. At work, I found it challenging to go up and downstairs. I had to take more breaks than I used to, and thankfully my work was more than accommodating with me. During my lunch breaks, I was taking naps, and as soon as I returned home, I had to lay down and sleep for at least 30 minutes. On July 31st, I scheduled a primary care visit because I knew something was not right. I was diagnosed with pneumonia and was given a variety of medications to help with that. The following Monday, I went back to work.

On August 6th, I got home from work and just laid down on the couch. I found it very difficult to breathe and felt as if there was something just sitting on my chest. While at work that day, I was casting a patient's arm and was barely able to finish because I felt like I could not breathe. My mom came home, saw me struggling to breathe, and decided to go to the emergency room. I got looked at by doctors with lots of tests being done, but every test came back normal. I was sent home since they did not know what was wrong with me.

I called out of work the next day, and I have not returned since. I spent most of my days sleeping, and I was having difficulty walking across my kitchen to get myself a glass of water. I was at my PCP (primary care provider) again and received some pain medications to help with the sharp pains I was having in my chest.

On the morning of August 16th, I woke up at 4:00 am with severe chest pains, and I tried everything I could to make it go away, and nothing was working. By 6:00 am, I went and woke up my mom to have her take me to the hospital. Once again, all of my tests were coming back normal. But this time, my oxygen saturation was in the low 80s, and my white blood cell count was slightly elevated, so they admitted me for observation. They ran some more tests to look at

my lungs and heart, and everything was still looking completely normal. I was still testing positive for covid, so I was placed in the covid wing, where all of the people there were still contagious even though I was out of my infectious phase. Many of the doctors did not want to come into the room to talk with me; most of the visits were over the phone or very brief conversations because they did not want to be in the same room as me. Luckily, they let my mom stay with me, and since she is a Physician Assistant, she was able to advocate for me about which medications may be helpful.
While in the hospital, we noticed how my heart rate would change rapidly and respond inappropriately to the stimulus, demonstrating signs of tachycardia. For example, I would be lying down in my bed, and my heart rate would be around 70 beats per minute, where usually my heart rate would be in the 60s because I was in such good shape from running. Then I would sit up, and my heart rate would increase to 90s. I would get to a standing position, and it would again jump into the 120s. Walking the three to four steps to the bathroom would have my heart rate anywhere from 130 to 150 depending on how long I was standing for. Due to this, my mom advocated for me to be put on a beta-blocker and a heart anti-inflammatory. I started metoprolol and colchicine even though the cardiologist never came into my room and listened to my heart.

I was discharged from the hospital on August 19th because they could not diagnose me, and my oxygen saturation was back up to 97 while walking slowly. I spent the next few weeks just lying on the couch and listening to the tv because watching it made my headache much worse. I had to have my brothers make and bring me meals because I was too exhausted to do that small amount of movement. I had more appointments throughout August and September, but it did not feel like any real change was being done because the doctors did not know what to do to help me other than try and manage my symptoms.

On September 29th, I had a cardiac MRI where it showed fluid around my heart. I was diagnosed with pericarditis, costochondritis, pericardial effusions, and some pleurisy. I was still having difficulty breathing and moving around my house. Doing small acts of daily living was extremely challenging; sometimes, just taking a shower felt like too much work because raising my arms and washing my hair was too exhausting for me. I was still having stabbing chest pains, and when those weren't present, I had a dull ache throughout my chest, and taking deep breaths was very uncomfortable.

In October, I finally got a wheelchair to help me move around, so I wasn't always in my house. My mom pushed for me to start cardiac rehab to help get me up and moving around more, hopefully. It would also allow my cardiologists to see my heart while I was moving. By the end of October, I was able to watch a little tv without a severe headache. Still, I found myself only able to re-watch shows because following a plotline I did not know was too much for me to keep track of, and I found myself both exhausted and forgetting what happened right before in the show.

My first cardiac rehab appointment was on October 27th, and I was able to walk for 8 minutes, but at the 4-minute mark, my oxygen saturation was at 84%. It went back up to 97% after a

minute of a break. During the walk, I had shortness of breath, achy chest pain, and sharp pains throughout my rib cage. These symptoms continued after exercise. I continue to go to cardiac rehab once a week.

I was slowly improving because I could make my small breakfast in November and get up to get my water. I could watch an entire tv show without a severe headache, but I was still noticing the brain fog. I was forgetting words frequently and could not remember what I was doing mid-activity. I would become confused as to why I was standing in the kitchen when I had walked in there to get water. I still had chest pain and had to sit down and take frequent breaks. Showering was still the one big activity for the day, and I would often have to sit down and catch my breath afterward while I waited for my heart rate to calm down and for my breath to return. At cardiac rehab, I was able to walk for 10-15 minutes, and I would occasionally drop my oxygen, but it was becoming less frequent.

In December, I made much more significant improvements. I walked for 30 minutes at cardiac rehab without feeling incredibly out of breath and was not lying on the couch all day after a big day of movement. I still had sharp pains and chest aches, but I could take deeper breaths, and breathing felt more manageable. I was able to read for the first time in December; granted, it was only books I had previously read, and I had to reread pages and sentences a lot of the time because I would forget what I just read or what was happening. But I was able to do it, and that was a very exciting thing for me.

January is when I started working an online job where I only had to work for 5-10 hours a week, and through this health care company, I got my covid vaccination. I tried slow jogging in January. It was something I could do, but the next day I was still having an increase in chest pains and feeling overly exhausted. I still had fatigue and found myself very exhausted after doing too much movement. I started wearing compression socks to help my blood circulation because I found my feet and hands extremely cold and occasionally blueish-looking. When I wore my compression socks or leggings, I felt much better fatigue-wise and found it easier to be standing for more extended periods of time. I got my vaccination at the end of January, and I was on the couch like I was in September for the entire week following my shot.

This same type of reaction occurred after my second shot in February. After receiving my vaccination and recovering from the shot, I made much more extensive improvements. My energy was slowly returning, and I did not use my wheelchair at all anymore. I was able to walk for 60 minutes by the end of March. I was slow running for a max of 2-minute intervals, which I did for a maximum of 5 times by the end of March as well. I could do a spin bike workout for 30 minutes. I felt like I was returning to my old self just because I could finally do a small workout.

Currently, I can run for a maximum of 15 minutes continuously. I can read new books, and I have started taking two new classes at my local community college. I am unable to focus on my homework for long periods and still find myself getting exhausted and having chest pains; if I do too much movement. Sometimes a headache will follow a stretch of too much thinking and focusing. My brain fog seems to be improving the more I use my brain, but it took a very long

time for me to use it like I used to. I still find quick thinking challenging, and my reaction times are significantly slowed, which can be seen on my Sunday tennis drills with my family. They play slower for me so I can try and get my left-right brain moving once again. I have not been able to return to my previous cast technician job because that would be too much movement for me at this time.

I am very fortunate that I have improved, but that would not have happened had I not had the time and space to truly rest my body and allow it to recover at the pace it needed. I have seen other Long Haulers try to push themselves too early in the process, and they end up in more pain than when they started. I am also very fortunate to still be on my parents' insurance. As a recent college graduate, I do not have the funds to pay for all my medical bills that occurred from my hospital stay, many appointments, and frequent testing for my heart and lungs. I am very supported by my family, and I would not like to think about what would have happened had I not had their support. I am currently living at home, unable to work more than 5-10 hours a week. Granted, I am helping out with coaching a team and taking two online classes, but that still does not amount to a full-time job. Had I not been at home during this difficult time, I would not be recovering the way I am. I would be in massive amounts of debt, unable to work to pay the medical bills, along with being unable to pay for food and housing. I am also very fortunate because I had people who believed me when I said I was not feeling well. All my doctors and family members listened and understood that something was not right with me. Not everyone has that type of support from their caregiving team, and I am fortunate to have had people in my corner helping make sure I got what I needed and when.

Thank you for listening to my story.

Ms. ESHOO. Well, thank you very much. That is quite a journey from the Fourth of July in 2020 you said——

Ms. HAKALA. Yes.

Ms. ESHOO [continuing]. To the present. Thank you very, very much. We appreciate your testimony.

The Chair now recognizes Ms. Smith. You are recognized for 5 minutes. And you may begin. Welcome and thank you, again, for accepting our invitation to testify.

You need to unmute.

You need to unmute.

Ms. SMITH. Thank you.

Ms. ESHOO. There you go. You are recognized. Thank you. Glad you unmuted. We need to hear you.

STATEMENT OF CHIMERE L. SMITH

Ms. SMITH. Thank you so much for the opportunity to speak. I am sorry. I am getting my screen together. I apologize. Thank you.

I asked myself if I was nervous about being here, and I thought to myself that if I could spend 5 days a week for 5 years teaching brilliant, temperamental middle school students in Baltimore, I could do anything.

I know that you are a tough crowd, but those students made me even tougher.

I want to make it clear that I am no different than most of the people you know with long COVID, but there is a distinction. I am a Black—I am Black living with long COVID. I am a Black woman living with long COVID. You may not be able to tell, but I am a Black disabled woman living with long COVID, and I am now a poor, Black, disabled woman living with long COVID. Saying it aloud makes it no more easier to accept.

Long COVID is not just a White woman's condition no matter the picture our media tries to paint initially. I am not alone. Before we knew long COVID existed, there were many Black women who suffered with chronic conditions that went ignored or misdiagnosed. I don't know where these women are today because they have been shunned from medicine and forced into silence.

I was not raised to tell my personal business. Like many people, I was taught to be seen and not heard, that what goes on in my house stays in my house. Yet had I lived by those deeply imbedded mantras, I would not be sitting here before you today.

I knew who I spoke for when I shared these experiences with the NIH, and I know why I am here today. I am among Black women who are now unemployed, homeless, and depressed with broken bodies. Over the last year, Black women lost more jobs than any other race. That means our medical bills, rent, and utilities while struggling with this condition have been neglected.

If I did not have a loving family, I would be speaking to you today from my car, the only property I now own. Our circumstances may not seem different than others, but what diverges our path is we were already disadvantaged and abused by medicine, science, and government.

I was already poor during my childhood. I taught students in the 'hood who were already receiving inadequate and substandard healthcare. We have already been where COVID is threatening to

take people with privilege, power, and status. We are not new to this. Sadly, we are true to this. We have just been waiting and hoping for compassionate doctors and politicians who would acknowledge us.

Long COVID is another weight to what Black people have already been carrying. It just has another name. If you are wondering why Black people won't speak out, they fear they may end up like me. I lost my vision for 5 months because doctors ignored my dense cataract from COVID and called it a dry eye. They may end up with false negative tests, being gaslit into believing they never had COVID or like Leiah Jones from Charlotte, North Carolina, who wrote her own obituary before dying from long-COVID complications.

No one wants to hear that long COVID has decimated my life or the lives of other Black women. In less than a year, it has made me forgetful, unreliable, unemployed, nervous, with severe body aches and pains. It has destroyed our brains, the most beautiful parts of us.

I was an excellent teacher. Now, I wouldn't trust my memory or brain function with any child right now. Would you? However, I am proud of how relentless and angry I became to save my own life, and we are in desperate need of money, swift, sufficient disability policies and benefits, comprehensive educational and employment guidance that recognizes our condition, and accommodations that welcome us into research studies without conventional restrictions.

It is imperative that we create equitable research standards and practices to capture current and innovative data that focuses on Black people with long COVID. I was recently rejected three times for an important NIH study. That alone is a travesty. There are currently no studies reported that specifically focus on Black people with long COVID. Also, as there is a growing evidence of the direct connection between ME and CSF in long COVID, we must reconcile that there are millions of Black people who have already disappeared from our society. We should be funding studies that find and treat ME patients.

We need medical care that reflects equitable, cost-effective, safe, and timely education and treatment. We have recently learned from the CDC that Black people venture to their doctors for care up to 6 months after their acute COVID illness. This information is extremely telling because historically we know that Black people don't like to go to the doctor's. But now spending the last year as a poor, Black, disabled woman with long COVID, I no longer need to wonder why.

Post-COVID clinics cannot do this work alone in urban communities. I am working to create a hub for Black long-COVID patients using my church building to provide free mental health and other medical resources to support patients, their families, and caretakers, but I need funding opportunities to continue doing this work.

I am a poor, Black, disabled woman living with long COVID trying to make and be the difference.

Thank you.

[The prepared statement of Ms. Smith follows:]

Written Statement of Chimere L. Smith
Long Covid Patient Advocate for Urban Communities
Before the Subcommittee on Health
Congress of the United States
House of Representatives

Chairwoman Eshoo and Members of the Subcommittee, thank you for the opportunity to appear before you today to represent Long Covid patients — specifically black patients in urban communities. I would like to provide you an overview of my experience with Long Covid over the last year, key accomplishments of my advocacy, and the important factors we must consider as we seek to study, treat, and fight Long Covid in underserved communities.

I am not much different than many of the people who have shared their experiences living with Long Covid.

I was denied testing the first two weeks of my symptoms.

I was told over a dozen times that I never had COVID.

I tested negative for the virus and its antibodies.

The difference and challenge I face is that I am a black woman who carries the weight of other black women who have — with different but no less traumatic conditions — been left misdiagnosed, humiliated, and frightened.

Before March 2020, I can recall haphazardly listening to stories from black mothers, sisters, friends, and cousins, thinking my blue and white insurance card would absolve me from it all. From intracranial hypertension to endometriosis to cancer to arthritis to neurological diseases, these women would share with me tales of our country leaving a trail of untreated and forgotten women in hospital rooms and doctors' offices.

Over the last year, I sadly learned that even with a respectable career as a middle school English teacher, money in the bank, and a giving heart, I am still a black woman in America who doesn't know enough words to convince doctors and medical staff to take my bout with Long Covid seriously.

I have become one of the many black women I know.

Even while doing everything right, in a year, my life has become reminiscent of the little girl I tried to shed: I am once again poor, on the verge of losing my health insurance. If I didn't have a loving family, I would be living in my car — now the only possession I truly own.

Following every rule elders ever taught me about how to receive medical treatment as a black woman didn't serve me well during five horrific months without my vision as Covid caused a dense cataract to form in my left eye. Doctors shrugged it off as "dry eyes" each time I stumbled into their offices or tried to send photos of my condition. At one of the most prominent hospitals

in Baltimore, doctors refused to document my laundry list of symptoms but conferred with each other about how to convince me to enter their psychiatric ward for more evaluative mental health care.

I have spent all of my savings. I am unable to return to work. I have developed occipital neuralgia, which causes my head to feel swollen and frozen, and a misaligned spine. I am often bedbound due to fibromyalgia. My cognitive and memory functions have declined at frightening rates. As I type this, I am in awe that I am able to put these sentences together.

I have become another black disabled woman in America.

I am now a black woman with Long Covid.

I was racially profiled for complaining of a burning brain, witnessed white men receive preferential treatment while I waited for hospital staff to acknowledge me, and had to hire a patient advocate for surgeons to take my eye condition seriously.

As one would imagine, I am not eager to return to any hospital for fear of being dismissed again. However, during one of my last visits, I gained clarity on two things: I had to challenge the systemic racism I blatantly saw happening in healthcare — and now in medicine. And I would use my experience to speak to and for black, disabled women in urban communities in America with Long Covid -- millions of them I will never know or meet.

It is painfully clear that science, medicine, and research is not designed to consider the plights of black people beyond noting certain buzzwords — *underserved* and *inequities* — for notoriety.

Recently, I found encouragement in Vice President Harris' request for urgent action in black women's maternal health issues. She also noted that Covid-19 has "exacerbated racial inequities in health care." In one of the highest offices in our country, a government official has publicly acknowledged what so many of us have known for decades -- and what I had to learn in the most painful way.

It is my mission to aid government officials, researchers, and doctors in meaningful, integrous methods to include and engage black people with Long Covid in urban communities. My fear is that we've spent far too much time tracking hospitalizations and deaths, while those of us with Long Covid are suffering in silence.

And if black women have lost jobs at a greater rate than any other race over the last year, it is my hope that government and medicine act quickly as Long Covid has proven to be a crippling, disabling condition that will undoubtedly harm millions of families — especially in low-income communities, like Baltimore, which are already devastated and ravished by the effects of Covid-19.

Last December, I was proud to contribute my experiences with Long and its impact on my community with the NIH. Shortly thereafter, Congress provided $1.15 billion to the agency to study Long Covid.

I urge you to continue to impress upon the CDC and NIH that it is imperative that we create equitable research standards and practices to capture current, innovative data that focuses on black people living with Long Covid, and medical care that reflects equitable, safe, and timely education and treatment. Currently, there are no controlled studies solely focusing on the very people who have been hardest hit by Covid the most — besides American Indians and Indigenous populations. While it is impossible for me to report on any scientific data that reflects this, if my social media and email inboxes are any indication of the perils we face by not moving with urgency to study and treat black people with Long Covid, we have already reached the danger zone.

As board members of both the Body Politic Covid-19 Support Group and Long Covid Alliance, I have the unique opportunity to design and support efforts to engage and educate black patients, stakeholders, doctors, and scientists who wish to study and learn about Long Covid. But this is not enough. We are in desperate need of swifter, more succinct disability policies, comprehensive educational and employment guidance that recognizes our condition, and accommodations that welcome us into research studies without conventional restrictions. Also, as there is growing evidence of the direct connection between myalgic encephalomyelitis and Long Covid, we must reconcile that our unwillingness to recognize chronic conditions we can't visibly see has contributed to generations of black people who have already disappeared from society.

I often reflect on what may have happened to me had I not been angry enough to fight for my life and the lives of so many others. As a teacher in Baltimore, I learned early in my career that it was my duty to advocate for the equitable treatment of my students. There was nothing I wouldn't do to assure my "middle school babies" had the best of everything — textbooks, field trips, and social-emotional care. I wasn't afraid to speak up for them because I understood that sometimes this country does not. And I'm not afraid to speak up for them now. Losing my career has been devastating: I speak to you as an award-winning educator who planned to serve Baltimore students in an instructional leadership capacity far longer than five years. I wanted to inspire other educators to impart equitable, radical education to black students. However, what I strived for in education mirrors what I advocate for every day for black people with Long Covid.

I carry a heavy weight. I speak now so I am not just *another* disabled black woman in America carrying the sorrow, humiliation, and pain of this and other conditions on my shoulders. I speak now so my former students can access comprehensive education and treatment for Long Covid years after this is no longer a trending topic. I am now structuring a plan to use my church building and organization as a hub for black patients and their caretakers to receive Long Covid education and mental health treatment in Baltimore. Yes, I will need local, state, and federal funding. No, I don't have skills to write grants or ask for said funding. But I understand that even with a disability, in the words of Pastor Michael Todd, of Transformation Church, in Tulsa Oklahoma, "all I have is all I need."

Had my voice not gotten loud enough, I may not be talking to you today. And if I can assure that the next wave of black people with Long Covid receive better treatment and care — far better than Leiah Jones, who recently died of Long Covid, received — then the benefits of sharing my story as often as I can far outweigh the comforts of staying silent.

Thank you for your time and consideration.

Respectfully,

Chimére L. Smith
Patient Advocate and Consultant for Black Long Covid Patients in Urban Communities
www.chimereladawn.com

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Ms. ESHOO. Thank you very much, Ms. Smith, for your really compelling testimony.

The Chair now recognizes Ms. McCorkell for 5 minutes for your testimony, and, again, we all thank you for accepting our invitation to be a witness today. You probably didn't realize that you were signing up for an entire day, but all of our thanks.

You are now recognized.

STATEMENT OF LISA MCCORKELL

Ms. MCCORKELL. Good afternoon, Chairwoman Eshoo, Ranking Member Guthrie, and members of the subcommittee. I appreciate the opportunity to speak to the long-COVID experience and to shed light on the barriers that patients face that you have the power to do something about. I am testifying today as a long-COVID patient and as a member of the leadership team of the Patient-Led Research Collaborative, a group of long-COVID patients with backgrounds in research, policy, and data analysis who were the first to conduct research on long COVID.

My symptoms began on March 14, 2020. Like many of what we call first-wavers, I was not afforded a COVID test because at the time tests were limited to hospitalized patients and those with shortness of breath, cough, and fever, the last of which I didn't have. I was told by a doctor to isolate and, within 2 weeks, I would be recovered.

A month later, I was in worse health than in that initial stage. I couldn't walk more than 20 seconds without having trouble breathing, my heart racing, and being unable to get out of bed the rest of the day. My story is not unique, and this was evident when I joined the Body Politic support group last April and saw thousands of people who were also experiencing prolonged symptoms. Patient-Led Research Collaborative was born, and we conducted a survey of 640 patients documenting these symptoms and experiences. The result was the first study on long COVID and the first to document numerous neurological symptoms and extensive multiorgan impact of the illness. It was clear then, 1 year ago, that the death/recovery binary that COVID has been framed to be is simply not true.

Our research helped raise awareness of the illness and got the attention of CDC, NIH, and WHO. Our most recent survey asked about 205 symptoms over 7 months and received almost 7,000 responses. In our recent paper, 92 percent of respondents were not hospitalized but still experienced symptoms in 9 out of 10 organ systems on average. We found that patients in their seventh month of illness still experienced 14 symptoms on average. The most commonly reported were fatigue, post-exertional malaise, and cognitive dysfunction.

In fact, 88 percent experienced cognitive dysfunction and memory loss, impacting their ability to work, communicate, and drive. We found that this was as likely in 18-to-29-year-olds as those over 60. Lesser-known symptoms include tremors, reproductive changes, months-long fevers, and vertigo.

Over two-thirds require a reduced work schedule or cannot work at all due to their health condition; 86 percent experience relapses where exerting themselves physically or mentally can result in a

host of symptoms returning. Long COVID is complex, debilitating, and terrifying. But patients aren't just dealing with their symptoms. They are dealing with barriers to care, financial stability, and recovery. Due to the lack of a positive COVID test alone, patients are being denied access to post-COVID clinics, referral to specialists, health insurance coverage, COVID-related paid leave, worker's comp, disability benefits, workplace accommodations, and participation in research.

When we know that not everyone had access to COVID testing, that PCR test had a false and negative rate of 20 to 40 percent, that antibody tests are more accurate on men and people over 40, and that multiple studies have shown that there is no difference in symptoms between those with a positive test and those without, why are we preventing people who are dealing with real symptoms from accessing what they need to survive?

Even with a positive test, patients are still being denied benefits or have to wait months until they kick in. Medical bills are piling up. People are being forced to choose between providing for themselves and their family and doing what is best for their body. The toll that having inadequate paid leave, workplace protections, and benefits will take on our economic and healthcare systems over the next several decades is of a magnitude like we haven't seen before.

As COVID continues, more and more people are developing long COVID. Waiting lists for post-COVID clinics keep getting longer, and yet many clinicians continue to gaslight us and tell us that our symptoms are in our head. This is particularly true for people of color, women, and the LGBTQ community. I am both privileged in my financial stability and lucky that people with ME advised me early on to pace, which allowed me to continue working.

But I want to mention something. Those stimulus checks that you all provided us to get through the pandemic—I do really appreciate them, but every cent of mine was spent on urgent care and doctor's visits where I was repeatedly told that my tachycardia, my inability to exercise, and brain fog was caused by anxiety, and there was no way that I could have had COVID since I didn't have a positive test.

Post-viral illnesses are not new. The cracks in our system that long COVID has exposed are not new. It is just that now more people are paying attention. We are counting on you, members of the committee, to use the power your constituents gave you to address these issues head on, to listen to you and work alongside the disabled and chronically ill community to prevent more people from becoming ill.

I understand these are big challenges and big topics to address, but at this point there is no other option. Thank you so much for inviting me to speak to you today, and I look forward to answering your questions.

[The prepared statement of Ms. McCorkell follows:]

Hearing Before the United States Congress
The Long Haul: Forging a Path Through the Lingering Effects of COVID-19
House Committee on Energy and Commerce, Subcommittee on Health
April 28, 2021

The Long COVID Experience

Evidence from Patient-Led Research and the Patient Community

Lisa McCorkell, MPP
Team Lead and Researcher
Patient-Led Research Collaborative



Introduction

At least 21 percent of people who contract COVID-19 experience prolonged symptoms, spanning all organ systems and causing significant impacts to people's lives.[1] With over 31.8 million cases of COVID-19 reported in the United States, this translates to ***over 6.7 million people experiencing prolonged symptoms, referred to as Long COVID***.[2] While initial reports of COVID-19 warned of severe disease that could result in hospitalization or death, the outcome of Long COVID has proven that the pandemic is also a mass disabling event, the effects of which will be seen for decades.

The patient-preferred term for this illness is Long COVID.[3] We define Long COVID as continuing to experience symptoms after a confirmed or suspected SARS-CoV-2 infection for at least 28 days. Long COVID encompasses a group of conditions that patients face following acute infection, and may include organ damage, post-viral illnesses, reinfections of previously dormant viruses like Epstein-Barr virus, and more. Some patients may have one of these subsets of Long COVID, some may have all. It affects people of all ages, genders, races, and ethnicities across the country.

Patient-Led Research Collaborative (PLRC) is a group of Long COVID patients who were the first to conduct research on Long COVID. Our mission is to facilitate patient-led and patient-involved research, and to advocate on behalf of Long COVID patients. After our symptoms from a mild/moderate COVID-19 illness did not subside after several weeks, each of PLRC's co-founders joined the Body Politic COVID-19 Support Group.[4] PLRC was founded in April 2020 when the group of us recognized the need to aggregate all of the information people were sharing within the support group to understand what was happening to our bodies. PLRC has grown to now have over 30 contributors, with backgrounds in data analysis, neuroscience, public policy, participatory design, machine learning, and more.[5]

PLRC's primary form of research is conducting surveys of the Long COVID patient community. Our survey questions are developed from what the Long COVID patient community is asking and reporting. This ensures that the surveys capture the various Long COVID experiences. Patients have a more intimate understanding of an illness than any doctor or researcher who has not experienced it. This is reflective in the types of research questions patients ask and what patients want to be asked by doctors and researchers.

Over the last year, we have presented to the World Health Organization (WHO) and been part of their Long COVID working group, and have held ongoing meetings with the Centers for Disease Control and Prevention (CDC) Post-COVID Conditions Unit in partnership with Body Politic. Our research has been cited in and contributed to over 70 scientific publications, guidance for clinicians, and policy documents,[6] and been written about by the National Institutes of Health (NIH) Director Dr. Francis Collins.[7] We are also part of the Long COVID Alliance, a network of

patient-advocates, scientists, and disease experts whose aim is to educate policymakers and accelerate research into all infection-triggered illnesses.[8]

PLRC Research

Our first report, released on May 11, 2020, analyzed 640 responses of people who experienced prolonged symptoms from COVID-19.[9] The report documented the prevalence of non-respiratory symptoms, particularly neurological, many of which were not yet acknowledged by the medical community and major media outlets. Since the respondents who completed this survey became sick at a time when diagnostic testing for COVID-19 [such as polymerase chain reaction (PCR) and antigen] was widely inaccessible, nearly half of respondents (47.8 percent) were not tested (either denied or had no access to a test). Of those who were tested for COVID-19, the only differences between those who tested positive and those who tested negative was: (1) *when they were tested* (day 10 from original onset of symptoms on average for those who tested positive, day 16 for those who tested negative) and (2) those who tested positive were more likely to experience loss of smell and taste than those who tested negative. Only 28.5 percent of respondents felt very supported by medical staff, while 21.5 percent did not feel supported and 50 percent felt somewhat supported. This report was cited in some of the first media articles on Long COVID,[10] has been cited in academic journals,[6] and led to conversations with the WHO and CDC.

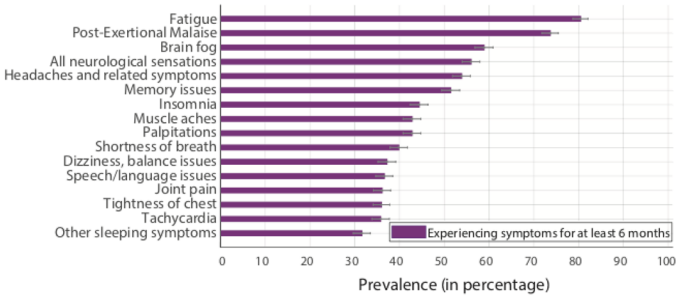
Our second report is awaiting journal acceptance, and was posted as preprint (not peer reviewed) on December 26, 2020. “Characterizing Long COVID in an International Cohort: 7 Months of Symptoms and Their Impact” analyzes responses from 3,762 participants ages 18 years or older with confirmed or suspected COVID-19, with illness duration of at least 28 days. 41.2 percent of respondents are residents of the United States.

Here are the key findings from our second report:

- Long COVID symptoms span all organ systems, with 205 symptoms documented.
- ***45.2 percent of respondents who had been working before getting COVID reported requiring a reduced work schedule compared to pre-illness, and 22.3 percent were not working at the time of survey due to their health conditions.***
- 91.6 percent of respondents were not hospitalized. (Some of these patients may have needed hospitalization but were not admitted due to overwhelmed hospitals. Most, however, had an initially mild or moderate COVID-19 illness.)
- ***The primary difference between respondents who tested positive and those who tested negative via a diagnostic COVID-19 test was when they were tested:*** those who tested positive were tested on day 6 of symptoms while those who tested negative were tested on day 43 of symptoms on average. Symptom prevalence and trajectory between the two groups were remarkably similar, with only loss of/changes to smell and taste showing a significant difference.

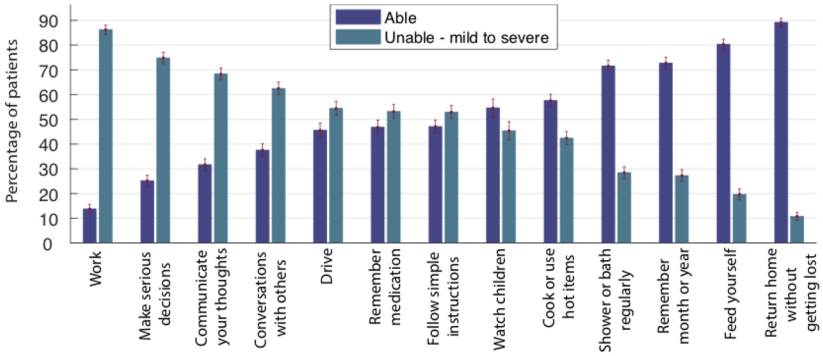
- The most common symptoms reported by patients were fatigue (reported by 98.3 percent of respondents), post-exertional malaise (89.1 percent), and cognitive dysfunction/brain fog (85.1 percent). Fatigue and cognitive dysfunction were also in the top three of the most debilitating symptoms reported by respondents, in addition to breathing issues. See Figure 1 for the most prevalent symptoms reported in respondents after month 6.

Figure 1: Most prevalent symptoms in respondents after month 6 of illness



- Of those who experienced memory issues and/or cognitive dysfunction, 86.2 percent felt mildly to severely unable to work, 85.3 percent were unable to make serious decisions, and 74.8 percent felt unable to communicate thoughts and needs (Figure 2).

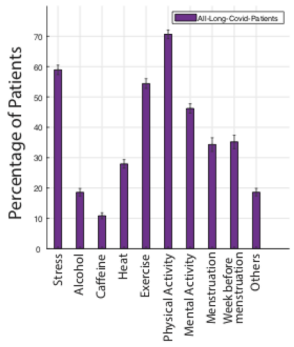
Figure 2: Impact of memory and cognitive dysfunction on daily life



- There was *no significant difference in memory issues, cognitive dysfunction, or impact on life by age*, meaning that the prevalence and impact of these symptoms for respondents ages 18-29 was similar to respondents ages 70+ .
- Respondents with symptoms over 6 months experienced an average of 13.8 symptoms in month 7.

- 85.9 percent of respondents experienced relapses, with exercise, physical or mental activity, and stress as the main triggers (see Figure 3).

Figure 3: Triggers of relapses



- 4.4 percent of respondents experienced a temporary break in symptoms, only to have symptoms return later on.
- 40.7 percent of unrecovered respondents experienced extreme levels of fatigue at time of survey.
- The following organ systems were most impacted: 100 percent of respondents experienced HEENT (head, ears, eyes, nose, throat) symptoms, 99.7 percent of respondents experienced systemic symptoms (such as fatigue, weakness, and fever), 93.9 percent experienced musculoskeletal symptoms, 93.0 percent experienced pulmonary/respiratory symptoms, and 91.4 percent experienced sensorimotor neuropsychiatric symptoms.
- 36.1 percent of respondents who reported having a menstrual cycle reported experiencing period/menstrual issues.
- Other serious symptoms reported by respondents include hearing loss (reported by 9 percent of respondents), vision loss (1 percent), facial paralysis (3 percent), and suicidality (12 percent).
- Many of the symptoms documented, as well as what diagnoses patients had already received at time of survey, suggest that a subset of patients develop postural orthostatic tachycardia syndrome (POTS; a type of dysautonomia), myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), and mast cell activation syndrome.

This paper has been viewed over 118,000 times, downloaded over 56,000 times, and is in the top 0.1 percent of outputs on medRxiv, the preprint website it is posted to.

Barriers for Long COVID Patients

From our research, others' research on Long COVID, and what we hear from the Long COVID patient community, we are intimately aware of the barriers Long COVID patients face to adequate care, treatment, and recovery, and how that will translate to impacting healthcare and the economy.

Testing

Long COVID patients who do not have a positive COVID-19 diagnostic (PCR/antigen) or antibody test are often denied access to services that are afforded to those who do have a positive test such as healthcare services for diagnostic and symptom management, health insurance coverage of those services, school and workplace accommodations, research participation, and worker's compensation or disability benefits. There is no evidence to support the justification of this, and in fact, several studies have shown what ours has in that symptoms do not differ between Long COVID patients who have a positive test and those who do not, with the exception of loss of smell and taste.[11]

At the beginning of the pandemic, and for some communities throughout, access to COVID-19 diagnostic testing was extremely limited. Once tests were developed, for several months they were reserved for hospitalized patients, patients with history of international travel, or patients who exhibited specific symptoms. As testing became more accessible, communities who are outside of the traditional healthcare system still may not have received a test. Further, a recent study has documented that 32% of people reporting symptoms after two months were initially asymptomatic at time of SARS-CoV-2 testing, indicating that testing could be missing a group who were initially asymptomatic but did not have a known exposure or access to a test.[12] Therefore, some patients who may have otherwise tested positive were either not tested at all or tested at a time when the test would not capture the virus, leading to some patients not receiving the care and benefits they deserve.

Additionally, PCR and antibody tests are not guaranteed indications of SARS-CoV-2 infection. The likelihood of false negatives from a PCR test increases after day 3 of symptom onset, when the false negative rate is 20 percent, reaching 66 percent by day 21.[13] In fact, up to 54 percent of patients could have an initial PCR false negative result.[14] Additionally, antibody tests are not completely accurate in detecting the presence of SARS-CoV-2 antibodies. Antibody tests have been shown to be less accurate in women than men, and less accurate for people under 40 years old and over 70 years old.[15] Even if the test is accurate, low antibody levels in the earlier stages of patients' illnesses were associated with persistent symptoms 7 months later, indicating that Long COVID patients may not be developing antibodies in the same way that COVID patients who do not develop Long COVID do.[16]

Therefore, the lack of a positive COVID-19 test must not preclude patients from being covered by insurance, having access to post-COVID clinics, being eligible for government benefits, accessing accommodations, and participating in clinical research and trials.

Clinical diagnoses, and retrospective clinical diagnoses, must be accepted as a valid indication of COVID-19. Limiting any access to care and benefits to patients with a positive test will further exacerbate inequities in care amongst racially and ethnically marginalized and low-income populations, who experience more barriers to testing and therefore are more likely to not have a positive test.

Currently, PLRC has heard from patients who are denied the following because they do not have a history of COVID-19 test result:

- Access to Post-COVID treatment centers;
- Referrals or specialty appointments to evaluate for organ damage following suspected COVID-19 infection;
- Health insurance coverage of testing and treatment related to Long COVID;
- COVID-related paid leave from work;
- Worker's compensation and disability benefits;
- Workplace accommodations related to Long COVID; and
- Participation in Long COVID research.

Medical Care

There are several barriers Long COVID patients face in receiving proper medical care.

First, Long COVID patients are often not believed by doctors. They can be told that the symptoms are "in their head" and attributed solely to anxiety, especially when blood tests and imaging do not show abnormalities. However, post-viral illnesses are documented in medical and historical literature, though historically have been very underfunded and poorly understood. People of color, women, and LGBTQ(IA+) face additional prejudice and discrimination throughout the medical field, increasing the prevalence of gaslighting and disbelief by medical professionals.

Every patient has the right to be believed. Only they know what they feel. When doctors come to the conclusion that symptoms are imaginary and not worth investigating further, this assumes that modern medicine has discovered everything about the human body. Medical research says otherwise.

A recent CDC study found that of nonhospitalized adult patients with a positive COVID-19 test, two-thirds had at least one outpatient medical visit between one and six months post-diagnosis, and 38 percent went to a specialist.[17] Because of the multi-organ impacts of Long COVID, many patients see multiple specialists. When patients go to different specialists who do not

collaborate with each other, valuable information is lost and patients suffer.[18] Additionally, for patients with limited energy, seeing multiple specialists is draining and not conducive to recovery. Medical care must include meeting patient needs by helping patients navigate the healthcare system, whether by making it easier to see multiple specialists in one visit or performing home visits to run lab tests.

At the beginning of the pandemic, several academic and large medical centers opened post-COVID clinics to aid in rehabilitation of COVID-19 patients who had lengthy ICU stays and required intensive rehabilitation. They quickly saw demand for their services by many COVID-19 patients who continued experiencing symptoms weeks or months after their infection, and had never been hospitalized. Many post-COVID clinics have adapted to serve this need by providing interdisciplinary specialty care in partnership with rehabilitation professionals. Many of these clinics offer interdisciplinary coordinated care for Long COVID patients, resulting in better care for patients.[19] However, patients have reported that a majority of these clinics require a positive COVID-19 test, patients often have to wait months for an appointment, and clinics are not covered by all insurance policies.

Related to reimbursement, the CDC National Center for Health Statistics proposed adopting a diagnosis code for Long COVID, ICD-10-CM code of U09.9 - Post COVID-19 Condition. Adopting this code will assist in proper reimbursement of associated healthcare costs and will assist in the tracking of prevalence, mortality, and morbidity of Long COVID patients who have access to healthcare. As it stands now, though, if adopted it will be implemented in November 2021, leaving several months without a proper Long COVID code.[20]

The mental health impacts of the global pandemic are well-documented but rarely fully explored in COVID and Long COVID patients. Becoming ill with a novel virus that is often framed within a death-recovery binary means that those who experience prolonged symptoms, protracted recovery, or an evolving and unstable health status can experience a tremendous amount of cognitive dissonance, confusion, and shame along with the acute trauma and post-traumatic stress disorder-like symptoms from having become ill with COVID-19. Especially for those from marginalized communities or identities, such as women, people of color, or LGBTQ people, there is also an open door to medical mistreatment and gaslighting. Patients are perceived as being “recovered” or labeled a “survivor” but who are far from their previous baseline of health, and are often subsequently psychopathologized and under-treated for their symptoms. Further, given the extensive neurological symptoms documented for COVID-19 and Long COVID, it remains an open question for clinicians to investigate whether symptoms of depression, anxiety, and other mental illnesses or chronic conditions like insomnia are actually neurological in nature and will resolve with adequate treatment for Long COVID neuropathies. Mental health treatment for Long COVID patients should be readily accessible but should also be viewed as secondary for symptom-management and processing the grief and loss caused by debilitating symptoms and new chronic illness, and not as a primary treatment strategy for Long COVID.

Lastly, patients are having difficulty paying their medical bills and navigating insurance companies' policies. When many patients are unable to work or have decreased their working hours, paying for multiple specialist visits, diagnostic tests, and potential treatments is often not possible. Ensuring reimbursement is done correctly can also take hours of phone calls between doctor's offices and insurance companies, though many patients do not have the cognitive function nor energy to make these calls.

Research

Prior and current research on Long COVID is often not representative of Long COVID patients. Much of the research is on hospitalized patients; while this research is important, it cannot claim to be representative of a group who was largely non-hospitalized. Additionally, the vast majority of research is limited to people with positive PCR or antibody tests, excluding the large subset of patients who were untested or received a negative test but present as a Long COVID patient. Communities who are Black, Indigenous, and people of color have been historically excluded from medical research, and must be prioritized in research into Long COVID especially due to COVID-19's disproportionate impact on these communities. Due to the lack of funding in research for illnesses like ME/CFS, there is a lack of awareness among the research community of the research that *has* been done that could help in solving Long COVID. Because of this, there is a risk of funding going towards research that has already been completed and/or is uninformed.

To ensure that many of these concerns are addressed, it is critical that Long COVID research engage patients through all stages of research development. Patient engagement in research leads to more relevant research that address patients' real-world needs and concerns.[21]

Lack of Education

Despite being over one year since Long COVID patients began sounding the alarm for what they were experiencing, many clinicians and researchers are unaware that a large subset of COVID-19 patients are experiencing these prolonged symptoms. This has led to poor medical care and dismissal of symptoms. While the CDC and NIH have publicly recognized Long COVID, many patients are not seeing the results of this education in the doctor's office.

Further, many common Long COVID symptoms that patients report are not being acknowledged by medical and public health professionals who are aware of Long COVID, particularly menstrual and genitourinary symptoms. People who make decisions about and for Long COVID patients must have a deep understanding of the evidence of Long COVID to date, as well as related illnesses like ME/CFS, dysautonomia, and mast cell activation syndrome. This includes clinicians, CDC leadership and staff working on Long COVID, as well as NIH leadership and staff who are currently reviewing research proposals for the first round of Long COVID research opportunities.[22]

The public also needs to be educated on Long COVID. The narrative that young people (including children) without pre-existing conditions are not at risk from a COVID-19 infection doesn't address the risk of Long COVID, which is happening in up to a third of people with COVID-19 infections. It is imperative for the public to understand the risks of Long COVID when making decisions about their risk tolerances, vaccination, and reopening.

Workforce Impact

67.5 percent of our respondents were unable to work or had to reduce their hours as a direct result of their illness. Inadequacy in paid medical leave, disability benefits, and accommodations exacerbate the impact Long COVID has on patients' financial stability.

Lack of access to comprehensive paid medical leave from work has led to worse outcomes in Long COVID. Pacing, an activity management strategy which prioritizes avoiding overexertion, is key to recovery and symptom management.[23] Our survey found that pacing was the treatment that patients found most "significantly helpful"; another paper found that those who were able to get adequate rest in the acute stages were less likely to have a more debilitating course of Long COVID later on.[24] Further, overexertion in the early stages of ME/CFS, another post-viral illness, was found to be associated with deterioration and severity.[25] ***However, many patients have to choose between providing for themselves and their family, or giving their bodies the ability to recover during the crucial early recovery period.***

For patients who require lengthier medical leave while recovering from COVID-19 infections *and* have a short term disability insurance policy, there are significant barriers in receiving approval for short term disability benefits. PLRC has heard from patients who have been denied these short term disability benefits due to insufficient evidence of disability caused by Long COVID, which is likely due in part to the lack of adequate tests to measure symptoms of Long COVID.

For patients who require lengthier medical leave who do *not* have a short term disability insurance policy, **there is no federal short term disability benefit**. The Social Security Administration (SSA) website says they "assume that working families have access to other resources to provide support during periods of short-term disabilities, including workers' compensation, insurance, savings, and investments."[26] This assumption is not reflective of Americans' financial situations: prior to the pandemic, 45 percent of Americans had no savings, and 24 percent had less than $1,000 in savings.[27] For many Long COVID patients' families, any savings that existed was likely wiped out by the financial impacts of the pandemic alone. In order to receive unemployment insurance, individuals must certify they are "willing and able" to work, but these patients are not able to work. Additionally, worker's compensation benefits are not an adequate safety net --- PLRC has heard from several Long COVID patients who were undoubtedly exposed to COVID-19 on the job and have been denied worker's compensation benefits for the long-term effects of the infection.

Additionally, there are patients who even with pacing will be unable to work substantially and therefore will require long-term disability benefits. Many of these patients face barriers applying for and receiving long-term disability benefits, including Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) as well as private long-term disability benefits. Social Security disability benefits are difficult to obtain due to SSA's requirement of proof that a condition significantly limits one's ability to do work-related activities like sitting, walking, and remembering for at least 12 months, in addition to work requirements for approval. With a relapsing-remitting illness that some Long COVID patients experience, in combination with the newness of the condition, proving this length of disability is difficult to do.[28] Further, patients have just started to mark their year anniversary of symptoms so can only now indicate that their condition affects their work. Additionally, the average processing time of these applications is over 100 days, and many Social Security offices were not open to the public during the pandemic unless for emergency situations. Compounding on barriers to application and approval, there is a five month waiting period before SSDI benefits are paid and a two year waiting period for Medicare coverage, starting from date of disability.[29] All of these barriers combine such that at this point, these patients have been without financial assistance for months.

Patients have also reported being denied accommodations at work. Accommodations like working remotely, having a flexible schedule, and restructuring the job or reassignment as appropriate can make the difference between a patient being able to work and not work.[30] Further, patients do not have enough workplace protections, with patients reporting being fired as a direct result of their illness or being denied accommodations because their employer does not believe they have Long COVID or that it can be considered a disability.

Prevalence

Estimates for the prevalence of Long COVID are wide ranging. Depending on how studies define Long COVID and when they capture prevalence in relation to the patient's illness, estimates range from 2.3 percent[31] to 35 percent.[32] Many of these studies that claim to represent prevalence often limit the symptoms they ask about and require a positive COVID-19 test which will miss a subset of patients. These estimates can be helpful, however, in seeing the extent of Long COVID and who it is impacting. For example, Table 1 contains the United Kingdom's Office of National Statistics estimates, which shows that ***children as young as 2 years old*** have been documented having prolonged symptoms after a COVID-19 infection.[1] Performing a prevalence study in the United States, and attempting to include people who did not have a positive COVID-19 test or are outside of the healthcare system, will be important to understanding the the extent of impact Long COVID will have on healthcare systems, the economy, and marginalized communities.

Table 1: Estimated five- and twelve-week prevalence of select symptoms among Coronavirus Infection Survey participants testing positive for COVID-19[1]

Group	Estimate at 5 weeks	Estimate at 12 weeks
All people	21.0	13.7
Male	18.7	12.7
Female	23.0	14.7
Age 2-11 years	9.8	7.4
Age 12-16 years	13.0	8.2
Age 17-24 years	16.9	11.5
Age 25-34 years	22.6	18.2
Age 35-49 years	25.6	16.1
Age 50-69 years	25.1	16.4
Age ≥70 years	15.9	11.2

Tracking Long COVID death rates is also critical. Long COVID patient deaths are often not included in COVID-19 death numbers because the deaths occur after the length of time local health departments track COVID-19 deaths, doctors do not attribute the deaths to COVID-19, or the patient never had a positive COVID-19 test.

Recommendations

Support the COVID-19 Long Haulers Act

Representatives Don Beyer (D-VA) and Jack Bergman (R-MI) announced on April 21, 2021 that they will be introducing the COVID-19 Long Haulers Act.[33] The Act will do the following:

- Accelerate Long COVID research through data harmonization;
- Research Long COVID treatment efficacy and disparities, including access to treatment for veterans, the elderly, disabled, and low-income communities; and
- Educate Long COVID patients and medical providers. The Act will authorize funding for the CDC to develop and disseminate information for medical providers and the general public about common symptoms, treatment, related illnesses, and proper billing.

We urge the Committee Members to support the Act. If passed, we urge the responsible agencies to include Long COVID patients in the research authorized and the development of educational materials.

Create a Federal Advisory Committee

We urge Congress to establish a Federal Advisory Committee on Long COVID within the Department of Health and Human Services, composed of Long COVID patients as stakeholders, external experts in researching and treating post-infectious chronic illness and their comorbidities, and disability advocates. This committee would be similar in structure to the Tick-Borne Disease Working Group, established in 2016 as part of the 21st Century Cures Act.[34] A Federal Advisory Committee is needed to facilitate timely and necessary coordination between relevant federal agencies and stakeholders. It would assist in providing coordinated recommendations related to Long COVID in response to the urgent crisis of a subsequent pandemic of disability in the wake of COVID-19 infections. Further, this Federal Advisory Committee should ensure that all staff at the CDC, NIH, and other federal agencies working on Long COVID, particularly reviewers of research proposals, be educated on the biomedical evidence of ME/CFS and related illnesses. Additionally, we urge that these meetings be live streamed with closed captioning for accessibility. We also recommend that this committee meet on a frequent basis, due to the urgency and scale of the issue.

Increase Access to Post-COVID Clinics and Integrated Medical Care

We urge Congress to appropriate funds for states to open additional, and fund existing, post-COVID clinics. The COVID-19 Long Haulers Act will help determine equitable and effective treatment, but additional dedicated funding is necessary to carry out said treatment in clinics nationwide with adequate reimbursement rates for the lengthy interdisciplinary visits necessary to support Long COVID patients. To improve access, more clinics must be opened to cut down on waiting times, and these clinics must be open to patients with and without a positive COVID-19 test, be geographically accessible, and be inclusive of Medicaid-served patients and communities who are disproportionately Black, Indigenous, and people of color. We must ensure that those who have been disproportionately impacted by the virus, infections, and deaths have access to knowledgeable, comprehensive care, including specialist care, diagnostics, and effective treatments equal to what is afforded to more privileged patients with private insurance. Where clinics are unable to be established, Congress should urge the CDC to provide guidance for clinicians to work together to address a patient's physical and mental health holistically.

Count Long COVID

We urge Congress to task the CDC with estimating Long COVID's prevalence. Efforts must be made to include people who do not have access to healthcare and those without a positive COVID-19 test in prevalence estimates.

Ensure Long COVID Research is Inclusive and Historically Informed

Congress must urge NIH to prioritize research into Long COVID that is inclusive of patients who were not hospitalized, those who do not have a positive COVID test, and of marginalized communities. In any future appropriations for Long COVID research, Congress should mandate inclusion of these populations. Further, research that builds on prior ME/CFS and related chronic illness research and that considers links between Long COVID and ME/CFS, dysautonomia, and mast cell activation syndrome should be prioritized. Additionally, projects should be funded that include patients in the development and execution of the research study.

Ensure Medical Care and Treatment is Affordable

Short term solutions:

- Congress should urge the CDC to implement the proposed ICD-10-CM code immediately to ensure proper reimbursement. Congress should also urge the CDC to ensure that medical providers know to code U09.9 regardless of a positive COVID-19 test.
    - If this is not possible, interim guidance is needed for providers, health insurance companies, disability insurance and worker's compensation benefit companies. We recommend in the interim to use Z86.16--personal history of COVID-19 as well as B94.8--Sequelae of infectious and parasitic disease, and pair it with applicable codes such as G93.3 postviral fatigue syndrome based on patient's symptoms
- Congress should urge the Centers for Medicare & Medicaid Services to establish a payment strategy for post-COVID clinics that offers adequate reimbursement for longer length appointments and interdisciplinary care.

Long term solutions:

- ***Congress must pass universal healthcare.*** Health is a fundamental human right; it must no longer be tied to one's ability to pay.

Increase Workplace Protections and Accommodations

We urge Congress to ensure that Long COVID patients' jobs are protected by enforcing existing laws such as the Americans with Disabilities Act and Family and Medical Leave Act, and consider whether additional employment protections are needed. As part of provider education (which may be provided through the COVID-19 Long Haulers Act), Congress should urge the CDC to encourage clinicians to refer their patients to vocational rehabilitation services as well as occupational therapy, and be willing to work with their patients to support paperwork for school or employment accommodations that are right for them, including flexible work schedules and telework.[30] Patients should be able to take extended paid leave from work and have the opportunity to return to their same position, or to have metered returns to allow for pacing at the beginning stages of their illness.

Expand Access to Disability Benefits

We urge Congress to ensure that Long COVID patients who are unable to work have access to sufficient financial assistance. This includes:

- Introducing federal short term disability benefits for Long COVID in the next federal relief bill, or amend unemployment insurance to include this population.
- Overhauling Social Security disability (both SSI and SSDI) to provide shorter application processing times, update SSI benefits to 100 percent federal poverty level, remove waiting periods between approval and benefit payment as well as Medicare coverage, review and update work requirements necessary to qualify to apply for SSDI which may disproportionately impact marginalized communities and women with employment gaps due to child rearing, update outdated asset limits and income exclusions and require they increase with cost of living, remove the marriage penalty and in-kind maintenance and support component of SSI, and expand criteria for approval of both SSDI and SSI. A dedicated Social Security disability program for post-COVID conditions should be explored by a Long COVID Federal Advisory Committee which includes Long COVID patients as stakeholders.
- Initiating a federal investigation of private disability benefit and worker's compensation insurance practices to investigate why Long COVID patients, many of whom were exposed to COVID-19 infections in the workplace, are being denied benefits they qualify for and they/their employers paid into.

Expand Access to and Amount of Paid Sick Leave and Family Leave

We urge Congress to expand access to paid sick and family leave for people who are not a covered employer under the Families First Coronavirus Response Act. Further, Congress must increase the amount of paid sick and family leave available to account for Long COVID - the previous authorization did not consider the possibility of an employee or loved one getting Long COVID, the need to pace particularly in the beginning of recovery, and vaccination reactions.

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Ms. ESHOO. Thank you so much, Ms. McCorkell, and that is exactly why we called you as witnesses today. So thank you very, very much.

I now would like to recognize Dr. Possick. Thank you for your patience in waiting, and we feel very honored that you would join us, and you are recognized for your 5 minutes of testimony.

STATEMENT OF JENNIFER D. POSSICK, M.D.

Dr. POSSICK. Thank you, Chairwoman Eshoo, Ranking Member Guthrie, and members of this committee. And thank you, too, to my fellow panelists whose company it is humbling to be within. I hope to share my perspective as a pulmonologist caring for people with post-COVID disease, including long COVID.

So in Connecticut the surge initially arrived in March of 2020. And within weeks thereafter, people were reaching out to us about patients who remained profoundly short of breath after their acute illness had passed. My colleagues and I were struck by how difficult it was to tell the difference between people recovering from mild acute COVID and those who had required ICU-level care. Both groups had the physical, cognitive, and psychological fallout we would expect from a critical illness or a prolonged intubation. And in addition to being short of breath, they reported a host of other symptoms.

I saw a teacher who had recurrent bouts of crushing chest pain mimicking a heart attack, a young mother who would have racing heartbeat and dizziness every time she played with her toddler, a local business owner who couldn't remember the names of his long-term customers or balance his books, and a home health aide who didn't have the stamina or strength to assist her elderly clients.

We assembled a team of pulmonologists, physical therapists, and a social worker to provide a comprehensive evaluation in a single clinic visit. A broader coalition with physicians in cardiology, neurology, and psychiatry, all with COVID–19 experience, worked together to untangle complex symptoms.

We have spent this year learning alongside our patients, about half of whom were never hospitalized. They are mostly working age, previously high functioning. Many were frontline or essential workers. Many were initially disbelieved.

Their quality of life has been seriously impacted. Some can't walk to the mailbox or remember a shopping list, much less resume their everyday lives and work. They have used up their paid sick leave, they have cut back their hours, they have left or lost jobs. They have difficulty accessing workmen's compensation benefits and FMLA or securing workplace accommodations. Some have even cut back on food, rent, or utilities to pay for mounting medical expenses.

As was seen in SARS and MERS, we do have some patients with persistent lung disease, but routine testing is frequently unrevealing for these patients and requires more detailed evaluation to investigate symptoms that span multiple organ systems.

Some of our patients have completely recovered with time. Others have made progress but continue to experience debilitating symptoms.

Consensus practice supports many forms of rehabilitation services, but insurance approval and coverage have been beyond challenging, and demand outpaces availability in any case. For patients with ongoing oxygen needs, requests for portable oxygen concentrators can be delayed or even denied, complicating physical recovery and mobility.

We are a well-resourced program at an academic medical center, but we are swamped by the need in our community. This year, we have seen more patients with post-COVID–19 conditions in our clinic alone than we have of new cases of asthma and COPD combined.

Looking ahead, the magnitude of the challenge is daunting. There are over 31 million survivors of acute COVID–19 in the United States. And we don't know how many people will be affected, what kind of care they will need, or how long—what kind of care that will entail, or how long they will need it.

Research will ultimately help us to understand the origin of these symptoms and to identify effective treatment. But in the meantime, their care cannot wait.

First, we must increase public awareness of post-COVID–19 disease, highlighting that it can occur after mild acute illness in young individuals and in those without preexisting comorbidities.

Second, we must ensure early and equitable access to care for individuals with post-COVID–19 conditions, which cannot practically be confined to specialty centers. Patients need access, not only for evaluation but also to services like pulmonary rehab, neurocognitive rehab, and mental health services. Moreover, clinicians must be liberated from prior authorization and appeals processes so that we can focus on the care of our patients.

Finally, we must address the socioeconomic consequences of post-COVID disease on working people, including the impacts on their livelihood and health insurance access. We must recognize that this condition, including occupational acquired infection, has prevented many from returning to work despite their desire to do so, and must ensure access to services and benefits.

We have made great strides and accomplished a great deal in this unprecedented year, but as we move into the next phase of response we must realize that we are pacing for a marathon rather than a sprint.

I thank you again for the opportunity to take part in this important discussion.

[The prepared statement of Dr. Possick follows:]

Yale SCHOOL OF MEDICINE
Department of Internal Medicine

Jennifer D. Possick, MD

Associate Professor of Medicine
Pulmonary, Critical Care and Sleep Medicine
Medical Director, Winchester Center for Lung Disease
Yale New Haven Hospital

PO Box 208057
New Haven CT 06520-8057
t 203 785-6359
f 203 785-6954

courier
Winchester Center for Lung Disease
6 Devine Street, 3rd Floor
North Haven, CT 06510

The Long Haul: Forging a Path through the Lingering Effects of COVID-19
Committee on Energy and Commerce, Subcommittee on Health
April 28, 2021

Testimony of Jennifer Possick, M.D.

Chairwoman Eshoo, Chairman Pallone, Ranking Member McMorris Rodgers, Ranking Member Guthrie, and the members of the committee, thank you for the opportunity to participate in discussion of this critical issue.

I am an Associate Professor in the Section of Pulmonary, Critical Care and Sleep Medicine at the Yale School of Medicine and the Medical Director of the Winchester Center for Lung Disease. As a group, Pulmonary and Critical Care physicians care for critically ill patients in the intensive care unit, hospitalized patients with acute respiratory issues, and outpatients with a variety of chronic lung diseases. As a result, the acute and chronic care of patients with COVID-19 has been our central focus for the last year. I have focused on the care of patients with complicated pulmonary conditions and unexplained respiratory symptoms for over a decade and would like to share my experience in caring for individuals with persistent symptoms following COVID-19.

In Connecticut, the initial surge began in March 2020. To date, our state has had over 334,000 documented cases of COVID-19 and over 8000 deaths (1). Though the spring was mostly marked by the response to the inpatient crisis, particularly for the critically ill, in the outpatient realm a second storm was brewing. Clinicians in our community reached out for assistance with patients who had passed the acute phase of COVID-19 illness but remained profoundly short of breath and generally debilitated. This was perhaps not unexpected in the wake of viral pneumonia and convalescent quarantine but was worrisome nonetheless.

My colleagues and I began to see these patients in telehealth visits in April 2020. The majority were young. Many were frontline or essential workers who had been leading active lives with minimal health issues before COVID-19 (2). With time, we did see patients with severe disease who had gone through harrowing hospitalizations with prolonged respiratory failure and classic post-intensive care physical, cognitive, and psychological sequelae (3). But patients with milder disease were struggling with identical

issues (4). In some cases, they had not been hospitalized at all. They were all extremely short of breath, but also reported a host of other symptoms (4, 5):

- A teacher experienced recurrent bouts of crushing chest pain mimicking a heart attack.
- A young mother described palpitations and dizziness while playing with her toddler.
- A local business owner could no longer remember the names of long-term customers and was unable to balance his books.
- A home health aide no longer had the stamina or strength to assist her home-bound clients.

These people were desperate to return to their everyday lives and were devastated that they could not physically or mentally resume their work. Moreover, they were young people who now had difficulty taking care of their families, shopping for groceries, or walking to the mailbox. Parallel to this early experience, data about post-COVID-19 disease emerged from across the globe that echoed these stories (6-9).

In response, we assembled a multidisciplinary team of pulmonologists, respiratory therapists, physical therapists and a social worker that could provide a comprehensive patient evaluation in a single clinical visit. We formed a broader coalition with physicians in cardiology, neurology, occupational medicine, and psychiatry with post-COVID-19 expertise and coordinated their care across disciplines. As we reopened face-to-face outpatient services and adjusted existing clinical space to meet new infection control standards, we were able to officially launch our Post-COVID-19 Recovery Program in July 2020 (10).

Our patient group is heterogeneous, but there are recurring themes. About half were never hospitalized, but their symptoms and functional limitations are like those who were. They are primarily young to middle-aged, previously healthy, and high functioning. Shortness of breath, fatigue, palpitations, mood changes, and cognitive impairments are the most common symptoms reported at initial visits that occur weeks to months after their acute illness. All dimensions of quality of life are impaired, sometimes severely. They have used up their paid sick leave, cut back hours, left or lost jobs. They have had difficulty accessing workman's compensation and other benefits. In some cases, they have cut back on essentials such as food, rent, utilities, and medication to pay mounting medical expenses (11). As with serious coronavirus infections prior to the current pandemic (e.g., SARS and MERS) (12), we have seen patients with persistent inflammation or scarring of the lungs, persistent oxygen requirements, and abnormal pulmonary function testing, but this is not the majority of our current patients. Routine testing is frequently unrevealing, requiring more comprehensive evaluation to fully investigate their symptoms.

We have followed our earliest patients for a year now. Some have completely recovered. Others have made progress but have not yet returned to their baseline. Still others continue to have debilitating symptoms. Pulmonary rehabilitation is well known to help patients with lung disease (13). In post-COVID-19 patients, consensus practice supports rehabilitation (14), but insurance approval and coverage of these services have been challenging, and demand has outpaced availability. Some patients who do require oxygen cannot get access to portable oxygen necessary to effectively participate in rehabilitation. Many patients require evaluation and care from multiple health care professionals, which is difficult for patients suffering from fatigue or cognitive changes to navigate or tolerate.

We are a well-resourced program at an academic medical center, but we are swamped by the need in our community and have only seen the tip of the iceberg. In ten months, we have seen more referrals for post-COVID disease than for asthma and COPD combined. Looking ahead, the magnitude of the challenge is daunting. There are over 31 million survivors of COVID-19 in the United States, and, though we have

learned much in the past year, much remains incompletely understood. We do not yet know how many people will be affected by post-COVID disease, how long they will need care, and what that will entail. My colleagues and I strive to see these patients as quickly as possible, but we are the same physicians providing care for hospitalized COVID-19 patients on wards that are stretched beyond capacity.

You have provided $1.15 billion in funding for the NIH to support new and ongoing research into the long-term health consequences of COVID-19. This vital work will help us understand the origin of these symptoms, identify potential treatments, and promote the recovery of our patients. But in the meantime, **care can't wait**. Therefore, we must do more:

- **We must increase public awareness about post-COVID-19 disease,** highlighting that it may occur after mild acute illness and in young individuals, and we must have a platform to rapidly share state-of-the-art information as knowledge evolves. While individual professional organizations provide one forum for this, COVID-19 conditions cross multiple specialties and disciplines. Information should be centralized and accessible to primary care providers in any community.
- **We must ensure early and equitable access to care for individuals with post-COVID-19 disease**, including not only initial evaluation and treatment, but also therapeutic services such as rehabilitation and behavioral health support. Coverage of rehabilitation services for the entire duration of need is essential, including specialty services such as pulmonary rehabilitation, cardiac rehabilitation, and cognitive rehabilitation.
- **We must appropriately resource healthcare institutions** to meet the needs of this emerging patient population. Telehealth, which has proven to be a valuable modality of care, should be supported and enhanced for evaluation and treatment of COVID-19 disease. For patients with barriers to technology access or limited digital health literacy, telephone consultation should be supported and reimbursed at equitable rates. Furthermore, clinicians must be liberated from prior authorizations and insurance coverage appeals for necessary services so that we may carry on caring for our patients.
- **We must address the socioeconomic consequences of post-COVID-19 on working-age people** including impacts on their livelihood and health insurance access. We must recognize that post-COVID-19 disease, including occupationally acquired infection, has prevented many from returning to work.

We have made great strides and accomplished a great deal in this unprecedented year. But as we move into the next phase of COVID-19 response and care, we must acknowledge that we are pacing for a marathon rather than a sprint.

Thank you again for the opportunity to take part in this important discussion.

Jennifer Possick, M.D.

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Ms. ESHOO. Thank you very much, Dr. Possick.

There is so much to absorb from our hearing today, but I think that every Member is hanging on each word that is uttered by our witnesses. So all of our thanks to you.

Dr. Deeks. A colleague said, I said Dr. Deeks is the lead scientist for the long-term impact of infection with the novel coronavirus study. So, Dr. Deeks, thank you, and welcome to our subcommittee. And you are recognized for your time to give testimony to us.

STATEMENT OF STEVEN DEEKS, M.D.

Dr. DEEKS. Thank you. It is tough to go last. Much of what I was going to say has been said, so I will go through this quickly.

I want to talk about three things that are sort of known scientifically and four or five things that are not known and are key to sort of figure out just to provide a platform for the questions, right?

So in terms of what is known, the syndrome is real, OK? And that is, as our three first speakers sort of outlined, there is a lot of stigma associated with this syndrome. And external validation from NIH, from medical societies, from Congress that this is a real problem, to me, is going to be very therapeutic and hopefully reduce a lot of stigma around this. And so that is great. There is not universal consensus, though, so there are some skeptics out there. I will talk about that in a second.

Second, there are many different flavors, many different spectrums, phenotypes we call them in medicine, in terms of what is going on with COVID. And I think this is very important, because I think they are going to end up having different mechanisms.

The vaccine story, right, so we heard these stories about how vaccines make people better, and that is possibly because the virus is persisting in certain people and the vaccine makes the immune system stronger and the virus goes away. Our experience in our cohort is that the vaccines actually make some people worse. And we think it is because the vaccine is enhancing inflammation.

So I think, you know, there are three or four different pathways here that are at play with different syndromes. And so it is not—I don't think it is long COVID. We are going to have to basically slice and dice this, figure out the clinical phenotypes, figure out the mechanisms, and then figure out the therapies.

Third thing that is known is that symptomatic post-COVID is common: 20, 30, 40, 50 percent of people have symptoms 4 to 12 weeks. Disabling disease, like we heard from the three stories today, fortunately is not that common, but it exists and is probably the thing that we need to focus in on in terms of, I think, digging up mechanisms and therapies. So that is what is known.

What is not known. First, we don't have a way of measuring this, right? Everyone who has got a cohort or a clinic measures it differently, they report stuff differently. As a consequence, the epidemiology is a mess, right? We don't really have a good sense of what is going on. We need—and this has been said before—general consensus on how to define the syndrome, how to measure it in studies so that we can all basically be saying the same thing.

Second, we—and this is really to the first—we don't really know the prevalence of either the minimally symptomatic stuff or the very symptomatic stuff. And we don't really know its natural his-

tory. And these things are actually stuff that, hopefully, we are going to play out.

We do have a sense of who is at risk, right? And I think there are a couple issues here. People who are very sick early on are high risk, but asymptomatic people get it. Women—in almost every cohort, women are more likely to get this than the men. And this, to me, is probably the strongest hint that we have in terms of the biology, because women, in general, are more susceptible to many autoimmune diseases, and we know why. And so paying attention to that fact of why it is more common in women, I think, is providing very important insights into the mechanism and is directing how we are going about our science to identify therapies.

Third—and this is an important issue we haven't really talked about. It is very complicated, and it is why there are some skeptics out there. At the same time people are getting acute COVID, they are living in a society that is broken. There is lots of social isolation, there is lots of depression, there is lots of people struggling who did not have COVID. And the way in which these have—the way this social economic environment that we are living in has interacted with this acute infection is likely contributing to what is happening in ways that are very important but I think ultimately are going to be hard to untangle and something that has not been discussed.

Fourth, we don't know the mechanism, but fortunately the NIH is on it. And this is what the NIH does very well, right? Go back to the history of HIV. They figured out very quickly what the mechanism was of HIV. And once that happened, industry got involved. And once that happened, we had 20, 25 drugs for HIV. And so we need the mechanism. So what NIH will do, and then once that happens, we will get industry involved.

And that leads to sort of the last two things, right? We need more engagement from industry. Academics are not going to fix this. We are going to describe the natural history, we are going to figure out the mechanism, but we are not really good at doing the drug development. And so we need to de-risk what is happening in terms of industry. When you give them a mechanism, we need to have the FDA and other people involved saying, "This is a disease, this is a syndrome that you can treat. And if you do so, we will give you [inaudible] drug indication."

And finally, as illustrated by today's discussion so far, we need at the table industry, regulatory, academic, we need representatives from all affected communities, because every voice counts. And how people are experiencing this very much depends on where they are coming from.

Thank you.

[The prepared statement of Dr. Deeks follows:]

My name is Steven Deeks. I am a Professor of Medicine at the University of California, San Francisco. Like many people working on COVID, I was prior to last year engaged full time in the study of HIV. I directed a cohort devoted in part to determine how HIV affects long-term health. Our extended team has also been studying how other infections, including Ebola, caused long-term complications.

We realized early in the pandemic that people who survived acute COVID might develop long-term complications. We repurposed our HIV cohort to study COVID and began enrolling study participants in April. We are now doing intensive investigations on "Long COVID", or PASC. Given our expertise, we are primarily focused on identifying possible mechanisms and treatments for this disease.

With regard to today's meeting, I wanted to describe in general terms what is known and what is not known about Long COVID.

There are only a few things we know with some certainty.

First, the syndrome is real. There is almost universal consensus that undefined proportion of individuals who survive the acute infection will have some residual symptoms that persist for weeks to months. Achieving consensus within the medical establishment that syndrome is real is very important, as prior post-infectious complications not received much attention by the biomedical community. It is my hope that by simply acknowledging that the syndrome is real will reduce much of the stigma around these issues.

Second, there are several different types of long-COVID. Some have predominantly cardiovascular symptoms, such as cough, palpitations and reduced exercise reserve. Other have primary more neuropsychiatric symptoms. Still others have chronic malaise and other factors that have high effect on quality of life. We assume the biology and treatment for these syndromes will be different.

Third, although symptomatic long-COVID is common, only a proportion – maybe a few percent – have profound and disabling symptoms. Still given that there may be over 50 million people in this country alone who have had COVID, the number of people who will be profoundly affected

by long COVID will likely be in the millions. This has huge implication for our health care system and Social Security.

This is all that we can say for sure. We have many important unknowns.

First, there is no consensus on how to define, diagnose or measure this syndrome. In fact, there is no universally accepted name. Everyone is using different definitions and the state-of-the-art is a mess.

Second, we do not really the prevalence and natural history of the syndrome. Most studies suggest that about 20% of adults develop long-term problems. The problem is more common in those who had very symptomatic acute disease but importantly can occur in those who were relatively asymptomatic. Women are more likely to suffer long-term issues than men, which I think provides important insights into the mechanism. Anecdotally, most clinicians feel the symptoms slowly improve for most but not everyone.

Third, we do not know how much of what people are experiencing is solely due to the infection. The pandemic has had a massive effect on the health of everyone. Social isolation can affect one's health in complicated ways, as can the loss of one's livelihood. Untangling all of these issues will be challenging.

Fourth, we do not know the mechanism for long-COVID. This may now be the most critical question for the field to address. It is also what the NIH does best. In the 1980s, massive investments from the NIH led to the discovery of how HIV replicates. Once this happened, industry was able to rapidly develop effective therapies. Fortunately, the NIH is now investing heavily in such work.

Fifth, we need to engage industry and the regulatory agencies. Developing therapies will not happen unless we somehow find a way to incentivize our partners in the pharmaceutical industry.

Finally, we need to engage all of the affected communities more fully. This will require dedicated resources and the input of experts on health disparities and related issues.

Ms. ESHOO. Thank you, very, very much, Doctor. It is really compelling testimony.

Where do I start? I am going to recognize myself for 5 minutes of questions.

To Dr. Possick, on the issue of the multidisciplinary team of specialists that were formed at the clinic, I always look for what we already have established in our country that we could make use of, such as, you know, the federally qualified, you know, community health centers across our country. We have made some very heavy investments through all the legislation that we passed last year and I believe again in the American Rescue Act.

In your view, can these be—you know, what we have in clinics that are attached to academic institutions, but we don't have that in every community in rural areas in the country and we are not going to, especially moving through this. Can that team, do you think, be replicated and stood up through the community health clinics in our country?

Dr. POSSICK. Thank you for that question. I think it is a really important one. I think it is important to acknowledge too that the different kinds of post-COVID clinics that have stood up around the country are all really different from one another, and they are very much grassroots efforts. Whoever had the resources, had the time, was able to take the initiative and forge the relationships, because most of them are multidisciplinary.

Ms. ESHOO. How many are there, do you know?

Dr. POSSICK. Over 60.

Ms. ESHOO. Ah.

Dr. POSSICK. Yes. So, you know, I think that it was necessary to engage subspecialists to aggregate information quickly and aggregate experience, but now is the time to bring that back out into primary care and, particularly, community organizations and federally qualified health centers, because I think that the shear math of the potential problem will make it essential that we do so and also not to leave any community behind.

Ms. ESHOO. Well, obviously, that is always our goal, our North Star. Because, boy, going back and trying to repair the holes in the safety net is really an ordeal, and a lot of people are hurt as a result of it.

I want to go to Dr.—what is the matter with me? Fog. Dr. Deeks, are you aware of the study that is coming out of Texas relative to this whole issue that COVID–19 alters human genes and explaining the mystery behind the coronavirus long-haulers? Are you familiar with that? And if you are, can you elaborate on what is part of that?

Dr. DEEKS. I am afraid I am not familiar with [inaudible] study that you are talking about specifically.

Ms. ESHOO. OK.

Dr. DEEKS. Virus infections and inflammation do affect the methylation, and I am assuming that is what we are talking about here, but I cannot honestly provide anything beyond that.

Ms. ESHOO. OK. Well, specifically, the scientists reveal that the spike protein of SARS–CoV–2, the virus causing COVID–19, creates long-lasting changes to human gene expression and that these tiny spikes cover, you know, much of that. But maybe you can re-

search this a little bit and give me a written answer to it, because I am very curious about it.

To Ms. Hakala and Ms. Smith, you have—if there is anything you have driven home to members of the committee, is that you have not been listened to. You have not been listened to. So today, obviously, it is your chance to be heard. What do you think is the most important thing that you want Congress to understand about long COVID? And why don't we start with Ms. Smith and then go to Natalie.

Ms. SMITH. Thank you for asking that. I appreciate that question. It has been so important to me, because I am a Black woman who understands that, historically, Black women have not been believed for so many different chronic conditions. It has been important for me to drive home how important it is to invest in equitable research and treatment and healthcare for other Black women who are suffering with long COVID.

Many of us are afraid to speak out because, historically, we understand that we have not been believed. We have not been taken seriously. Some of my friends that I have met, my new friends, my wonderful friends that I have met that have long COVID now have mentioned to me—we share stories of being racially profiled and discriminated the several times we have gone to hospitals and medical centers for treatment, and that is devastating.

So it is important for me to assure that Black people who live in urban communities, underserved communities, low-income communities where I have taught, where I have lived, and where I have served for the past 5 and 19 years, that we receive education and care that is comprehensive to us. We have not received that yet. We have not received that yet. And there are no studies that speak to that. So thank you for asking that question.

Ms. ESHOO. Well, thank you for your answer. With all the passion in the world, you are teaching us. You are.

Ms. SMITH. Thank you.

Ms. ESHOO. Anybody who doesn't start paying attention to you, you tell them that you were a witness in the Congress of the United States.

Ms. SMITH. I will.

Ms. ESHOO. Start with that one. And if they don't believe you, have them call me.

Ms. SMITH. Thank you. I will.

Ms. ESHOO. Natalie and Lisa, do you want to add something to that?

I know I am over the time, but I think that, you know what, we are spending—this is important time. Do you want to add something to that that Congress needs to know?

Ms. HAKALA. Yes. I want just say that, like she mentioned, really making sure there is enough research. And like just getting the word out to people that this is a recurring problem for a lot of people in a lot of communities. And it is primarily like frontline people and people who are not protected initially and then weren't believed after they were, like, serving all these other people. And they weren't believed when they were told, "You are having these problems."

I was in the hospital and some of the doctors didn't even want to come into the room and listen to my heart, because they were—I don't know if they were afraid that I was going to get them sick, even though I was past my 2 weeks of initial infection, so I was no longer contagious, but they still did not want to come in and treat me. They were afraid that—I don't know if I would get them sick or what they were afraid of. But it is very disheartening to not want to be heard. And it is, like, really appreciative that you guys are listening to us and wanting to help those people who weren't listened to for so long.

Ms. ESHOO. Lisa, do you want to add something to that?

Ms. MCCORKELL. Yes. Thank you for the opportunity. I would say, to echo Chimere and Natalie, I think including making sure that there is equitable access to care and to research is one of the most important things. It needs to be affordable care as well. We are not really seeing that.

And then also, people need the ability to and the knowledge to rest. That is one of the most important things that people can do, particularly at the beginning of their illness. There is research that shows that people who rest in the beginning stages of their illness are less likely to have prolonged symptoms at month six. But people don't have the ability to do that financially. And that is a problem with our paid sick leave, with our disability benefits, with worker's compensation. So we really need to make progress with workplace accommodation and our safety net in order to really help long-haulers.

Ms. ESHOO. Well, I think that what each one of you said is enormously helpful to all of the Members. And I thank the Members for their patience in the Chair going way over her time.

I now yield to the ranking member of our subcommittee, Mr. Guthrie of Kentucky, for your time to question.

Mr. GUTHRIE. Thanks, Madam Chair. And I am going to try to stay within my 5, but if one of my colleagues wants a little extra time, maybe we can be indulgent as well.

Ms. ESHOO. I have been very generous with everyone, so——

Mr. GUTHRIE. I know. Exactly, exactly, as we move forward.

I just have—well, with all the questions I have had, you guys have talked about it. And, one, Ms. Smith, we had hearings on maternity and different disparities between people of different ethnic backgrounds, and healthcare results is something that this committee has looked at from, not just in this respect, but a lot of others and holds serious and wants to get to the bottom of and move forward.

The thing is I think all three of you said that you were either underdiagnosed or misdiagnosed or not diagnosed, or I am not sure moving forward. And it seems like Dr. Deeks kind of had maybe one of the best explanations that it sounds like, in your profession, you guys are trying to figure this out as well. But it does seem—I think to quote, you said it is a mess. That is what you said in your testimony.

But it does seem that people are presenting with some issues, whether the physicians or the healthcare providers seem to think that it is long COVID or some other issues. It just seems like they are getting dismissed.

And, Dr. Possick, I spent a couple of years in the Yale New Haven area. I have a lot of—very impressed with the Yale New Haven Hospital there. And I think you also said that you have more people presenting for COVID long haul than asthma or COPD combined.

And so, why do you think that people are coming—to the two physicians here, why do you think people are coming to the hospital and having the type of experience they are having when they really do have some kind of illness? I know it is difficult to diagnose and it is also new, so we are trying to figure it out, as Dr. Deeks said, trying to sort through it. But could you just give us some insight why you think your colleagues in the healthcare world are dismissing people as not being sick when they are? Dr. Possick, do you want to go first?

Dr. POSSICK. Sure. Well, first of all, I think implicit bias and cognitive bias are not issues that are new. But, as one of the members pointed out in the first panel, it has sort of thrown all these things into sharp relief, and we have had to face them. But I think one of the particular challenges with post-COVID conditions is that it is new and physicians don't necessarily even know what to be looking for. I think some of us are still not entirely convinced that this is all a single entity, you know, and we are all just putting our hands on different parts of the elephant. It may be that with time we come to recognize, as Dr. Deeks says, that there are multiple phenotypes. But I think our implicit biases have gotten in the way at multiple points during this pandemic, and we need to take steps to rectify that.

Mr. GUTHRIE. Are you collaborating with other pulmonologists? Are you seeing—I mean, how are you guys sharing this? Because that is what we are trying to—I am trying to figure out. I am not speaking for all of us. But how does this get disseminated as we are learning, as we go, since it is so new?

Dr. POSSICK. The CDC has been incredibly helpful in this regard. You know, the COCA calls have been essential. They brought all of us to the table together to talk about our first impressions, a general consensus, helping to simply name it. Naming has power, and we need to do that sooner rather than later and come up with clinical criteria so that primary care physicians can feel empowered to codify a diagnosis for a patient where maybe without guidance they don't feel comfortable doing so.

Mr. GUTHRIE. OK. Thanks.

Dr. Deeks, kind of my line of questions, if you have some comments on that as well.

I think you are muted.

Dr. DEEKS. I can't believe I did that.

There are two things I would say. Clinicians like to be able to measure stuff, right? They like—they want to measure something and then they want to give a drug, right? That is what we as physicians do. We want to test, right? So—and there does not exist one for this problem, because the symptoms are very difficult to quantify, and they are somewhat vague and they vary from person to person.

There is, within this whole long COVID, a subset of people who have tachycardia. And even—like me, I gravitate to that, because

that is measurable, right? People stand up, they have fast heart rate. That is a diagnostic test. That is another spectrum within this whole COVID. And I particularly, you know, engage more in that because I can measure it and we can treat it. There is treatment for that one. And so it is a cultural thing, right? That is what physicians do. We want to be able to say, here is the test and here is the treatment. And right now, we have no test and we have no treatment, and this is the fundamental problem.

Another issue, which I did mention, is a lot of clinicians think, well, you know, we are all depressed. It has been a lousy year. You know, let me tell you about my problems. And I will tell you, I have colleagues at work who say, "I don't believe why you are studying this phenomenon," right? Because if I have the same problem and I never had COVID, it is because of the pandemic. And so these are the kind of discussions that are happening in the clinic. And this is what people who have [inaudible] are confronting this kind of culture, which will be difficult to overcome.

Ms. ESHOO. It is his connection.

Mr. GUTHRIE. Well, thanks, thanks.

And that is why we are having this hearing, so that is just helpful. Thanks.

And I did overspend my time. And I will yield back, Madam Chair.

Ms. ESHOO. Well, you are most welcome, Mr. Guthrie, and thank you.

The Chair is pleased to recognize the gentlewoman from California, Ms. Matsui, for her 5 minutes of questions.

Ms. MATSUI. Thank you very much, Madam Chair.

And I want to thank the second panel for sharing your stories and your experiences with us today. That gives us a sense of how people who have had this COVID–19 long haul have experienced all of this. And we are just beginning to understand what long COVID looks like, and your voices are key to helping us determine where to go from here.

Now, we know that the COVID–19 pandemic and the resulting economic recession have negatively affected many people's mental health. Increased stressors such as job loss and financial insecurity, as well as the physical distancing necessary to slow the spread of the virus are difficult enough. But patients with long COVID face the added challenges in managing physical and mental symptoms of a new chronic illness. Furthermore, patients with long COVID are often first referred to healthcare professionals specializing in respiratory or rehabilitation medicine.

Dr. Possick, as you reopened face-to-face outpatient services, what strategies did your pulmonary practice take to meet the multifaceted needs of patients presenting with post-COVID–19 symptoms?

Dr. POSSICK. Thank you for that question. So we had very deliberately created both an in-clinic and a beyond-clinic model that was multidisciplinary, because we could tell, even with the patients we met earliest via telehealth alone, that it was not purely a respiratory issue. And we know that too from post-ICU syndrome that it is multidimensional, really needs a multidimensional approach.

We were lucky that we were able to assemble other stakeholders in respiratory therapy, physical therapy, and in other medical specialties to tack that on. But probably one of the most important things we did is we built a collaboration between our social worker and psychiatry services, which has really been instrumental in helping support patients while we work through the medical issues.

Ms. MATSUI. That is wonderful.

Let's see. Lisa, I appreciate your testimony on integrated medical care that is needed to treat long COVID. Can you elaborate how mental health treatment fits in with that approach?

Ms. MCCORKELL. Yes, absolutely. Thank you for the question. I think with long-COVID patients, and I think, like Dr. Deeks said earlier, you know, there is—we are all going through a lot right now, and particularly with long COVID, there is a lot that needs to be treated but as a secondary treatment. And what is happening with a lot of long-COVID patients is that, like what happened with me, anxiety is being treated as a primary treatment. And just because we may present with anxiety doesn't mean that is causing our symptoms. I think that is really important for a clinician to understand. We are dealing with having a new chronic illness, newly becoming disabled, as well as just living during a pandemic.

And I think in terms of an integrated care, it is really important that in any kind of post-COVID clinic or any kind of clinician setting, that the mental health treatment is available and is recommended for folks, but, again, as a secondary treatment.

And I did want to mention just something in regards to post-COVID clinics. I think a lot of them have provided a lot of really great care, but currently there is no Medicare reimbursement strategy that is happening. And that is something that really needs to be prioritized, because, without that, it is really inaccessible and inequitable.

Ms. MATSUI. OK. Well, thank you, Lisa.

Dr. Deeks, you made the salient point that untangling symptoms related to infection versus other issues will be difficult when it comes to treating long COVID. Do you agree that integrated care is the best approach here?

Dr. DEEKS. I worked—before 2020, I did full-time HIV care. And HIV care, since the late '80s, has been one in which we integrate all aspects of care in the same clinic, and it works. And a really important part of the care that we provide in the public health clinic is access to social workers and people who have expertise in sort of working through all the issues with insurance and so forth.

So, yes, we need integrated care with physicians, physical therapists, psychiatrists, and I actually think a lot of social workers and people who can do patient support groups. And that is what these clinics would do and provide people with access to all this stuff. But it is navigating these complicated economic issues that is really, really difficult. And that needs to be part of the clinic. And I think the three stories we heard today sort of made that point.

Ms. MATSUI. Absolutely. Thank you very much, Dr. Deeks.

And I yield back. Thank you, Madam Chair.

Ms. ESHOO. The gentlewoman yields back.

Pleasure to recognize the ranking member of the full committee, Ms. Cathy McMorris Rodgers, for her 5 minutes of questions.

Mrs. RODGERS. Thank you, Madam Chair.

Ms. Smith, you say that we must reconcile our unwillingness to recognize chronic conditions we can't visibly see. What do you believe can be done to educate health providers and patients about long COVID?

And in your testimony, you discuss using your church as a hub for patients and their caregivers to receive long COVID education and mental health treatment in Baltimore. Would you describe that project in more detail?

Ms. SMITH. Sure. You know, I am in the planning process and in the grant-writing process of that proposal, hoping that I can get some funding from somewhere so that I can make that a reality. And I think that is important.

Both questions that you ask tie in together. I am talking to the post-COVID clinic at Johns Hopkins, which I did not qualify for, sadly, because I have never tested positive for COVID. But one of the doctors there—who I can't recall, because I have brain fog, and memory loss, and I am excited—she and I will be working together to try to find a way, a safe way, a protective way to reach some of those patients who need additional support outside of that care clinic.

And so it is my hope that the proposal that I write will explore a safe way, you know, for the residents of the northwestern Baltimore community to come to a place where they can receive mental health treatment or counseling sessions, to receive any additional medical education that we can provide for them and their families. It is so important, because I had to travel to Washington, DC, to get—to be even qualified for a post-COVID clinic appointment. And so people like me who live in a low-income neighborhood should not have to travel so far. So those doctors at that postacute-care clinic, we are talking together to find a safe, equitable way for us to educate the people of Baltimore.

Mrs. RODGERS. Thank you for sharing.

Dr. Deeks, I heard about a recent study of patients diagnosed with COVID–19 that found, 6 months after their diagnosis, a third of them were experiencing psychiatric or neurological illness. Would you speak to what we know about the impacts of COVID–19 on mental illness?

I think you are muted. Sorry.

Dr. DEEKS. I have been doing this for a while. I should figure this out.

So you can't untangle these things, right? The mental health issues, anxiety, depression, they contribute to physical symptoms, and physical symptoms contribute to them. And this is particularly true of people who have the neuropsychiatric flavor of the symptom, but it applies to everything. So it is an absolutely critical part of what people are experiencing [inaudible] consequence of what their experience is not known. It probably goes a little [inaudible] but it requires access that people who have the expertise to treat it. It is a big part of people's—what they are experiencing.

Mrs. RODGERS. Thank you.

Dr. Possick, I just wanted to ask you very quickly about young people in particular who are thinking that they are invincible to COVID. Would you tell us about the importance of increasing pub-

lic awareness about the post-COVID–19 disease and especially highlighting the mild acute illness and what young people are experiencing?

Dr. POSSICK. Certainly. Thank you for the question. Young people have been part of our patient cohort from the start, in part because of the healthcare workers that we were treating early on, a lot of them were young Black women. But as time has gone on and vaccines have been rolled out to older and at-risk individuals first, our clinic population has shifted younger and younger.

These patients often report that they were minimally sick at the onset and really taken by surprise with how much they are struggling now. I think it is difficult to message, but an important part of the message that I think, as Lisa said, you know, it is not a binary outcome, survival or not. There are many possible downstream effects of getting ill with COVID–19, and this is an important one for people who view themselves as low risk or no risk need to hear about.

And we need to also work to understand and address what motivates vaccine reluctance so that we aren't simply finger wagging, that we are engaging in that dialogue and understanding what that is about.

Mrs. RODGERS. Thank you so much. Thank you, everyone.

I yield back, Madam Chair.

Ms. ESHOO. I thank the ranking member. Yields back.

There are many Members that rank on the list here in terms of themselves presenting themselves this morning, but there are at least maybe 10 that are not available. So I am going to go to and recognize Congresswoman Dingell from Michigan for her 5 minutes of questions.

Mrs. DINGELL. Thank you, Madam Chair. And I want to thank all of the witnesses for your patience today but also your testimony.

I have to tell you that—and you can tell as Members have been talking to you that there have been patients that have reached out to us, told us their stories. And we know the trauma many of you are suffering from, of people even taking you seriously, where do you go, how do you get support, et cetera. So what I have found very impressive in the testimony today and in discussions with other people is the Patient-Led Research Collaborative. The U.S. has unmatched research infrastructure, and we have started to advance patient-centered research through organizations like PCORI.

But I am really impressed with the ability of patients to self-organize around a new condition like long-haul COVID and get your voices together and to be effective quickly. And I think that is really important and to get your results quickly into the medical literature.

So I would like to ask Ms. McCorkell some questions. Thank you for being here, first of all. Can you share more about the patient-led research group and how your team formed?

Ms. MCCORKELL. Yes. And thank you so much for those really kind words. I completely agree with you that patient-led research is filling a gap right now.

So Patient-Led Research Collaborative formed back in April of last year. We just celebrated our 1-year anniversary. And it was after all five of the team leads, we all got sick in March and real-

ized after a month that we were still. We joined the Body Politic support group, which has helped so many people just find a community of other folks who are going through the same thing. And we all have research backgrounds. Mine is in policy. And we realized that there was just so much information being shared and someone needs to document it, because it was clear at that point, which was April of last year, no one was really paying attention to us. Doctors were gaslighting us. We weren't able to get tested. And the media at that point wasn't covering us either.

So we put out a survey, we got 640 respondents, and that was the first research on long COVID. And I think that really helped to bring to the forefront of the conversation this issue and this illness. So that is a little bit about how we formed.

Mrs. DINGELL. And I hope that you all at our hearing today and are going to take back to your coalitions that we are hearing you. And that is why Chairman Eshoo doing this hearing is so important, because you are helping spread the word via this, and we want to support you. But my next question is, how is your organization engaging with researchers at the NIH or with PCORI? How are we making sure it is coming together the way it needs?

Ms. MCCORKELL. Yes. So thankfully we have had a lot of outreach with different researchers, and there are definitely researchers out there that we have been in conversations with. We actually have applied for part of the funding that NIH is providing. So I guess we will hear back from Dr. Collins in the next few weeks. So we have applied in partnership with other researchers on that funding.

So with PCORI as well we are hoping to do a project with them. So we are in communication with a lot of folks.

I think our biggest hope, though, is that, you know, there were over 200 applications for this NIH funding, which is awesome. But our worry is that not all of them are going to incorporate the patient voice. Not all of them are going to incorporate the patient voice, not all of them are going to incorporate past research into post-viral illness, like ME/CFS, not all of them are going to incorporate ME/CFS patients. And these are very critical in order to actually create findings that are going to be useful for long-COVID patients.

Mrs. DINGELL. Well, I am running out of time. So I think if we could maybe get your input for the record on some issues, like how do we advance patient engagement in our country's research efforts, and how do we build—would it help us build trust in research and diversity efforts?

But I really hope you are hearing from Republicans and Democrats alike. There is no—we are hearing you, and we want to help you all. And I have heard from people in my district, as you all are saying, "People don't believe us, they don't know it." We believe you, and we are here. We are going to help you.

So, thank you, Madam Chair.

Ms. ESHOO. The gentlewoman yields back, and thank her.

A pleasure to recognizes Dr. Burgess for your 5 minutes of questions.

Mr. BURGESS. Thank you.

Appreciate everyone being on this hearing and staying around for this part of it. It is so terribly important. And just like every other Member, I have heard from a number of people [inaudible] different time there was something called Gulf War Syndrome. And while my clinical practice was not taking care of people who had Gulf War Syndrome, my clinical practice was taking care of a number of spouses of people with Gulf War Syndrome and the original assignments that this is malingering, imagined, it is not real.

It was actually the actions of Ross Perot, Sr. who got some epidemiologists at Southwestern Medical School involved and discovered an actual pathologic pathway where there was an inactivity of one of the pseudo phosphodiesterases enzymes, and these people could not metabolize even small amounts of nerve gas that they might have encountered in the first Gulf War. And as a consequence, they ended up to go on first with a set of nonspecific symptoms but then did progress to something that very much resembled ALS. But by the time that was in evidence, it was probably past the point of being able to do much besides just make someone comfortable.

So this work that is going on is so incredibly important. And I appreciate so much patients, I appreciate the clinicians who are working on this, and I know it is not easy, and I appreciate the perspective the patients are bringing to us. It is hard to not be listened to. And let me just tell you, from the standpoint of someone who at one time ran a very, very busy medical practice, you get behind and you are able to devote 6.2 minutes to every patient, and it can be hard to give the proper amount of attention.

And I guess what I would ask Dr. Deeks and Dr. Possick on the call, is it possible with what we know now with telemedicine with the way that has come into its own, is it possible to provide some additional help to the people on the front lines, both diagnostic and/or some of the therapeutic interventions that might be entertained?

Dr. POSSICK. I can tackle that first. I think I would say that we found telemedicine to be indispensable. We probably were late to adopting it the way we should have, and COVID–19 forced our hand in a good way. It has been helpful. We need better support and infrastructure for it, because telehealth is not an equitable access resource for all patients. And there are barriers to reaching people who have technology barriers or health literacy barriers in other ways. But I do think that it will play an important role.

We use it interchangeably with our face-to-face visits now, depending on where our patient is and what they can manage, because navigating all this multidisciplinary care is exhausting for people. And sometimes it is easier for them to engage with a visit from their home than to come into the clinic.

Mr. BURGESS. Sure.

And, Dr. Deeks, do you have anything you would want to add to that?

Dr. DEEKS. Well, if you had a lot of money, you would do it right. If you would do what you did with the Ryan White programs, right, which was money was basically put aside in urban centers to provide disenfranchised, uninsured people who had HIV with access to these integrated-type clinics in which they didn't have to worry

about paying for anything. They just showed up and they got everything they needed. And it was incredibly therapeutic and effective. And, you know, ultimately, I——

Mr. BURGESS. Let me just ask you——

Dr. DEEKS. Initially——

Mr. BURGESS. We had some experience with Project ECHO in more rural parts of my State where the access to specialists can be a force multiplier for patients who wouldn't have the availability of sophisticated specialists. Is that something we can incorporate into the care of a long-COVID patient?

Dr. DEEKS. Since there's so many specialists involved and there is a need to bring them to the same place so people can navigate it, yes. How they go about doing that is going to require resources and some original thinking.

Mr. BURGESS. Yes. You know, I was thinking when Dr. Collins was talking about, you know, some of the things that we don't know, is this a lingering effect of the virus in someone's system? Is this an effect of a vasculitis? And then he mentioned a third thing that now I don't recall off the top of my head. But there is a possibility it is also in the individual, it may be any one of those things. In some there may even be a combination or a spectrum. It just strikes me there is a lot we have to learn about this. But anything we can do as a force multiplier on the provider side is ultimately going to benefit our patients. And, clearly, with the stories we have heard today, we are not doing necessarily the best job in hearing and listening to the patients who have presented to us today.

I thank you all for your input on this committee. It has been very valuable. I will probably have some questions to follow up on the questions for the record in a written response. So thank you all for being here today.

Ms. ESHOO. The gentleman yields back.

And it is a pleasure for me to recognize the gentleman from California, Mr. Cárdenas, for your 5 minutes of questions.

Mr. CÁRDENAS. Thank you very much, Madam Chairwoman. And once again, thank you and to the ranking member for having this important, important hearing and certainly bringing on this second panel to enlighten us some more so that we can make better decisions with the taxpayer dollars and also with the policies that we advance across the country. So thank you all very, very much for being here to help enlighten us.

I also want to especially thank all of the witnesses and those of you who have given us your heartfelt experiences. And you have been willing to share with us in view of every person who chooses to tune in across this country. And these are important stories because they are real stories. And we have to do things to make sure that they do not repeat themselves. This is literally life and death that we are talking about.

My first question is to you, Ms. Smith. In your testimony, you express that you carry the weight of other Black women who, like you, have been misdiagnosed and frightened. But also I am going to put upon your shoulders, you have expressed what I heard personally from Hispanics, from Native Americans, and a lot of people who have, unfortunately, received less than the care that should be

available to them when somebody else is, rightfully so, getting that care. So thank you for being here and representing yourself——

Ms. SMITH. Thank you.

Mr. CÁRDENAS [continuing]. And especially those people and every person—man, woman, and child—who has received less than what merits them in our amazing system when it works well.

My first question to you is, do you think racism exists in America? And is it limited or does it stop at the door of healthcare?

Ms. SMITH. It absolutely exists in America. I have experienced it. I am a middle school teacher in Baltimore, Maryland, and I have experienced it even in some of these—on some of these, you know, meetings and organizations and corporations and these talks. While I am excited and thankful for the opportunity, I still see that we are doing a—we are at a deficit with how we include Black stakeholders and researchers and scientists and doctors into this conversation. It is what—before I became ill last March, it is what I tried and strived so hard to teach my students about. We were in—you know, I teach low-income students and families but in an affluent neighborhood. I wanted them to be aware that just because they were Black and sometimes underrepresented, that they still had a place in the educational system.

As I mentioned in my testimony, I had been repeatedly, repeatedly racially profiled over the course of the last year. I think the assumption for me is that because I am Black and a woman in a low-income neighborhood, that I am not aware of my body, that I can't research what is happening to me, and that I am not articulate enough to share those experiences. But what I think I have been able to do is to challenge that perspective. And so I also have talked to other women—I talk to them every day—and our fear is that we will be left behind because we may be too afraid to speak out.

So it is my hope to challenge doctors who racially profiled me, who called me too aggressive, who used microaggressive language with me to change the dynamic and change the narrative of what long COVID looks like. It is not just a White woman's disease, and, sadly, that is the way it has been painted.

Mr. CÁRDENAS. Well, thank you for expressing those truths.

And one of the things that I would like to point out, I know the word "racism" hits people like a dagger.

Ms. SMITH. Yes.

Mr. CÁRDENAS. And I think some people think that somebody who is expressing or treating somebody in a racist way has got a bad heart. Unfortunately, I think many times it is just ignorance. It is just the person doesn't recognize that we all have biases, doesn't recognize that this person whose voice might be a little different than mine, whose mannerisms might be a little different than mine or what have you, it is not a negative thing, it is just different. It is just different. But, unfortunately, the weight of those actions day after day, especially when your life depends on this person giving you the respect and the attention that they are actually paid to give you, the respect and the attention you have actually paid for, it is kind of like, if I were to put a little pebble in my hand, I could hold it, but add one pebble and 1,000 pebbles and

2,000 pebbles and somewhere along the way, my arm is going to go down because the weight is too heavy.

So I just want to say how much I appreciate you coming forward and expressing yourself and enlightening us to the fact that racism isn't something that starts from ugliness, but the results of racism far too often are ugly, they are damaging, and in some cases could lead to ending someone's life. And entire communities are receiving that. And it is important that we recognize that we are not calling people bad people who participate in contributing to that. We are just saying please look in the mirror and recognize it, check yourself. And if somebody checks you, please understand, be open, be open to being checked, and then be willing to apologize if you recognize that you have acted in ignorance.

So, anyway, I apologize for going over my time, Madam Chair. Thank you all so much for coming today.

Ms. ESHOO. Wonderful. The gentleman yields back.

A pleasure to once again recognize the gentleman from Virginia, Mr. Griffith, for your 5 minutes of questions.

Mr. GRIFFITH. Thank you very much, Madam——

Ms. ESHOO. There you are.

Mr. GRIFFITH. I am here. Thank you very much, Madam Chair.

Ms. ESHOO. Sure.

Mr. GRIFFITH. I do appreciate it.

Dr. Deeks and Dr. Possick both, as you may have heard in the prior—and I understand it has been a long day—but in the prior testimony, I talked about a friend of mine who has long COVID. He has been in and out of the hospital four times, mostly with breathing issues and, of course, just generally being weak. His doctors are telling him that, you know, as he moves along, that he should be doing, you know, more exercise and that that will take care of the problem.

Do you think that makes sense, or is it just that every case is so different that it is just very hard to say what makes sense across the board? Go ahead and start, Dr. Deeks, and then, Dr. Possick, if you want to.

Dr. DEEKS. Well, Dr. Possick is an expert on this very specific issue, so I will defer to her.

Mr. GRIFFITH. All right. That would be fine.

Dr. POSSICK. I think we have seen great value in many different kinds of rehabilitation therapy for our patients, which may not be true for all patients. But I also think that we have to approach statements about rehabilitation carefully, because it is not a one-size-fits-all solution and has to be adapted to the patient in front of us: their particular condition, their particular symptoms, our hypothesis about why they feel the way they do, and how they respond to initiation of rehabilitation.

And it is not merely physical rehabilitation. It can involve speech therapy, cognitive therapy, occupational therapy, and specialized programs like pulmonary rehab and cardiac rehab. And the appropriate solution for any given patient requires assessment by a professional in physiatry or physical therapy.

Mr. GRIFFITH. And I think what makes it so difficult, from listening to the testimony of you all today and our prior panel, because, originally, my questions were what is the answer and what should

the fix be, what should the treatment be. And it sounds like it is different for every person. And doesn't that make it difficult for the frontline physician or medical care professionals? Because somebody comes in presenting, it may not be the same way that somebody else with long COVID presented just last week. And doesn't that make it hard on the primary care doctors to be able to figure out that they are dealing with long-term COVID issues?

Dr. POSSICK. That is true, but it is not true of only this circumstance. We face that with a lot of different medical conditions. And there is a high degree of heterogeneity in nearly every disease that we treat.

I think that a starting place is dialogue like this, and also definitions and best practice guidelines from CDC and from professional organizations that then give frontline primary care providers a tool to tease out what they think is going on with any particular patient in front of them.

But, you know, heterogeneity is not novel to this one circumstance. It is something that we face in a lot of cases. But we need to just start by acknowledging that that is also the case here.

Mr. GRIFFITH. Yes. And I think this hearing is good, and so I appreciate your time in this long day, and everybody's time on the panel this long day, because I think there is a public misperception on this too. Because I will tell you that I don't know exactly why we thought he was getting better and he really wanted to get back to work. And at one point, months ago, I had lunch with him and then he had a relapse. And I think there is this perception that, you know, OK, you had COVID, get over it, come back to work or get over it and get back to your regular routine. And for so many people, that is just not possible. Is that a fair statement?

Dr. POSSICK. Yes. I think that, in this condition, like many, recovery is not linear.

Dr. DEEKS. So this waxing and waning of symptoms is difficult to explain why that would be, but it is very common. It is very common. So I don't—we don't have a mechanism for it. We don't know why that would be, but it is something, I think, certainly in our clinical cohort, we have seen that. People have good days, they have bad days. And it is hard to explain why.

Mr. GRIFFITH. Yes. I appreciate that very much.

And, with that, Madam Chair, I yield back.

Ms. ESHOO. The gentleman yields back.

The Chair now recognizes the gentlewoman from Illinois, Ms. Kelly, for your 5 minutes of questions.

Ms. KELLY. Thank you, Madam Chair.

And thank you to the witnesses and all of your patience.

Ms. Smith, thank you so much for coming today to share your experiences as a Black woman. As a Black woman, I really, really appreciate that. You shared some things, but can you tell us what areas of opportunity that our healthcare system could have supported you more? Like what would you have liked to have seen? What do you want to happen? How can you improve the system?

Ms. SMITH. Absolutely. Thank you for the question. I would have loved from the very beginning to have doctors who documented my experience and the narrative that I shared with them about my experiences. What I find now is one of my biggest problems, and I

know it is the problems of many long-COVID and ME and CSF patients, is that the notes that are being written about us do not depict an accurate picture of our experiences.

I have had to go through pages and pages and pages of medical records that don't even indicate that I said as the patient that, even though I tested negative for COVID, that I believed—even though I tested negative, that I believed that I have it. And so—there has also been so much inaccuracy in what has been reported about me.

I have been recently reading a doctor who says that he doesn't know whether I worked over the last year. I can tell anybody that I have not worked a single day since March 23, 2020. And so it is my hope that, especially in the Black community and other urban areas and even rural communities, that our narratives, our experiences are documented into those notes.

It makes our lives a little bit easier when that happens, because now I am facing challenges with my employer because of the notes. I was dismissed from the NIH studies because they claimed that I didn't have medical notes that represented my condition.

And so copious notes from doctors are so important, and ironically I just got an email from a doctor recently as a couple minutes ago who said that he has added my experience to documentation.

So that is going to help me when I apply for disability benefits, which I know I will need in the next couple of months. So that is the most important step that we can make to helping long-COVID patients.

Ms. KELLY. Thank you so much for sharing. I am the chair of the Congressional Black Caucus Health Braintrust, and I do a lot of work around maternal mortality and what has happened to Black women. So I appreciate you sharing. We need more people to do that.

Dr. Possick, as we know, COVID–19 disproportionately impacted Black and Brown communities, which is evident in that data of infection rates and mortality rates. And it seems like we are seeing this trend in long COVID disease. What barriers are keeping people from receiving the equitable post-acute care that you state is necessary for all to receive?

Dr. POSSICK. There are many. I think trust of the medical system is one. They can be more prone to be reluctant reporters, particularly if they are trying to return to work, return to their lives. There is a stigma associated with reporting these symptoms at all, and if they have encountered discouraging interactions early on, then they stop offering up the symptoms.

I think that, for working people, it is difficult to access medical appointments, period. Even if you can get an appointment, getting time off of work to go and do that, engage in the testing, engage in therapy can be really prohibitive. If I tell a patient of mine I think they need to go to see three other people, how can they possibly do that if they are also trying to earn a wage?

So I think that those are among the issues, you know, particularly with respect to underserved populations and people who don't have access to transportation, to telehealth-ready devices, that it can be very difficult to access care from afar that other people of means can. And also just generally navigating the system, trying

to work through how to apply for workman's comp for disability is incredibly complex. And so, without empowering people and helping them to access those services, they just face insurmountable challenges.

Ms. KELLY. Thank you so very, very much and thank all of you for being here today.

I yield back, Madam Chair.

Ms. ESHOO. The gentlewoman yields back. Pleasure to recognize the gentleman from Florida, Mr. Bilirakis, for your 5 minutes of questions.

Mr. BILIRAKIS. Thank you so much, Ms. Chair. Thank you very much. This has been a great hearing, a bipartisan hearing, and I appreciate that so very much.

Ms. KELLY. What you need real quick what I am setting up for them?

Mr. BILIRAKIS. Can you hear me? OK.

Ms. ESHOO. If Robin Kelly would mute. OK?

Mr. BILIRAKIS. OK. All right. We are good. We are good.

Dr. Deeks, is there a universal definition for long-term COVID, or is it a catch-all term?

Dr. DEEKS. There is not even an accepted name, let alone a definition.

Mr. BILIRAKIS. Yes, yes. So the lack of standardization, does it impact research? And if so, how, and how can we standardized—how can it be addressed? I know it is tough, like you said. It is a very difficult to get your arms around it, but please if you could respond.

Dr. DEEKS. Yes. So I think Dr. Possick is maybe involved in some of these discussions more than me, but there is—there is an effort underway by various people around—various groups around the world to come up with case definitions. And my concern is that we may end up with several, and everyoneis going to use things that are different, but it is an absolutely essential thing—do you have any comments on this, Dr. Possick?

Mr. BILIRAKIS. Yes, Doctor, please.

Dr. POSSICK. Yes. I think that when I read these very important and enlightening studies that are based on EMR culling of data, I wonder about who we are missing. Because when I see a patient in a visit and I enter a diagnostic code, I have to use what I think best aligns with the patient I am seeing. So, even if I use a code that includes a personal history of COVID–19 or suspected COVID–19, the primary diagnosis may still be the thing that I am seeing them for.

So pulmonary infiltrates or interstitial lung disease or shortness of breath, and because we all approach this and code in different ways, because we are just trying to do our best, I don't know that studies that rely on EMR data are capturing everyone whereas, if there was adoption of uniform ICD–10 code for post-COVID conditions, yes, it might be a relatively blunt instrument that doesn't capture the phenotypic diversity, but it would at least identify people more readily. And I think that is really important.

Mr. BILIRAKIS. OK. Thank you.

Dr. Deeks, why do COVID long-haulers initially seem to be asymptomatic only then to suffer these devastating symptoms like,

again, we had with one of the presenters today? Can COVID hide in our system? If so, what does that mean for diagnostics and targeted therapies? And what are the most common long-term symptoms of COVID–19?

Dr. DEEKS. Let me deal with the first one, which is the——

Mr. BILIRAKIS. Sure. Absolutely. Please.

Dr. DEEKS. That is my area of expertise. Why would someone—so people who have very little symptoms begin with——

Mr. BILIRAKIS. Yes.

Dr. DEEKS [continuing]. Probably don't have much virus to begin with.

Mr. BILIRAKIS. OK.

Dr. DEEKS. So why would those people be sick months later? It is the way—these people when they are exposed to anything, just a little bit, it sets off an inflammatory response, an autoimmunity. So people develop antibodies to their own body, and that makes them sick. That is a leading theory for why someone who—it doesn't take a lot of virus in the right person to stimulate these autoimmune disorders. So that is—as to what the most common symptoms are, I don't know.

Dr. Possick sees these patients more than me. What do you think?

Dr. POSSICK. So, depending on the study you look at, you get different statistics and ranking for that. I am a pulmonologist in a lung clinic. So the most common symptom I see is shortness of breath, probably followed by tachycardia, fatigue, and what I would broadly term exertional intolerance. And sometimes orthostatic intolerance like difficulty sitting or standing for a long period of time, much less exerting one's self, but really we have seen symptoms that span every single organ system, depending on the patient.

Mental health symptoms are very prevalent, both in the population that was hospitalized and those that were not. And this includes new mental health symptoms, not just exacerbation of preexisting conditions.

Mr. BILIRAKIS. OK. Well, thank you very much. I know my time has expired, but I appreciate it very much. Thanks for the testimony. We learned a lot today. I know there is more to come. So thank you, Madam Chair.

I yield back.

Ms. ESHOO. The gentleman yields back. And I appreciate his questions and comments.

I now would like to recognize the gentlewoman from Washington State, one of our great doctors, Dr. Schrier. 5 minutes.

Ms. SCHRIER. Thank you, Madam Chair.

First, let me just say to our three patients—Ms. Smith, Ms. McCorkell, and Ms. Hakala—I just have profound sympathy and empathy for you, and I am so sorry for what you are going through and the way that you have been treated. And I do understand that—you know, that struggle that doctors go through when it is so frustrating to not be able to put your finger on it and do something, but I just want to express that sympathy.

To Dr. Possick and Dr. Deeks, thank you for diving in and embracing this uncertainty and the patients who are in distress where you don't necessarily have a way of fixing. And I am listening to

all of these comments and thinking that, of course, we need research at the NIH and CDC, but I am thinking about the things that Congress can do, like how can—this is the doctor thinking—like what can we do?

And one it sounds like we need to work with CMS to get an ICD–10 code, even if it is sort of like possibly in post-COVID symptoms not otherwise specified, something along those lines. It sounds like we really need to continue to work on our social safety net and healthcare coverage and FMLA to just keep people afloat. And it also sounds like we kind of need like a new RADx or a new warp speed to try to just take a stab at possible therapies. And so I guess my first question—I have a couple questions about this. One is we heard from Ms. Smith and Ms. McCorkell about negative antibody tests leading to this reluctance to diagnose, and I was just wondering, Dr. Deeks, could you talk about how common this lack of an antibody response is, and maybe does that then suggest a pathway to this maybe being like a chronic viral infection that never really stokes the immune system?

Dr. DEEKS. So great question. Depending on how you define it, maybe about 10 percent of people who develop COVID end up being—either have low antibodies or they are sero negative. They don't actually sero comport. Their antibodies remain negative. And, interestingly, those are the people you would think would have a lot of virus that would persist particularly in tissues. And, interestingly, those are the people that you would think would benefit from a therapeutic vaccine. They didn't generate an immune response. They have no antibodies. The virus is around causing disease. You get a vaccine. Now, they have antibodies. The virus goes away. And I have heard many anecdotes of people who have done that.

So it is one of those testable hypotheses. So we need to go out and find people who are antibody-negative who have these symptoms and do special tests to see if they are truly infected. And they are easy to do, but only in research centers. And to be honest, then you build up the immune system to fix it.

Ms. SCHRIER. So here is the next question, which is related to that, which is kind of like, right now, you have very few tools, if no tools in your toolbox. And if there are all these different pathways, you know, one is lingering infection, one is autoimmune, one is, you know, blood clots. Do you ever consider just empirically throwing everybody on aspirin, or it is kind of opposite things? Do you just put people on steroids for an overresponse or people on some sort of, you know, immunomodulator if you think that you are going down an autoimmune pathway? I am just wondering if you are already thinking through those possible treatments.

Dr. DEEKS. Yes. So that is happening, right. So you go to clinics right now, and people will be doing that. They will be giving statins because they are antiinflammatories. They will be given hydroxychloroquine because it blocks certain inflammatory pathways, and it is safe, and people give aspirin for clotting. And, actually, I think, the various clinics have their own sort of brand. And that is what a good clinician would do that, right? I mean, you have a person in front of you. They are sick. There is no treatment. You do the best that you can. There is some rationale.

And so that is happening. And, from that, people will write papers saying, "Here is my hundred patients. I did this, and here is what happened."

And that will lead to clinical trials. So we are in that process right now where I think clinicians are making it up as they go along, as they should, doing the best that they can and teaching each other what is happening.

But it is going to be years before we have targeted drugs and randomized clinical trial data. In the meantime, I think, not everyone would agree, you are somewhat obligated to try your best.

Ms. SCHRIER. I hope it is not years. Thank you very much.

I yield back.

Ms. ESHOO. The gentlewoman yields back.

Pleasure to recognize the gentleman from Georgia, Mr. Carter, for your 5 minutes, followed by Mr. Doyle of Pennsylvania. And I don't have any other Members on tap. So take it away, Mr. Carter.

Mr. CARTER. Thank you, Madam Chair.

And thank you, Dr. Possick, Dr. Deeks for being here. We appreciate this.

Dr. Possick, I wanted to ask you, in your written testimony you mentioned that many of your patients are young adults and adolescents. Why do you think that is?

Dr. POSSICK. Well, young adults certainly. We are not a pediatric clinic, so haven't been seeing adolescents, but, you know, I think it reflects potentially many things. We don't know if perhaps younger people are more susceptible. There are, as was referenced before, a large number of people in the 18-to-39 age group who have been infected with COVID. As time has gone on in older individuals and at-risk individuals have been vaccinated first, we have seen the age profile of our clinic population shift down. It is also possible that sicker people with more comorbidities at baseline and a higher level of disability at baseline don't register the changes to their health in the same way that a healthy long-distance runner who was working for a time would, right?

So some of it is where you started compared to where you are, but I do think that there are—especially now a lot of young people who are getting newly infected, unfortunately. And that is reflected by the patient profile that we are seeing in our ICUs as well, to some extent.

Mr. CARTER. What are the treatments that are working?

Dr. POSSICK. I don't think that we can broadly say that there is any treatment that is working for all patients. We don't have that answer yet. As Dr. Deeks had suggested there are things we try empirically. Sometimes they work for some patients, other times not, but we are not in a position yet to say that this is the regiment, this is the treatment that works.

Mr. CARTER. You mentioned something a little while ago that concerns me, and that has to do with about how can we ensure that we don't have a stigma that develops along with those who have long COVID? I am very concerned about that, and obviously you are too.

Dr. POSSICK. This hearing is an important place to start. The fact that you have invited patient panelists is incredibly important and sends an incredibly important message to the establishment and to

our whole community, but I think that, again, naming has a powerful message. So arriving on agreed-upon terminology for what patients are experiencing, then going on to create our best guess at clinical criteria for what that is, is important so that we can acknowledge and validate what people are experiencing.

Mr. CARTER. Dr. Deeks, any comments from you on that?

Dr. DEEKS. I am passionate about that last question. You know, HIV—we treat HIV, but people with HIV have stigma. It never goes away, and maybe a couple days of living in that kind of environment, but years of feeling—it wears you out. It is a huge impact.

So we have got to destigmatize this syndrome—give it a name, find a mechanism, have congressional hearings, have the NIH devote a billion dollars to it. This is all good, and all the media that is happening because these very powerful patient groups, their impact is through the media, right? The New York Times, Washington Post have been covering this extensively, and that is partly why we are here today.

So the stigma is something we are fixing, and I cannot overemphasize how much respect I have for this group spending an entire day talking about this. I can't get doctors to spend a whole day talking about this. So what you are doing today is very therapeutic.

Mr. CARTER. Well, thank you both for mentioning that about the stigma part of it. I mentioned in the first panel that I have got a dear friend who is, unfortunately, suffering through some psychotic episodes and mental health issues as a result of this, and that concerns me because I am very concerned about his health, but this is real.

I think a lot of people said, "Oh, I had COVID, and I didn't even know it." And they just kind of passed it along as being something that is not serious, but it is serious. And it is something that we have to take seriously.

So thank both of you for being here today. And thank you, Madam Chair. This has been a truly bipartisan hearing and a good hearing today, so thank you for this.

And I yield back.

Ms. ESHOO. The gentleman yields back.

Now I believe, last but not least, my pal, Mr. Doyle. You can wrap it up for us today. Five minutes.

Mr. DOYLE. Thank you, Anna. And thanks for holding this hearing. It is. It is very important. Thanks to both panels, especially the second panel because you guys had to sit here as long as we do. It is our job to sit here through the hearing, but boy, sometimes when you are on that second panel, this can be difficult. I really—I just want to thank Dr. Deeks and Possick for being here. The questions I had were the ones I wanted to talk to the NIH about, but I just stayed on, Anna, because I wanted Chimere and Lisa and Natalie to know that, to hang in there.

My son Kevin is a COVID long-hauler. I have been watching this up close and personal every day how this young, healthy athletic person, who was the most physically fit guy in our family and had COVID and had no—wasn't hospitalized. You know, couple days he didn't feel good and remember him calling me on the phone and said that was nothing. And here we are going on 4 months later

with the, you know, sleep disorders and the trouble breathing and pain in his chest and just this fatigue.

This is a guy who couldn't sit at a house. I mean, he was just out exercising. He has a gym in his basement that he works out in every day, and now he can't get out of bed sometimes and had to start going on disability at his job. So, you know, there is a lot we don't know about this yet, but there is a lot we do know. And there's doctors out there, by the way, that are treating. You are not going to get treatment in the establishment hospital. I live in Pittsburgh. We have one of the largest academic medical centers in the country, UPMC, and we have Allegheny General. And they have COVID long-hauler clinics.

But right now there is really no treatments there. You go there—because my son has been to both of them, and they ask you a bunch of questions, and, you know, and they treat symptoms. If you say you are having trouble breathing, they will let you see the pulmonologist. If you have neurological problems, they will send you to the neurologist. But they are not treating—there is not a prescribed approved cure or treatment, I should say, for COVID long hauler right now that NIH or FDA or CDC—but there are doctors out there, as Dr. Deeks said, trying to do their best with what they can. There's antiviral medicines out there. There's other medicines that have been used to treat HIV/AIDS.

I know the regimen my son is on, and it is starting to help him. But know this: We are going to continue to push the people here at NIH and CDC to make sure that we are not leaving any stone unturned. We may not need to reinvent the wheel. That is why I pressed the NIH to also test some of these drugs that are available that are off-label right now being used to see if they are effective or not. And, you know, we have really got to press—we have got to do research. There is no question about that.

NIH does a great job. We have given them the funding they need, but they need to also step up their foot on the gas on treatment because there is a lot of you out there suffering every day, and I know you can't wait a year or two for some study to come back saying we think we have got this figured out now.

So I just want to thank the three of you for coming and telling your stories, and that is the only reason I stayed on for this second panel to make sure that I expressed to the three of you that we all have a lot of empathy for what you are going through.

And Anna, thank you. This is an important hearing that we needed to have, and we need to like—we need to not forget about it after this hearing. We need to keep pressing ahead, and I know you will. So thank you for that. And that is all.

I will yield back my time.

Ms. ESHOO. Well, thank you, Mike. And I think that, too, our patient witnesses that you wouldn't have thought that you would hear a Member who is a dad and described his son and what his son is going through. But this virus is not discriminatory. It doesn't care—it doesn't regard ZIP Codes, job titles, and all of that.

All of my thanks on behalf of all of the Members, and many of them have signed off because they already got to ask their questions and we have been together for a long time today. I also thank you for listening in—not necessarily being part of, but you were

there for the first panel, and I can't help but think that what they shared with us is important information to you because it is a piece of it. It is not all of it, but it is a very important piece of it. And that very important piece, the Congress has already put in place significant dollars for the research.

To each one of you, we really are very, very grateful to you. There is nothing like the voices of those that are the ones that are affected, but then also those that are the professionals that are one-on-one with the patients, know the setting, know where the shortfalls are.

To Dr. Deeks, you are looking way into the future using the experience of your work of the past with HIV/AIDS patients, and I think that that is highly instructive as well. So, you know what? We have been the students, and you have been the teachers, and for that, we are all very grateful. And we are not going to let go of this. Seems to me that we need to come up with a designation and go from there, but in between the responses from the researchers and others, we need to have wraparound services for people because they can't function.

I mean, you know, you have said over and over again, you have told your stories and left an imprint on us of how debilitating this is and that, you know, with that debilitation, what do you do? You can't—you simply can't function. So we need wraparound services that are designated for those that have this.

So bravo to all of you and our thanks. Many Members will be submitting written questions to you, and we ask you to respond in a very timely way, and we thank you in advance for that.

So now we have just a little housekeeping, and that is that I want to ask my colleague, we do have 12 documents to submit to the record, Mr. Guthrie. I don't think you want me to read through all of them. I am sure they are all important and wonderful documents for the record.

So I would ask for unanimous consent, to put in a unanimous consent request that the statements be placed in the record.

Mr. GUTHRIE. OK. Before I say I don't have any objection, I just want to say thanks to all the witnesses too. Your testimony is compelling. The physicians that have been on, the healthcare providers that have been on this, and we are dealing with this in real time, and we are learning as we go and we are making a big effort to really understand this on both sides of the aisle, and your testimony today was very helpful. Very helpful in that. And so we thank you so much.

And I don't have any objections. I assume everything we submitted is on the list there. I think our staff has looked at that, so I don't have any objection.

[The information appears at the conclusion of the hearing.]

Ms. ESHOO. OK. Thank you, Mr. Guthrie.

And pursuant to committee rules, Members do have 10 days to submit your additional questions for the record. And I have already asked that the witnesses respond promptly to any questions that you have received.

And with that and our collective thanks, the subcommittee is now adjourned.

Thank you, everyone.

[Whereupon, at 4:56 p.m., the subcommittee was adjourned.]
[Material submitted for inclusion in the record follows:]

Congress of the United States
House of Representatives
Washington, DC 20515

April 21, 2021

The Honorable Nancy Pelosi
Speaker
United States House of Representatives
United States Capitol Building H-232
Washington, DC 20515

Dear Speaker Pelosi:

We are writing to you as members of the House GOP Doctor's Caucus. We are 18 Members of Congress with medical training, clinical experience, and time in practice who have completed educational programs and hold medical degrees. Prior to our service in the House of Representatives, all of us had professional careers in health care, and most importantly, our pre-political service involved direct patient care. We are all well-versed in evaluating risks and benefits for patients and proposed courses of action.

Following the Emergency Use Authorization for the Pfizer and Moderna COVID-19 vaccines in December, 2020, you rightfully made vaccines available to Members of Congress and their staff, consistent with Presidential Policy Directive 40 (2016), to meet long-standing requirements for continuity of government operations, and for that we are grateful.[1] Many of us chose to get vaccinated as part of our effort to continue leading by example in conveying trust in the science, trust in the process, and trust in the safety and efficacy of the vaccine. We did so because of the criticality of the continuity of Congress, and it was our expectation that the COVID-19 vaccine would enable us to return to more normal operations.

We all now realize that the current state of Congress is not working. The restrictions on voting process, the phenomenon of widespread proxy voting, and remote hearings have all contributed to the current state of dysfunction. Yet, this state of dysfunction could change, and you have the authority to do that.

On March 8, 2021, the CDC issued its "Interim Public Health Recommendations for Fully Vaccinated People."[2] According to the new guidance, vaccinated individuals can gather with other fully vaccinated people indoors without maintaining a 6-foot distance or wearing masks. With a significant portion of Members and staff now being fully vaccinated, we request that you resume normal voting intervals, resume in-person hearings, and allow for select meetings in Congressional offices.

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[1] https://attendingphysician.house.gov/sites/attendingphysician.house.gov/files/documents/e-Dear%20Colleague%2012_17_20.pdf
[2] https://www.cdc.gov/coronavirus/2019-ncov/vaccines/fully-vaccinated-guidance.html

If a majority of Members are vaccinated or recovered from COVID-19, why are you still preventing normal operations? As Members of Congress with medical backgrounds, we have worked vigorously to educate our constituents, and fellow Members in the House, that though the timeline of the COVID-19 vaccines was accelerated, the process was safe. The promise of a return to pre-pandemic normalcy was the goal, and Congress must set an example as many of us are fully vaccinated.

On March 19, 2021, members of the GOP Doctor's Caucus wrote a letter to the Attending Physician, Dr. Brian Monahan, asking for his medical opinion on why House procedures are still limited. While we appreciate Dr. Monahan's response to our letter, he stated that current House guidelines are based upon CDC guidelines. We would again like to emphasize that with most Members and staff being vaccinated, the science indicates that the probability of infection and transmission of COVID-19 is very low .[3] As noted in the April 9th House Operations Updated Guidance, where high vaccination participation exists there are reduced COVID-19 risks and additional modifications can be made. With most Members and staff having been vaccinated, what else do you believe is needed for the House to return to regular business? We have made every effort to return to normal at this point and remain concerned that we are still operating under amended House procedures based on outdated circumstances.

This era of higher hygiene pretense must end. Let us resume the people's business, as we were all elected to do.

Sincerely,

Rep. Michael C. Burgess, M.D.
Member of Congress

Rep. Andy Harris, M.D.
Member of Congress

Rep. Brad Wenstrup, D.P.M.
Member of Congress

[3] https://www.medrxiv.org/content/10.1101/2021.02.08.21251329v1.full.pdf



Rep. Brian Babin, D.D.S.
Member of Congress



Rep. Larry Bucshon, M.D.
Member of Congress



Rep. Earl L. "Buddy" Carter
Member of Congress



Rep. Scott DesJarlais, M.D.
Member of Congress



Rep. Neal P. Dunn, M.D.
Member of Congress



Rep. A. Drew Ferguson, IV, D.M.D.
Member of Congress



Rep. Paul A. Gosar, D.D.S.
Member of Congress



Rep. Diana Harshbarger, Pharm.D.
Member of Congress



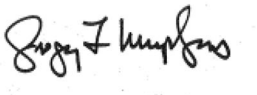
Rep. Ronny L. Jackson, M.D.
Member of Congress



Rep. John Joyce, M.D.
Member of Congress



Rep. Mariannette Miller-Meeks, M.D.
Member of Congress



Rep. Gregory F. Murphy, M.D.
Member of Congress



Rep. Mike Simpson, D.M.D.
Member of Congress



Rep. Jefferson Van Drew, D.D.S.
Member of Congress



Rep. Mark Green, M.D.
Member of Congress

AAFP
AMERICAN ACADEMY OF FAMILY PHYSICIANS

April 27, 2021

The Honorable Anna Eshoo
Chairwoman
Subcommittee on Health,
Committee on Energy and Commerce
U.S. House of Representatives
Washington, D.C. 20515

The Honorable Brett Guthrie
Ranking Member
Subcommittee on Health,
Committee on Energy and Commerce
U.S. House of Representatives
Washington, D.C. 20515

Dear Chairwoman Eshoo and Ranking Member Guthrie,

On behalf of the American Academy of Family Physicians (AAFP), representing more than 136,700 family physicians, residents, and medical students across the country, I write in response to the hearing: "The Long Haul: Forging a Path through the Lingering Effects of COVID-19" to share the family physician perspective and the AAFP's recommendations to ensure a successful recovery from the COVID-19 pandemic.

An estimated 10 percent to 30 percent of people who get COVID-19 suffer from lingering symptoms beyond three weeks of the disease, or what's known as "long COVID".[1] [2] With over 30 million cases of COVID-19 in the U.S., if even a small percentage of people experience long COVID, this could have significant and lasting health and economic consequences. Although research on long COVID is still in its infancy, it is clear that a comprehensive plan and federal investment is needed to fully recover from the COVID-19 pandemic and should include the following.

Investing in the Primary Care Workforce

Primary care physicians are the main source of care for patients managing chronic conditions. They are also in a unique position to provide and coordinate care for vulnerable patients with long COVID. Each year, 77 percent of adults and nearly 90 percent of children and adolescents see a primary care physician.[3] **As a result, primary care physicians will play a critical role in treating patients with long COVID.**

COVID-19 has both highlighted and exacerbated the physician workforce shortages facing communities throughout the nation. It has demonstrated the urgency of building and financing a robust, well-trained, and accessible primary care system in our country. According to the American Association of Medical Colleges, we will need up to 55,200 additional primary care physicians by 2033 in order to meet the health care needs of our growing and aging population and be prepared to respond to future crises.[4] **Congress should address the primary care physician shortage by increasing investments in the Teaching Health Center Graduate Medical Education (THCGME) program and the National Health Service Corps, which train and place primary care physicians in underserved and rural communities.**

Even prior to the pandemic, burnout among physicians and health providers was a pervasive public health concern, with some studies reporting burnout in more than 50 percent of clinicians. According

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to the American Board of Family Medicine, primary care physicians have experienced the highest rate of death (26.9 percent) among health provider specialties during COVID-19.[5] Physician burn out during the COVID-19 pandemic has become worse, negatively impacting happiness, relationships, career satisfaction, and patient care. A January 2021 report showed that 47 percent of family physicians are burnt out, and 20 percent of all physicians are clinically depressed.[6] **Congress should invest in the mental health needs of our nation's doctors, particularly during the pandemic, and fight the stigma around seeking necessary treatment by passing the Dr. Lorna Breen Health Care Provider Protection Act (S. 610).**

Health Care Access & Equity

Cost continues to remain a barrier to access primary care services and must be addressed to achieve equitable access and outcomes. According to a recent survey, nearly 3 in 10 Americans lost health insurance coverage in 2020, and more than half haven't bought new coverage and remain uninsured in 2021.[7] Community Health Centers (CHCs) provide primary care to more than 29 million people in communities large and small, regardless of individuals' ability to pay. Primary care physicians also make up nearly 90 percent of physicians working in CHCs, where they are often are the only sources of care for people in rural and urban underserved communities. **As such, we encourage Congress to invest in and leverage CHCs to mitigate inequities, improve our response to the COVID-19 pandemic, and increase access to affordable health care.**

Medicaid enrollment has increased by 7.7 million since the start of the pandemic and enrollment is expected to continue to increase as a result of pandemic-related job loss.[8] The demand for primary care physicians in the Medicaid program is more acute than ever. Inadequate Medicaid payment threatens access to primary care services in areas hardest hit by COVID-19, and without proper support during this public health emergency and beyond, family physician practices could be forced to close. **Congress should pass the Kids' Access to Primary Care Act (H.R. 1025), which would ensure Medicaid beneficiaries have timely access to primary care by raising Medicaid payments to at least Medicare payment levels.**

Family physicians have rapidly changed the way they practice to meet the needs of their patients during the COVID-19 pandemic. About 70 percent report that they want to continue providing more telehealth services in the future and it can be a valuable tool in treating long COVID patients. Telehealth can enhance patient-physician collaboration, increase access to care, improve health outcomes by enabling timely care interventions, and decrease costs when utilized as a component of, and coordinated with, continuous care. Given these benefits, patients and physicians alike have indicated that current telehealth flexibilities should continue beyond the public health emergency. **Congress should act to extend Medicare telehealth flexibilities and ensure telehealth is permanently recognized across payers as a valuable modality of providing primary care services beyond the public health emergency.**

Many vulnerable groups are highly represented in essential worker positions. As a result, these populations are more exposed to acute COVID-19 and may represent a higher proportion of long COVID patients. Given the occupational requirements of essential workers, these patients may have less ability to adapt their work functions while managing the symptoms of Long COVID. **Congress should act to protect these essential workers and provide guidance for employers on if and how ADA and FMLA accommodations extend to long COVID patients.**

Health Care Coverage

The AAFP firmly believes that all people should have access to affordable, meaningful health insurance. A 2019 analysis found that individual market premiums increased by 6 percent due to the repeal of the individual mandate and the proliferation of short-term limited duration and other noncompliant plans.[9] While noncompliant plans could expand affordable access to a minimal level of health coverage for certain individuals, these plans do not provide meaningful insurance coverage for all, including, most notably, those with complex medical conditions or the very ill. Noncompliant plans harm patients by reducing or eliminating coverage of the essential health benefits required by the Affordable Care Act. Among the protections at risk are the prevention of insurance discrimination based on health status, age or gender, and coverage for preexisting conditions. **Congress should pass legislation that limits or eliminates noncompliant plans to prohibit insurers from selling plans that fail to provide meaningful coverage.**

As individuals, families, and employers struggle with the escalating costs of health care coverage, many are seeking high-deductible health plans (HDHP) as a means of securing affordable coverage. Despite the increasing popularity of HDHPs, the deductibles associated with the plans are becoming an increasingly problematic hurdle to obtaining health care, particularly during the ongoing COVID-19 pandemic. The high out-of-pocket cost is causing patients to delay seeking care, extending lapses in health care maintenance,[10] and decreasing adherence to medication and treatment protocols. As we continue to deal with the pandemic, including long COVID, patients in HDHPs should not have to worry about delaying or losing access to their primary care physician. **Congress should pass legislation to enable individuals with an HDHP to access critical primary care services prior to meeting their deductible during and beyond the pandemic.**

Long COVID Research

As the federal government funds research efforts to better understand the impact and causes of long COVID, particularly in vulnerable populations, we urge the inclusion of primary care physicians. Importantly, primary care physicians and their staff can contribute to the collection of robust data on long COVID and the associated health inequities. Ongoing and future long COVID research funded should support health providers in real-time through rapid development and widespread dissemination of best practices. **Additionally, any legislative solution should include flexibilities since long COVID research will evolve over time and should account for these changes.**

We thank you for your leadership and actions to date to help our nation combat COVID-19. The AAFP stands ready to partner with you on additional legislation to recover from the pandemic. Again, thank you for holding today's hearing on this important topic. Should you have questions, please contact John Aguilar, Manager of Legislative Affairs, at jaguilar@aafp.org.

Sincerely,

Gary L. LeRoy, MD, FAAFP

Gary L. LeRoy, MD, FAAFP
Board Chair, American Academy of Family Physicians

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American Academy of
Physical Medicine and Rehabilitation

TESTIMONY FOR THE WRITTEN RECORD
FROM THE

AMERICAN ACADEMY OF PHYSICAL MEDICINE & REHABILITATION (AAPM&R)

SUBCOMMITTEE ON HEALTH
COMMITTEE ON ENERGY AND COMMERCE
UNITED STATES HOUSE OF REPRESENTATIVES

A COMPREHENSIVE FEDERAL RESPONSE TO ADDRESS POST-ACUTE SEQUELAE OF SARS-COV-2 INFECTION (PASC), OR "LONG COVID"

HEARING ON

"THE LONG HAUL: FORGING A PATH THROUGH THE LINGERING EFFECTS OF COVID-19"

APRIL 28, 2021

AMERICAN ACADEMY OF PHYSICAL MEDICINE & REHABILITATION
WWW.AAPMR.ORG

CONTACT: REVA SINGH, JD MA, AAPM&R DIRECTOR OF ADVOCACY AND GOVERNMENT AFFAIRS
(847) 737-6030 | RSINGH@AAPMR.ORG

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Chairwoman Eshoo, Ranking Member Guthrie, and Members of the Energy and Commerce Health Subcommittee:

Thank you for the opportunity to submit testimony today regarding Post-Acute Sequelae of SARS-CoV-2 infection, also known as "PASC" or "Long COVID." On behalf of the American Academy of Physical Medicine and Rehabilitation ("AAPM&R" or the "Academy"), I am grateful for the Committee's attention to this dire and complex issue. I would also like to take this opportunity to thank Congress for the $1.15 billion in funds allocated to the National Institutes of Health (NIH) in the recently passed Consolidated Appropriations Act of 2021, Public Law 116-260, as well as the work Congress and the federal government has undertaken over the past year to respond to the COVID-19 pandemic.

I am a physiatrist, working at University of Texas Health San Antonio Long School of Medicine and a member of the AAPM&R. The Academy is the national medical specialty organization representing more than 9,000 physicians who are specialists in physical medicine and rehabilitation (PM&R). PM&R physicians, also known as physiatrists, are medical experts in treating a wide variety of conditions affecting the brain, spinal cord, nerves, bones, joints, ligaments, muscles, and tendons. PM&R physicians evaluate and treat injuries, illnesses, and disabilities, and are experts in designing comprehensive, patient-centered treatment plans. Physiatrists utilize cutting-edge as well as time-tested treatments to maximize function and quality of life.

Due to the nature of our specialty and our experience working with and coordinating care for people with complex disabilities and chronic conditions, physiatrists have been recognized as the leading specialty for assessing and treating patients experiencing the condition known as Long COVID. It is currently

estimated that 10-30%[1] of people who had COVID-19 will experience long COVID symptoms. Even considering the conservative estimate of 10%, this represents well over 8 million people[2] given the infection rate of this virus. Additionally, these symptoms often appear in patients who were asymptomatic and may have never even known they were infected with COVID in the first place.

Over the past six months, physiatrists and other clinicians have come together to address Long COVID by opening multi-disciplinary Long COVID clinics, in addition to our existing physician duties. These multi-disciplinary clinics serve as a "one-stop shop" to help this population address their new, varied, and debilitating symptoms, including neurological challenges, cognitive problems such as brain fog, shortness of breath, fatigue, musculoskeletal pain, and mobility impairments. These clinics convene different physician specialists, therapists, social workers, and sometimes researchers who are gathering vital data from patients with PASC. I currently lead two such clinics, Post-COVID Recovery Clinic at UT Health San Antonio and the Post-COVID Recovery Clinic at University Health. AAPM&R has gathered 26 of these institutions to create a Multi-Disciplinary PASC Collaborative of experts to develop clinical guidance to improve quality of care, formal education, and resources to improve the experience of care and health equity. These collaborative discussions have illuminated the consistent infrastructure and access barriers we are seeing across the various multi-disciplinary clinics that have organically "popped up" across the country. Additionally, the needs of Long COVID patients are already spreading far beyond the clinical sphere, as patients face difficulties in returning to work, receiving necessary workplace accommodations, and accessing Social Security, disability, and other benefits. **AAPM&R has called on the Administration and Congress to develop a comprehensive federal plan to defeat the national**

[1] Rubin R. As Their Numbers Grow, COVID-19 "Long Haulers" Stump Experts. JAMA. 2020;324(14):1381–1383. doi:10.1001/jama.2020.17709.
[2] Estimated Disease Burden of COVID-19. Centers for Disease Control and Prevention. January 19, 2021. https://www.cdc.gov/coronavirus/2019-ncov/cases-updates/burden.html

Long COVID crisis. To develop such a plan, to assess the varied policy considerations and far-reaching impacts of Long COVID, and to obtain meaningful input from a wide range of stakeholders, AAPM&R recommends the immediate formation of a federal commission with a diversity of expertise to develop priority recommendations for addressing infrastructure needs and other gaps in access to timely and appropriate clinical care for all individuals with PASC.

Access Barriers

Not all insurers and health plans cover rehabilitation services, specialty home services, or post-acute care for brain injury and neurorehabilitation. These services are vitally important for this population that is experiencing a breadth of symptoms and who often have difficulty organizing and traveling to many different doctors' offices. Because there is not adequate coverage, many patients cannot access these services as chronic symptoms are typically not considered as acute or emergencies. Many patients are simply unable to afford the costs of Long COVID treatment out of pocket, especially given the wide range of services required for adequate treatment and the long-lasting, potentially even permanent, effects of this condition.

In addition to financial barriers, individuals experiencing PASC are subject to the same systemic barriers to care that individuals with other complex, chronic conditions experience. For instance, when a patient visits their primary care provider to discuss their PASC symptoms, they are often provided with several referrals to specialists to address the confluence of their symptoms. Such patients may receive a referral to a cardiologist, pulmonologist, neurologist, psychiatrist, and orders for various labs and other tests. This puts the patient in the position of coordinating their own complex care and having to attend many different appointments, if they are even able to secure appointments in a timely manner. This is particularly difficult for a population encountering significant fatigue and other debilitating PASC

symptoms. The multi-disciplinary clinic approach, to the contrary, creates a hub where a patient can see a physiatrist and consult with all these specialists, complete their testing, and meet with any needed therapists through a comprehensive, coordinated approach. It is one of the reasons these clinics have months-long waiting lists just to be evaluated for the first time.

The PASC clinics that are growing across the country are typically part of an academic medical center or other health system that has the resources and capacity to develop these clinics quickly. These systems have significant financial reserves, physical space, and existing networks of specialists to erect these multi-disciplinary clinics quickly. In addition, practitioners leading these clinics can be given the leeway to devote their time and energy to developing a new model of care for their patients with PASC. For the vast majority of health care providers across the nation, these capabilities will not be available to adequately support such multi-disciplinary clinics without some form of financial assistance to jumpstart their development, even as they are proving highly effective in meeting the needs of patients with Long COVID. To put it plainly, the need for these clinics far outstrips the resources available in many areas of the country.

Payment Issues for Patients and Providers

Typically, clinical visits to evaluate, diagnose, and coordinate treatment for patients with Long COVID symptoms take an hour or more. Such complex and lengthy visits are simply not in sync with the typical reimbursement models for medical practice and the existing Evaluation and Management (E&M) codes are not equitable for the work required to treat these patients. Existing E&M codes are based upon a standard 15-minute patient visit, which is not a reasonable amount of time to evaluate complex PASC patients. This discrepancy in reimbursement and the time expended may be why more doctors are not able to adequately care for these patients. Improved reimbursement policies, such as a Long COVID add-on

code, are desperately needed to ensure that physicians can dedicate the time and resources necessary to provide appropriate care to Long COVID patients. Such reforms will make it feasible for physicians to provide this care, increasing the supply of providers offering Long COVID treatment and reducing wait times and other barriers to accessing care for patients. Currently, the physicians working in these clinics are doing so as an adjunct to their existing clinical responsibilities, making it difficult for many physicians to participate in this new model of care. A relative dearth of physicians has resulted in wait times of four to six months for patients before they can even be seen by many of the specialists necessary to treat their Long COVID symptoms.

Multi-disciplinary clinics are proving to be successful and a sorely needed model for addressing the multi-disciplinary clinical needs associated with Long COVID, but as described, there are several barriers to patients accessing such care. Funding or grants to establish these clinics would help create more of these clinics, streamline care, and help patients optimize their health and function faster.

Other Access Issues

Telemedicine has rapidly evolved over the past year and has been widely adopted throughout the pandemic. For safety reasons and the nature of Long COVID, telemedicine has been vital in treating patients with PASC. It allows patients access to a multi-disciplinary clinic that may not exist in their geographic area, a common concern for many patients nationwide, especially those residing in rural areas. However, many individuals in rural and low-income neighborhoods and across the country still do not have access to critical broadband internet and other technological requirements to appropriately access virtual care. This needs to be rectified for patients enduring the effects of Long COVID and all patients seeking virtual health care during the pandemic and beyond.

Many patients experiencing PASC may not have been specifically tested for COVID-19 nor exhibit antibodies, which results in some providers not knowing to refer them to a PASC clinic. Since PASC symptoms can appear in people who had asymptomatic cases of COVID, many may not even identify their symptoms as COVID-related. Additionally, there have been barriers to accurate testing throughout the pandemic for different populations, especially communities of color and people with disabilities. As treatments and reimbursement for Long COVID patients evolve, it is crucial that we not create additional barriers to access, such as a requirement for a positive COVID-19 test to gain access to a multi-disciplinary clinic.

The nature of Long COVID also means that many patients present with symptoms that do not appear in a normally recognized test. For example, patients may complain of shortness of breath, but show no discernible physical issues in imaging of their lungs. This has been a longstanding problem for patients with other long-term, chronic, and not clearly delineated conditions, such as chronic fatigue syndrome and other complex disease states. We hope that the efforts to improve multi-disciplinary care for patients with Long COVID can also benefit individuals with other complicated medical conditions. This underscores the need for research on PASC to be conducted rapidly and translated to providers so that this new population can be recognized for the symptoms they are suffering, instead of being dismissed for not fitting existing medical paradigms.

The infrastructure and access issues encountered by these multi-disciplinary PASC clinics are not new issues. Patients with disabilities and complex conditions have experienced these same barriers in our health system for years. The influx of people into the disability and chronic illness community from the rapidly growing population of people with Long COVID has shone a light on these barriers and gaps in

care for so many American patients. Long-term, ongoing support for multidisciplinary care is desperately needed.

Additional Needs of Long COVID Patients

The significant and time sensitive clinical needs of Long COVID patients only reflect one aspect of the impacts of Long COVID on the country. As we continue to develop a deeper understanding of Long COVID, some patients are likely to experience long-term or even permanent Long COVID symptoms, potentially impacting their ability to function independently for years to come. As a result, we expect that many Long COVID patients will become members of the disability community in the coming months and even years. These individuals will face significant additional barriers because of their symptoms. It is critical to consider how individuals with Long COVID will be able to access disability benefits, including Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI); the accommodations these individuals may need to return to work, if they are able; the availability of Long-Term Services and Supports (LTSS) that may be necessary; the education these individuals may need to understand the services available to them and their rights under the Americans with Disabilities Act and other federal statutes; and much more. There are many facets to the Long COVID crisis, and the need for policy solutions is likely to only grow over the coming months. In order to coordinate the federal response to Long COVID, and to ensure that recommendations for statutory and regulatory changes can be made through a unified, recognized body with the imprimatur of the federal government, AAPM&R strongly recommends the formation of a commission, task force, or other federal interagency entity, led by the White House or at senior levels within the Department of Health and Human Services, and tasked with development of a crisis plan to address the immediate and long-term impacts of Long COVID-19. We encourage the subcommittee to consider this need and offer our assistance in any way we can to advance policy for those living with Long COVID.

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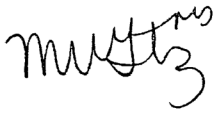
We thank the subcommittee for its leadership in recognizing this critical issue for individuals across the country and appreciate the opportunity to submit this written testimony. As the subcommittee, Congress, and the federal government continue to consider policies to address the Long COVID crisis, we offer our support as an organization and on behalf of the physiatry profession and urge the subcommittee to consider AAPM&R and the Multi-Disciplinary PASC Collaborative as a resource. We look forward to working with you to serve the needs of the millions of patients nationwide experiencing the debilitating effects of Long COVID.

Sincerely,



Monica Verduzco-Gutierrez, MD
Professor and Chair
Department of Rehabilitation Medicine
Joe R. and Teresa Lozano Long School of Medicine
UT Health San Antonio

Member of AAPM&R's Multi-Disciplinary PASC Collaborative
Post-COVID Recovery Clinic at UT Health San Antonio
Post-COVID Recovery Clinic at University Health

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Appendix I: Current List of Institution Members Participating in the Multi-Disciplinary PASC Collaborative

- University of Washington
- Icahn School of Medicine at Mount Sinai
- UT Health San Antonio
- Rusk Rehabilitation, NYU Langone Health
- UT Southwestern Medical Center
- Shirley Ryan AbilityLab
- Penn Medicine
- Beth Israel Deaconess Medical Center
- OHSU - Oregon Health & Science University
- Johns Hopkins Medicine
- University of Kansas Health System
- Ascension Medical Group
- Mayo Clinic
- Cedars Sinai – LA
- GW Medical Faculty Associates
- JFK Johnson Rehabilitation Institute at Hackensack Meridian Health
- UNC-Chapel Hill
- University of Colorado
- UC Davis Health
- Vanderbilt University Medical Center
- Kennedy Krieger Institute - Pediatric Post COVID-19 Rehabilitation Clinic
- Montefiore-Einstein COVID-19 Recovery (CORE) Clinic
- Hartford HealthCare's COVID Recovery Center
- Tulane Neurology Post COVID Care Clinic
- Northwestern Medicine Comprehensive COVID-19 Center
- MetroHealth Post-COVID Clinic

COVID Patient Recovery Alliance

AN ALLIANCE CONVENED BY LEAVITT PARTNERS

April 27, 2021

Frank Pallone
Chairman
House Committee on
Energy & Commerce

Cathy McMorris Rodgers
Ranking Member
House Committee on
Energy & Commerce

Anna G. Eshoo
Chairwoman
House Committee on
Energy & Commerce
Subcommittee on Health

Brett Guthrie
Ranking Member
House Committee on
Energy & Commerce
Subcommittee on Health

Dear Chairman Pallone, Ranking Member McMorris-Rodgers, Subcommittee Chairwoman Eshoo and Subcommittee Ranking Member Guthrie,

We applaud the Committee for holding the hearing "The Long Haul: Forging a Path through the Lingering Effects of COVID-19." As co-convenors of the COVID Patient Recovery Alliance, we see the importance of working together to provide care for patients with long-COVID.

As part of our national response to the COVID-19 pandemic, we need to better understand long-COVID and how its effects may impact our health care system, our communities, and our path on the road to recovery. The Alliance we lead seeks to support the energy and innovation of public-sector and private-sector leaders as they ensure care for individuals experiencing long-COVID. The Alliance is developing national strategies to link diverse data sources, inform the development of models of care, and ensure adequate payment for the care of these patients.

While much is not yet fully understood about long-COVID, the needs patients are facing are real and the breadth of need is extensive. Published estimates suggest that somewhere between 10 to 30 percent of patients who recovered from COVID-19 may have long-COVID to some degree for some period of time. With researchers suggesting that during the public health emergency an estimated 100 million Americans have been infected with COVID-19, the size of the long-COVID patient population is quite significant.[1,]

To help understand and meet the needs of patients, our Alliance is comprised of leaders in business, health care, patient and consumer advocacy, research, academia, and data science. Through our members, the Alliance brings together technical expertise, experience, regulatory knowledge, and public policy understanding to achieve the following objectives:

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[1] Estimate based on symptomatic confirmed cases and estimated asymptomatic cases. Centers for Disease Control and Prevention. Estimated disease burden of COVID-19 (updated January 19, 2021) of 83.1 million total infections from February – December 2020. https://www.cdc.gov/coronavirus/2019-ncov/cases-updates/burden.html *website accessed February 27, 2021.* And Institute for Health Metrics and Evaluation. COVID-19 Results Briefing (updated April 21, 2021) estimates 30 percent of people in the U.S. infected as of April 19, 2021. http://www.healthdata.org/sites/default/files/files/Projects/COVID/2021/102_briefing_United_States_of_America_15.pdf *website accessed February 27, 2021*

- **Data Collection and Evidence Generation:** Coordinate federated studies to characterize long-COVID by leveraging members' individual robust data assets and analytic capabilities. The Alliance will use the data work to inform policy positions and advocacy efforts, such as the development of targeted federal policy solutions and potential best practices.
- **Care Model Development:** Inform the development of models of care to help optimize the use of resources and improve the care of patients with long-COVID based on evidence, best practices, and patients' needs and characteristics.
- **Payment Model Development:** Inform the development of payment strategies, tools, and policies to ensure patients with long-COVID receive adequate care and support based on evidence, best practices, and patients' needs and characteristics.

While many patients with long-COVID face needs, there are several different patient populations to which the Alliance is paying close attention. The Alliance is particularly interested in patients with long-COVID:

- Who served their communities and nation when called to duty as essential workers, frontline providers, and workers in other key sectors;
- Whose COVID-19-related costs are extraordinary and burdensome or who are underserved by existing programs or sources of coverage; and
- Who come from communities that have been disproportionately impacted during the public health emergency from disparities and inequities.

The reality of many Americans who suffered from COVID-19 but have not yet fully recovered has important ramifications for their ability to be restored to full health, return to work, and reengage in their families and communities. Many of the common long-COVID symptoms can negatively impact an individual's ability to return to work following infection and be productive while at work; these symptoms include brain fog, dizziness, inability to focus, fatigue, anxiety and depression, and inability to exercise or be active.[2] Press reports have noted how individuals with long-COVID are finding they need accommodations from their employers, including modified schedules and expectations for near-constant digital communication.[3]

We applaud Congress's appropriation of $1.15 billion to the NIH to study long-COVID and other long-term effects of COVID-19. While it is critical to address many of these unanswered questions, the research will take time. Given the scope of the challenges, we believe there is also a need for near- and mid-term strategies to identify care gaps and ensure equitable care and coverage to patients with long-COVID. Collaboration amongst key stakeholders can help shape and support solutions to address long-COVID.

As Congress seeks to better understand and respond to long-COVID, the COVID Patient Recovery Alliance stands ready to engage policymakers and welcomes the opportunity to serve as a resource to you on these important issues on an ongoing basis. We are underway in identifying system gaps, data improvements, and actionable targeted approaches to help ensure quality care for patients with long-COVID and support our nation's road to recovery. We appreciate your interest and are ready to help inform the thoughtful bipartisan work for which the Committee is well-known.

Sincerely,

Governor Michael O. Leavitt
Co-convener

Nancy-Ann DeParle
Co-convener

[2] https://pubmed.ncbi.nlm.nih.gov/33532785/
[3] https://www.wsj.com/articles/the-challenges-of-getting-long-covid-patients-back-to-work-11613350801

COUNCIL FOR QUALITY RESPIRATORY CARE

Statement on the Importance of Home Respiratory Therapy in Response to Immediate and Long-Term Needs of Patients Due to the COVID-19 Pandemic

Prepared for the Subcommittee on Health,
Committee on Energy & Commerce, U.S. House of Representatives for
April 28, 2021 Hearing on
"The Long Haul: Forging a Path through the Lingering Effects of COVID-19."

The Council for Quality for Respiratory Care (CQRC) wants to thank the Subcommittee for holding today's hearing and focusing on the lingering effects of COVID-19. We appreciate the Congressional support for health care providers and suppliers during the COVID-19 pandemic. Home respiratory therapies, including home oxygen, sleep, and non-invasive ventilation therapies, continue to play an essential role in the recovery of many patients with COVID-19. For some COVID-19 patients, the long-haulers as they are known, these home respiratory therapies have become an essential daily treatment.

The CQRC is a coalition of the nation's six leading home oxygen and sleep therapy providers and manufacturing companies. Together, our members provide in-home patient services and respiratory equipment to more than 600,000 of the more than one million Medicare beneficiaries who rely upon home oxygen therapy to maintain their independence and enhance their quality of life. Similarly, we provide homecare services, equipment, and supplies to more than one million Medicare beneficiaries with Obstructive Sleep Apnea (OSA).

During the pandemic, CQRC members have been on the frontlines of the battle against COVID-19. They have experienced an increase in acute patients and fluctuations in the number of chronic patients, leading to shortages in equipment and supplies, and rising costs. As the pandemic moves into its second year, a significant percentage of patients continue to experience respiratory conditions that require their ongoing reliance on home respiratory therapies. However, Medicare has not yet committed to retaining the flexibilities that allowed these patients access to home respiratory therapies during the pandemic. These flexibilities are also important to rebuilding the home respiratory sector, which have been significantly weakened by years of flawed reimbursement, documentation, and audit policies.

I. Overall Increase in Acute Patients Needing Home Respiratory Therapy

The first challenge home respiratory suppliers and manufacturers have faced during the pandemic is the increasing demand for home respiratory therapies. This challenge continues today. In general, patients with chronic respiratory conditions have been less likely to seek medical help, putting off early screenings and health care visits out of fear of COVID-19. Based on data from the CQRC members, the number of patients with chronic

respiratory diseases seeking home therapies fell, especially during the first part of the pandemic. Yet, the percentage of patients with acute conditions, including those with COVID-19, increased by more than 229.46 percent, based on CQRC company data. These patients included those with conditions, like pneumonia, as well. Generally, Medicare will not cover home oxygen for acute patients, but it did extend coverage during the pandemic to allow these patients to recover at home instead of in a hospital. The percentage of new start acute patients in Medicare increased by 229.46%, while the percentage of new start chronic patients in Medicare decreased by 25.10%. These trends have continued as different surges of infection and hospitalization have spread across the United States.

These statistics were true for the general population as well. Data from "hot spot" states echoes this pattern. There is a substantial increase in acute patients and a substantial decrease in chronic patients.

State	**Acute Patients Percent change Jan-June 2020**	
	All payers	Medicare
Arkansas	220.90%	347.83%
California	299.12%	360.87%
Florida	166.22%	167.31%
Georgia	319.05%	210.96%
New Jersey	266.67%	159.38%
New York	82.95%	242.31%
Texas	251.45%	159.38%
Washington	80.12%	186.36%

This shift in treatment options has put a tremendous strain on the home respiratory sector.

II. Increases in Demand Have Led to Shortages

Because of the effects of COVID-19, the World Health Organization warned of an oxygen equipment shortage in 2020. As the media has reported, those warnings came true with shortages throughout the United States and around the world. During various times in the pandemic, CQRC companies have seen up to 45% of their oxygen new equipment orders from manufacturers being cancelled or backlogged. They experienced similar problems with positive airway pressure devices/respiratory assist devices, and nebulizers.

The shortages have resulted from a worldwide increase in demand for oxygen equipment and supplies, ventilator equipment and supplies, nebulizers, and positive airway pressure products. For example, for one manufacturer, demand for oxygen concentrators has doubled since the beginning of the pandemic. Manufacturers are experiencing problems obtaining common components like resin, resisters, and printed circuit boards. This problem has also strained access to proprietary parts manufactured for several products. To meet increased demand, manufacturers are experiencing increased component, manufacturing, and freight costs, some of which are passed along to customers.

In addition, other organizations that do not traditionally purchase oxygen equipment, such as prisons, are now doing so. Other providers, such as hospitals, that may have purchased oxygen on a more limited basis have increased their demand substantially as well. These additional purchasers have further strained access to respiratory therapy devices for patients in the home.

III. Increases in Costs

In addition, CQRC members, like other health care providers, have experienced supply chain problems, increased costs for personal protective equipment, and difficulties with vaccinating their employees who enter patients' homes. As a result, the cost of providing equipment and services to patients has risen to levels that exceeded anyone's expectations. While all of us had hoped that the pandemic would have ended by now, the reality is that it is likely to continue for some time. The economic challenges facing health care providers and suppliers will also likely remain in place at least through the duration of the PHE.

IV. Supporting a Sustainable Home Respiratory Therapy Infrastructure

As reported in the media, the changing demand, exponential increase in the need for home oxygen in "hot spots," and shortages of equipment have illuminated the systemic problems home respiratory therapy patients, suppliers, and manufacturers have faced for several years. The driving factor for these problems has been a flawed set of Medicare policies. As the dominant payer for chronic respiratory patients, Medicare policies have a disproportionate impact on the health of this sector. The Medicare competitive bidding program historically used a methodology that forced suppliers to accept rates below their bid amounts (and by extension costs). The result of this unfair system led to hundreds of suppliers leaving the business prior to the pandemic. It also led to the loss of access for certain types of equipment (such as liquid oxygen), limited access in rural areas, and a substantial reduction in the services suppliers could provide. In addition, it resulted in a stagnation in innovation in the areas of home respiratory products. Innovators have avoided working in areas of health care where they cannot recover their research and development costs.

With these problems unresolved, the pandemic hit the United States. The CQRC applauds the Congress and the Centers for Medicare & Medicaid Services (CMS) for acting quickly and implementing important policies that provided temporary relief. These policies included providing reimbursement increases in non-competitive bidding areas and removing the out-of-date budget neutrality requirements on home oxygen reimbursement. The Congress also has provided sequestration relief. CMS reduced the documentation and audit requirements. These steps eliminated barriers facing patients who required home respiratory therapy, especially those with COVID-19. Together, the Congress and CMS also expanded telehealth options to allow patients to access their health care providers remotely.

During the pandemic, the CQRC members have stepped up to meet the challenge, but they require help to be able to maintain the services needed today and to be prepared for potentially emerging new diseases. They especially need federal help to maintain the flexibilities implemented during the pandemic to create long-term reimbursement stability, simplify documentation requirements, and reduce unnecessary audits. In brief, the CQRC requests:

- **Grandfathering Beneficiaries Who First Received Home Respiratory Therapy During the COVID-19 Pandemic.** During the pandemic, the number of patients who required home oxygen therapy for acute conditions like COVID-19 increased substantially. Some "long-hauler" patients continue to require home oxygen. CMS rightly waived certain documentation requirements to make sure these patients received the therapy they needed. Once the pandemic public health emergency (PHE) ends, it will be important to streamline the documentation requirements to make sure that these patients continue to receive the therapies they need. We suggest grandfathering Medicare coverage for these patients so they do not have to relinquish their equipment or have additional copayment obligations.

- **Stabilizing the Reimbursement Rates for Home Respiratory Therapies.** Rates in rural areas are set at the urban competitive bidding rates plus 10%. These rates are dramatically below the cost of providing services to beneficiaries in these areas. The Congress provided relief to rural rates during the pandemic by setting the rates at 50 percent of the fee schedule rates + 50 percent of the competitive bidding adjusted rates. In the CY 2021 DMEPOS Fee Schedule rural rates, CMS proposed making this blended rate permanent, but has yet to finalize the rule. Finalizing this proposed rate modification is critically important to maintaining access to home respiratory treatments in rural America.

- In addition, CMS has removed most product categories from the Round 2021 competitive bidding program. While there were some anomalies in some of the product areas in some competitive bidding areas, the rates that would have been set were higher than the previous round rates. This outcome was expected, even by the CMS actuary, because the previous methodology was so flawed, as described in detail by the Pacific Research Institute in 2018.[1] The CQRC believes it is important to create a stable reimbursement system to allow for much needed predictability, which was lost because of the downward spiraling of rates created by the median bid methodology of the previous competitive bidding program. Stability and predictability are essential to rebuilding the home respiratory therapy sector to support the long-haul patients and to be prepared for the next public health crisis.

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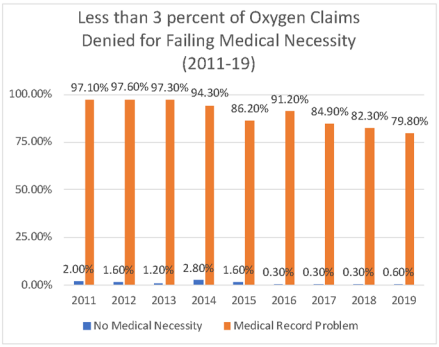
[1]Winegarden, Wayne. "Medicare Competitive Bidding Process Should Be Reformed." Pacific Research Institute. (2018) *available at https://www.pacificresearch.org/new-study-medicare-competitive-bidding-process-should-be-reformed-to-improve-health-outcomes-ensure-patient-access-to-medically-necessary-equipment/?platform=hootsuite.*

- **Stopping Medicare from Second-Guessing Physician Prescriptions.** During the pandemic, patient medical records were secondary to patient care. Prior to the pandemic, home respiratory therapy suppliers battled an overwhelming number of audits that result in claim denials, which Administrative Law Judges ultimately reinstated. As the chart below shows, the vast majority of these denials were due to insufficient wording in physician medical records.



Medicare coverage policy establishes objective criteria that do not require the medical record to determine medical necessity. Yet, the contractors insist on suppliers getting individual patient's confidential medical records from their physicians to "confirm" that the objective, independent test results the physician ordered are consistent with the physician's notes. Medicare should stop this game of "gotcha" by eliminating the requirement for contractors to review individual patients' medical records for home respiratory therapies or establish prior authorization process for home respiratory therapies.

While these policies are directed toward Medicare, they will also help support access to home respiratory therapies for all patients. Commercial insurers often look to Medicare policies as the basis for their own. Thus, addressing barriers to access in Medicare can have a positive effect for patients of all ages.

V. Conclusion

As the United States moves into its second year of the COVID-19 pandemic, there is hope for many with better treatment options and vaccines becoming more widely available. Yet, the crisis is not over. Many Americans remain unvaccinated. Mutations raise questions about whether new vaccines will need to be developed. We cannot predict how many more Americans will be infected and experience serious illness, hospitalization, and death. And, for some Americans, their battle with COVID-19 may never end.

The CQRC remains committed to working with federal, state, and local officials to make sure that COVID-19 patients and those with other chronic respiratory diseases have access to home respiratory therapies that reduce overall health care spending by preventing hospitalizations and readmissions. For these patients and in preparation for the next public health emergency involving a respiratory disease, it is important that the Medicare program provide a sustainable payment system that focuses on patient medical needs over paperwork and protects against fraud and abuse in a balanced and fair manner.

The CQRC looks forward to working with the Subcommittee to make sure that when Americans need home oxygen, sleep, or non-invasive ventilation therapies they are able to access these life-sustaining treatment options.

STATEMENT FOR THE RECORD
Submitted by
Rajarshi Banerjee, M.D., Ph.D., MSc., MRCP
"The Long Haul: Forging a Path through the Lingering Effects of COVID-19"
Hearing before the Subcommittee on Health
Committee on Energy and Commerce
April 28, 2021

Chair Eshoo, Ranking Member Guthrie, Chairman Pallone and Ranking Member McMorris-Rodgers:

Thank you for the opportunity to submit testimony today; I commend you for your foresight in scheduling this timely hearing on one of the most critical issues facing medicine and our health care delivery system today: the impact on patients and their care of long-COVID-19, or as some call it, "Long-COVID," or Post-Acute Sequalae of SARS-CoV-2 infection ("PASC").

For purposes of my testimony today, I will discuss PASC using the language NIH Director Francis Collins, M.D., Ph.D. put forward when he announced their new initiative to study "Long-COVID" on February 23, 2021. Dr. Collins said "I write to announce a major new NIH initiative to identify the causes and ultimately the means of prevention and treatment of individuals who have been sickened by COVID-19, but don't recover fully over a period of a few weeks.[1]"

I am Dr Rajarshi Banerjee — perhaps more easily known as "Banjo" — a medical doctor, scientist and co-founder of the United Kingdom-based company Perspectum; we deliver cutting-edge digital technologies that help clinicians provide better care for patients with liver disease, diabetes and cancer. With a strong focus on precision medicine using advanced imaging, Perspectum's vision is to empower patients and clinicians to achieve optimal health through quantitative assessments of health enabling early detection, diagnosis and targeted treatment.

In my testimony today, I wish to commend five important points to you for further study.

A brief mention about my background may help you put my remarks in context. I studied medicine at Oxford, and became interested in acquired heart and liver disease, which were alarmingly on the rise driven by obesity and alcohol use, conditions which are unfortunately all too present in the United States as well. I aim to improve care for these patients through earlier, safer and better diagnosis of their conditions using state-of-the-art, scalable scanning technology, enabling more speedy treatment and thus better outcomes. This led me to build a medical technology company, assemble a highly capable multidisciplinary team with many great diagnostic scientists, engineers and clinicians, and direct our focus to work on these challenges, starting first with liver disease.

As a company, Perspectum is committed to charting the uncharted in matters of public health and health care – and it became obvious to me early last year that we needed to focus our

[1] [https://www.nih.gov/about-nih/who-we-are/nih-director/statements/nih-launches-new-initiative-study-long-covid]

energies on the emerging public health challenge of our lifetimes: COVID-19. We quickly pivoted from our work focusing primarily on liver disease to research on the effect of COVID on internal organs using a holistic, scalable approach. We use one MRI scan at once of several organs, rather than multiple scans/visits as additional organ involvement might be suspected. Our products enable consistent, high-quality decision support to anyone with access to compatible MRI equipment, and empower patients to engage in the management of their health. Our advanced technology provides the metrics around which a better, more in-depth analysis of the location and extent of disease can be easily discovered.

The long-term impacts of COVID outside the lungs were not known in the period of March–April, 2020 when COVID first was discovered, so we undertook the world's largest study of mapping organ health in "post-COVID" individuals. This was before "long-COVID" was named that May in a tweet and then the phrase was picked up by patient advocacy groups. We built a medical device that could use existing MRI scanners coupled with our advanced software services to look at multiple organs in the torso, using a single 30-minute scan to find out if a patient has sustained organ damage from COVID.

It was not known if organ damage occurred in patients who had not been hospitalized, and we set out to study this. Our preliminary figures indicated that four to five months after infection almost 70 percent of COVID patients with persistent symptoms have sustained damage to one organ, and a quarter of these have two or more organs damaged. [2] The findings mirror another UK study which looked at 58 patients who had been hospitalised (so they were generally more severely affected in the lungs than the patients in our study).[3] At two to three months from disease onset, the study reported that MRI scans of COVID-19 patients post-hospital discharge revealed abnormalities in the lungs (60%), heart (26%), liver (10%) and kidneys (29%).

In January 2021, Perspectum received authorisation from the UK's Medicines and Healthcare products Regulatory Agency (MHRA) for special use of the service we developed to monitor post-COVID patients in the UK. Our service was cleared by UK regulators[4] for the benefit of public health with an exceptional use authorization, and we are now in discussions with your FDA to determine the best pathway to move forward.

Point one I wish to emphasize to you is that long-COVID must be treated seriously, because in the majority of persons whose COVID does not resolve in three months, there can be significant organ damage which should be treated early.

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[2] 'Multiorgan impairment in low-risk individuals with post-COVID-19 syndrome: a prospective, community-based study'
(https://bmjopen.bmj.com/content/11/3/e048391)

[3] 'Medium-term effects of SARS-CoV-2 infection on multiple vital organs, exercise capacity, cognition, quality of life and mental health, post-hospital discharge'
https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370(20)30427-2/fulltext

[4] https://www.medsci.ox.ac.uk/research/networks/national-consortium-of-intelligent-medical-imaging/news/world2019s-first-integrated-imaging-service-for-long-covid-approved-by-uk2019s-mhra/

This brings up the next point I wish to commend to your attention and this is somewhat intuitive but not often recognized. Long-COVID is a multi-system illness that must be treated holistically. The health care delivery system must recognize at the outset that a person who has had COVID can sustain organ damage, often in multiple organs. Some physicians have dismissed patient concerns as anxiety, or psychological. Those treating patients initially must have a broad conversation with their delivery system peers so that a patient presenting with, for example, fatigue and breathlessness is also assessed for heart, liver, spleen, pancreas and kidney. This is not necessarily happening now.

As an aside, you might ask why I stress the compunction to treat early? Not only is the old adage true here – an ounce of prevention worth a pound of cure – but being aware of potential organ damage is something a COVID or former-COVID patient should know. For example, we know from UK data that the risk of death in patients who have been hospitalized with COVID is **8x higher** that than those in matched control groups (Ayoubkhani et al, BMJ 2021[5]), and the risk of readmission is over 30%, mainly with cardiac presentations (arrhythmia, infarction, cardiac inflammation, heart failure).

Today, there are not enough multisystem physicians -- such as internal medicine specialists and infectious diseases physicians -- to manage COVID patients who have damage in one or more organs. Single organ specialists are not able to look at these patients efficiently. We all recognize that it is hard to change our health care delivery systems, but change is essential, starting with medical school education.

This brings me to my third point. We have no idea how long long-COVID can persist in a patient. We are operating in real time here. It is entirely possible COVID-19 could engender a whole new cohort of the disabled – the UK Department of Health is currently considering whether long-COVID patients should qualify for disability benefits, for example. From UK longitudinal data of long-COVID patients, we know many long-COVID patients improve somewhat over 12 months, but even so many are not able to work for **months**. We have no way at present to predict how long a long-COVID patient could be ill. This is one reason Perspectum is working so closely with the patient community to keep a watchful eye on the progression of this disease and its impact on patients. It is likely we will have a whole new cohort of disabled patients of working age whose illnesses are the result of COVID-19. The Committee should keep this in mind when continuing its study of long-COVID.

The next point I wish to commend to Members is that we are beginning to see signs that health care delivery systems cannot keep up with the growing need for patient treatment. I recommend that your study of the long-COVID issue extend to the impact on the health care delivery system and how it can be improved for long-COVID patients who need access to treatment. Your NIH, more so than our counterpart in the UK is using patient expertise to prioritise the research agenda effectively. Perspectum is proud to be collaborating with Survivor Corps, a fast-growing and extremely dedicated grassroots movement connecting, supporting, educating, motivating and mobilizing COVID-survivors to support all medical, scientific and

[5] https://www.bmj.com/content/372/bmj.n693 - a study of all the UK patients hospitalised with COVID in our first wave, cataloguing their clinical outcomes and readmission rates.

academic research. Our dialogue with Diana Berrent, herself a long-COVID survivor, who founded this advocacy group convinces me that there needs to be a systemic review of services long-COVID patients can receive from providers such as Community Health Centers and Federally-Qualified Health Centers, and then determine where there are gaps that should be addressed to help long-COVID patients in need. For example, MRI machines are not readily available in all areas, such as rural locations. The cost of the machine and also the cost of services can be barriers -- as can reimbursement – and, as a matter of cost containment, many states also have restrictions on the numbers of diagnostic systems that can be in operation.

In certain locales, specialized clinics operated by hospitals and other community entities are springing up to help long-COVID patients with their health care need. I want to take this opportunity to applaud a helpful step the Department of Health and Human Services took Friday when it announced nearly $150 million in grants to 100 health center "Look-Alikes" for several important purposes, including enhancement of health care infrastructure enhancement and services in local communities.

The Medicare, Medicaid, CHIP and other government programs are also vital. Even so, there may be gaps. We must recognize there are gaps, identify where they are, and prepare to address that. The Committee is especially well-positioned to conduct such an evaluation and propound needed solutions.

The fifth point I wish to emphasize is that there is not enough information known about the disproportionate impact of long-COVID on certain patient populations, be it race, income, geography or pre-existing illness to name a few. That is why we in the long-CID community are thrilled that Congress authorized the $1.15 billion in research at the National Institutes of Health. We commend you for this, and we commend NIH under the leadership of Dr. Francis Collins for their foresight with and attention to this illness. We have collaborated with prestigious universities in the States to submit applications for funding under these NIH Research Opportunity Grants announced on February 23, 2021. Use of our diagnostic technology will aid researchers as they seek to answer the many probing questions NIH proposes to answer through this and subsequent calls for other research which will include clinical trials to test strategies for treatment and recovery promotion.

As I have said, it is key that we begin to learn more about who long-COVID affects not only so we can locate and treat these patients, but so we can prevent illness if at all possible.

The Committee may find of interest the research results of a published study that I co-authored with Dr. Arun Sanyal of Virginia Commonwealth University and others using Perspectum's Liver*MultiScan* technology[6], which is authorized for use in the US as well as the UK. We examined underlying risk factors for COVID-19 and found that hepatic steatosis, or "fatty liver," rather than underlying obesity, increases the risk of infection and hospitalization for COVID-19. Those obese individuals who have fatty livers are most vulnerable to COVID, and we can diagnose and monitor them with community MRI and prioritise them for vaccine boosters in the future.

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[6] https://www.frontiersin.org/articles/10.3389/fmed.2021.636637/full

In closing, Madame Chair and members of the Subcommittee, we at Perspectum are thrilled that you have the foresight to turn your attention to the vexing public health problem that is long-COVID. From our work over the past year, it is clear that there is much to be learned about PASC – how it can be diagnosed and treated earlier, how the health care delivery system can best respond to the challenges it poses, whom the illness targets, and how long it can be expected to last.

It is my hope that the benefit of our experience will help direct you as you move forward, and I remain available to provide the benefit of our expertise to you at any time.

Thank you for this hearing, and thank you for the opportunity to submit this testimony today.

A Call to Action: Immediate Deployment Of Select Repurposed Drugs For COVID-19 Outpatient Treatment

Vikas P. Sukhatme MD ScD and Vidula V. Sukhatme MS

At the time of this writing approximately 3,000 Americans are dying of COVID-19 each day. While new cases have dropped off from a previous surge of 150,000-250,000 daily that was associated with holiday travel and increased indoor gatherings, the spread of new, more contagious variants of the coronavirus that causes COVID-19 threatens to reverse this reprieve. Health care systems could again face collapse and our economy is hurting badly.

The world embarked on an aggressive plan for developing effective vaccines which undoubtedly offer the best long-term solution to the COVID-19 pandemic. However, it will be mid 2021 before vaccine administration will show much impact and only if we resolve issues around delivery logistics, access and acceptance. Also, there will always be the threat of resistant strains evolving, the possibility of unexpected toxicities, and the uncertainty of how long the vaccine will be effective.

Thus, we desperately need approaches that can be deployed now and have the potential to save 100,000 to 150,000 lives in the next few months. We believe the approach we outline below can meet this need. But we also believe that, unfortunately, COVID will not be the last infectious disease threat the world faces, and the strategy we propose could be used to address future pandemics.

Repurposed drugs deployed nationally and evaluated by real world data

To have impact, any solution must be affordable, scalable, feasible, efficacious, safe, and—most importantly—immediately implementable.

Remarkably, a handful of drugs approved by the Food and Drug Administration (FDA), listed below, have shown promise in treating COVID-19 patients. These drugs have established safety records since they have been prescribed to millions of patients, and many are in chronic use. Given the minimal risk and the current state of the pandemic, shouldn't COVID patients, if they so desire, have ready access to these drugs "off-label"?

We believe the answer is yes and suggest immediate deployment of select FDA-approved drugs in the early outpatient COVID setting as important options that should be readily available—in addition to monoclonal antibodies, currently approved for those at highest risk for disease

progression. Such a strategy could dramatically reduce the number of patients requiring hospitalization in a matter of three-four weeks.

The gold standard for adopting new treatments is to conduct large randomized controlled trials (RCTs). Such studies, typically sponsored by pharmaceutical companies for new drugs, are time consuming and expensive. For an off-patent drug, manufacturers have little financial incentive to repurpose for another use. Academic clinicians do conduct such trials but due to limited resources and time, it often takes a long time to enroll a full complement of subjects.

A newer version of such studies, often referred to as a decentralized trial, can be used to enroll patients nationally in a trial run by a single health center through the use of telemedicine, but here, too, enrollment may be a challenge. Therefore, in a pandemic situation, these approaches may not offer timely results.

Real-World Data Contributing To Real-World Evidence

The National Institutes of Health, the Centers for Disease Control and Prevention, or FDA could issue temporary use guidance encouraging the repurposing and off-label prescribing for COVID-19 of existing drugs. The guidance would include inclusion and exclusion criteria, drug dosing, schedule, patient monitoring requirements, and an informed consent form. This approach would allow any doctor and any patient, irrespective of location, to immediately participate, allowing rapid enrollment of a diverse 'real world' patient population in rapid order.

The idea is similar to an Emergency Use Authorization (EUA), but an EUA does not typically provide tools for collecting patient data and for monitoring and evaluation of drug safety and efficacy. Under our approach, the temporary practice guidance would be coupled with one or more tools to track outcomes, such as the FDA-sponsored CURE ID app; a small 'stipend' to incentivize physicians to report their real-world patient data; and an analytics team to mine the data in real time and monitor outcomes and adverse events (e.g. clinical deterioration or improvement, hospitalization rate, mortality rate), so that the temporary use guidance can be terminated or modified.

Our proposal is most akin to France's Temporary Recommendation for Use, a "regulatory instrument which aims to allow, on a temporary basis, the use of a medicinal product to allow its effectiveness to be evaluated on the basis of its use." This strategy not only offers patients treatment options they may not currently have, but it promises to rapidly transform real-world data into real-world evidence.

Unpacking The Model

Advantages

Under our approach, a large network of primary care physicians could be engaged to treat patients in the community. Off-label use is legal in the US provided there is some supporting medical evidence; it should be a shared and highly individualized decision between patient and caregiver However, off-label use without RCT level data is generally frowned upon, evokes liability concerns and is variably reimbursed. Our approach mitigates legal as well as medical risks via standardization and outcomes assessment, issuance of an informed consent form, and guidance at a national level.

Furthermore, rapid enrollment of adequate numbers of diverse participants could potentially overcome the drawback of non-randomization our approach entails. It is worth noting that tightly controlled clinical trials may sometimes not simulate real world conditions. Finally, several drug combinations could be assessed simultaneously under our approach; the front-runner could then move to a large randomized trial if necessary.

Potential Concerns

Our approach will not work for all drugs. Oral drugs with few well-characterized drug-drug interactions and known minimal toxicities are best suited to this approach. By contraste, if a drug is rarely used in clinical practice, many physicians will not be familiar with its use.

Our strategy might expose more patients to 'adverse effects' than a randomized trial. Near real-time safety monitoring by a central analytics team and selection of non-toxic interventions would reduce this risk.

Real world data collected in this manner may not be conclusive. While this is a valid concern, it could be overcome if we design a simple data collection tool to capture relevant outcomes and enroll large and diverse populations.

Other Considerations

Who Pays For The Drug And Any Specialized Monitoring Needed?

Existing, off-patent drugs are inexpensive, and we suggest that candidate drugs be chosen in part based on having known risk profiles and thus minimal need for expensive monitoring. A fund to cover costs may be needed in case insurance companies do not pay. However, if Medicaid/Medicare agree to pay, insurance companies will likely follow.

Might Our Approach Make It More Difficult To Enroll Patients In Clinical Trials Of That Drug?

Those who might oppose this strategy may point to the hydroxychloroquine (HCQ) story. The FDA issued an EUA for HCQ to treat COVID patients in April 2020. But clinical trials were also initiated and did enroll a full complement of subjects. Once it was clear that HCQ was not effective, the FDA revoked the EUA in June 2020. Moreover, the real-time outcomes data monitoring we are proposing might actually inform the design of the RCT for the drug, e.g. by suggesting a population subset that might respond.

Who Will Champion The Real World Trials?

FDA in collaboration with the National Center For Advancing Translational Studies (NCATS) has launched the Cure Drug Repurposing Collaboratory (CDRC), which may be ideally suited to champion outpatient COVID-19 real world trials. This group has deliberated on the need for rapid implementation and readout, especially for infectious diseases. The release of the CURE ID app where clinicians report novel uses of existing drugs is an example. So, by providing treatment guidance, a simple tool to capture the data, and compensation for time, the CDRC could facilitate rapid testing of 'financial orphans', an example of which is off-patent drugs without a current champion.

Quicker Action?

While government agencies are best situated to take the lead in our approach, we acknowledge that this may take time to stand up because it may necessitate a change in the US drug regulatory framework. An approach that could be immediately implemented is for a few large health care systems to take the lead. By issuing a temporary use guidance for the promising marketed drugs, they could encourage their network of physicians to prescribe 'off-label' treatments in a standardized manner, ideally with an informed consent form. They could insist that the clinical records of patients treated in this way be anonymized and then analyzed for adverse events and clinical efficacy outcomes—all after suitable Institutional Review Board approval. A local patient registry could also be set up.

Repurposed Drug Candidates And Prioritization

Published papers relevant to COVID-19 suggest 100 or so potentially efficacious marketed drug candidates, based upon in silico and in vitro analyses. Interestingly, a dozen or so show hints of clinical efficacy in COVID-19 patients, as gleaned from retrospective observational analyses, case reports/series, and phase II studies.

Moreover, if we only select drugs that are commonly used, affordable, oral, have minimal toxicity, and have a plausible mechanism of action for COVID, with supporting animal data in a relevant model, the list narrows even further. Many of these interventions are being tested in clinical trials across the globe. The following are examples of drugs that we believe should be immediately tested in the outpatient setting through the issuance of a temporary use guidance, either at a health care system level or by government decree. This is not an all-inclusive list and is likely to evolve rapidly. Though many trials are ongoing, most are being conducted abroad, some are small and thus may not lead to definitive answers, and many are enrolling slowly, further emphasizing the need for rapidly gathering real world evidence in the manner we suggest.

Exhibit 1. Candidate drugs for testing in outpatient use to treat COVID-19.

Drugs	**Drug category**	**# of ongoing clinical trials**	**References**
Fluvoxamine	Anti-depressant	1 - Phase III	Ref Ref
Ivermectin	Anti-parasitic	36	Summary
Nitazoxanide	Anti-parasitic	20	Ref
Colchicine	Anti-inflammatory	20	Summary
Famotidine	H_2 blocker	5	(REF1, REF2, REF3, REF4)

Source: Authors' analysis

In summary, during a rapidly evolving pandemic, a small group of the most promising FDA-approved drugs could be repurposed for COVID-19 use using temporary treatment guidance by a government agency and/or health care systems. In either case, concurrent with such efforts, tools to track outcomes should be made readily available and data analyzed in real-time. Large RCTs should be pursued in parallel.

This approach would allow our nation to rapidly evaluate the safety and efficacy of existing drugs that are easy to administer, affordable, and readily available. If successful, this approach could *dramatically* alter the course of the COVID-19 pandemic in the next few weeks, while vaccines take effect. It should also be noted that these repurposed drugs may well be efficacious even against SAR-CoV-2 variants that may render current vaccines ineffective, since they are targeting mechanisms likely to be conserved even in the mutant strains.

Finally, COVID-19 is not the first pandemic the world has faced, and it will certainly not be the last. The infrastructure and experience gained from using our approach to address COVID-19 will enable the same strategy to be used against future pandemics.

Authors' note:

The views presented in this blog reflect those of the authors and are not necessarily those of the institutions to which they are affiliated.

BIOSKETCHES

Vikas P. Sukhatme MD ScD is the Robert W. Woodruff Professor of Medicine, Dean of Emory School of Medicine, and Chief Academic Officer, Emory Healthcare since 2017. He completed residency in medicine and clinical fellowship in nephrology at Massachusetts General Hospital and a fellowship in immunology at Stanford University. He held a faculty appointment at the University of Chicago as an Assistant Investigator of the Howard Hughes Medical Institute. He was chief of the renal division in the Department of Medicine at Beth Israel Deaconess Medical Center and Harvard Medical School. Later, he was the founding chief of the Division of Interdisciplinary Medicine and Biotechnology at Beth Israel and Chief Academic Officer, Harvard Faculty Dean for Academic Programs and Victor J. Aresty Professor of Medicine at Harvard. Sukhatme has made contributions in numerous areas of medicine in both basic science and clinical research. He has more than 200 scientific publications cited over 43,000 times. His longstanding interest in cancer currently centers on "outside-of-the-box" approaches for treating advanced cancer and preventing cancer recurrence using repurposed drugs. He is co-founder of a not-for-profit organization, GlobalCures, that aims to promote promising therapies for cancer not being pursued for lack of profitability. These ideas are being advanced at Emory through the Morningside Center for Innovative and Affordable Medicine, where Sukhatme serves as the founding director. Sukhatme received bachelors and doctorate degrees in theoretical physics from Massachusetts Institute of Technology and obtained his MD in 1979 as part of the Harvard-MIT program in Health Sciences and Technology, Harvard Medical School.

Vidula Sukhatme MS holds an adjunct appointment as an Instructor in the Rollins School of Public Health, Emory University, and is the founding CEO of GlobalCures, a non-profit that aims to promote promising therapies for cancer not being pursued for lack of profitability. These ideas are being advanced at Emory through the Morningside Center for Innovative and Affordable Medicine. Vidula is a co-founder of the Center and a consultant to it. She has a long-standing interest in repurposed drugs and other "financial orphans", a phrase coined in a Health Affairs blog she co-authored in 2014. She earned a master's degree in mathematics from Northeastern University and a masters in epidemiology from the Harvard T.H. Chan School of Public Health.

United States House of Representatives
House Energy & Commerce Committee
Subcommittee on Health

Hearing on “The Long Haul: Forging a Path Through the Lingering Effects of Covid-19."

April 28, 2021

Statement of the American Physical Therapy Association

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Chairwoman Eshoo, Ranking Member Guthrie, and Members of the House Energy & Commerce Subcommittee on Health:

On behalf of our 100,000 member physical therapists, physical therapist assistants, and students of physical therapy, the American Physical Therapy Association appreciates the opportunity to provide a statement for the record on the subcommittee's hearing "The Long Haul: Forging a Path Through the Lingering Effects of Covid-19." APTA is dedicated to building a community that advances the physical therapy profession to improve the health of society. As experts in rehabilitation, prehabilitation, and habilitation, physical therapists play a unique role in society in prevention, wellness, fitness, health promotion, and management of disease and disability for individuals across the age span — helping individuals improve overall health and prevent the need for avoidable health care services. Physical therapists' roles include education, direct intervention, research, advocacy, and collaborative consultation. These roles are essential to the profession's vision of transforming society by optimizing movement to improve the human experience.

The Role of Physical Therapy for Patients With Long-Term COVID-19 Symptoms

Early in the pandemic physical therapists and physical therapist assistants provided cardiopulmonary therapy to patients with COVID-19, as well as early mobilization of patients on ventilators to decrease the risk of ICU-acquired weakness (the muscle weakness that develops during an ICU stay that is present in at least 33% of all patients on ventilators) and rehabilitation for patients who were post-ICU who had limitations in strength and function. As we have seen, a percentage of people hospitalized develop post-acute sequelae of SARS-CoV-2 infections, or PASC, and physical therapists and physical therapist assistants are now working with those patients to improve their function and long-term recovery.

The effect of PASC is far-reaching, including cognitive, neurological, cardiac, vascular, muscular, and respiratory issues, which limit function and participation in daily living skills.[1] The impact on quality of life may persist for several weeks or months after acute infection. Symptoms, and their severity, vary from person to person, and include but are not limited to:

- Depression or anxiety.
- Fast or pounding heartbeat.
- Fatigue.
- Headache.
- Memory issues.
- Muscle and joint pain.
- Mobility and functional limitations.
- Poor endurance.
- Muscle weakness.

Physical therapists and physical therapist assistants have been working with patients who have PASC by providing therapy services that improve a client's strength, stamina, endurance, functional capacity, and cardiopulmonary function.[2]

[1] The effects of COVID-19 on lung morphology, lung function, respiratory symptoms, fatigue, functional capacity, activity limitations, and quality of life may persist for several weeks after acute infection: A systemic review of the literature.

[2] Physical therapist management of an individual with post-COVID syndrome: A case report (https://doi.org/10.1093/ptj/pzab098).

Charting a Path Forward With a National Plan

This is a critical time to act to address the health of the individual and ensure our path to recovery as a country. PASC has significant and growing ramifications on our health systems and economy. An incomplete response has the potential to exacerbate the opioid crisis and racial and ethnic health disparities. This will require national leadership, a multidisciplinary approach, and collaboration across the health community. APTA believes that Congress should work with the Biden administration in the establishment of a national plan to address the needs of the growing number of individuals with long-haul COVID-19 symptoms. The plan should consist of three major principles needed for a crisis response:

1. Resources to build necessary rehabilitation infrastructure to meet the needs of those with PASC. Such infrastructure should include expanding access to therapy services.

2. Equitable access to care for patients with PASC and addressing inequities in our health care system that result in diminished and limited access to sustainable quality PASC care due to race, ethnicity, neighborhood or geographic location, socioeconomic factors, and disability status.

3. Funding for research that advances medical understanding of PASC and evidence-based management strategies — such research must be inclusive of all populations, including people with disabilities and underlying health conditions.

Recently, APTA joined the American Academy of Physical Medicine and Rehabilitation in calling on President Biden and his administration to establish such a national plan.

Building an Equitable Therapy Infrastructure To Address PASC

To help build the rehabilitation infrastructure needed to meet the needs of those with PASC, including recruitment of a diverse therapy workforce that will assist in addressing health inequities, APTA recommends the following:

1. **Improve access to rehabilitation for patients with COVID-19 at community health centers.** Many patients recovering from the coronavirus face a long and difficult road to recovery. The lasting postacute impact of the virus on many patients' cardiopulmonary systems, as well as muscle weakness due to hospitalization, will require extensive rehabilitation to assist with their long-term recovery. Ensuring that patients have access to medically necessary rehabilitation, particularly Medicare and Medicaid beneficiaries, will be critical in the months ahead. During the 116th Congress, Rep. Ron Kind and Rep. Jackie Walorski introduced the Primary Health Services Enhancement Act (H.R. 5693), bipartisan legislation that would expand patient access to essential physical therapy services to children and adults who receive care at rural health clinics and federally qualified health centers, also known as community health centers. These community health centers provide primary health services to more than 29 million people in over 12,000 rural and urban communities across America, including nearly 3 million Medicare beneficiaries and one in five Medicaid beneficiaries. These facilities provide a lifeline to communities in need of essential health services whose barriers to health care include cost, lack of insurance, distance, and language. Presently, these facilities offer a range of health services, including access to physicians, advanced practice nurses, dentists, clinical laboratories, emergency medical services, and behavioral health services. However, community health centers are restricted in how physical therapy services are provided and reimbursed. The Primary Health Services Enhancement Act is anticipated to be reintroduced soon in the 117th Congress and would address this problem by allowing physical therapists to provide care to patients in these facilities and bill Medicare and Medicaid for the benefits covered by their plans.

2. **Expand the physical therapy workforce in rural and underserved areas.** In the 116th Congress,

Rep. Diana DeGette introduced H.R. 2802, the Physical Therapist Workforce and Patient Access Act, which would allow physical therapists to participate in the National Health Service Corps Loan Repayment Program. Currently there is no rehabilitative care component in NHSC, and physical therapists are not eligible to participate in the program. NHSC addresses the health needs of more than 11.4 million underserved individuals across the nation. The program allows for the placement of certain health care professionals in areas designated as a health care professional shortage area, or HPSA. NHSC has not only served as a pipeline for providers in underserved areas but has successfully retained many of its providers. For example, in 2018 nearly 80% continued to practice in an HPSA for at least one year after their service commitment ended. Including physical therapists in the NHSC Loan Repayment Program will improve functional outcomes and save costs by increasing access to critical rehabilitation services. Adding physical therapists to NHSC also will ensure that individuals in underserved communities have access to necessary therapy services for the treatment of PASC.

3. **Address health inequities by ensuring a diverse therapy workforce.** According to a United States Government Accountability Office study, a more diverse health care workforce is important because minority groups disproportionately live in areas with health care provider shortages, and patients who receive care from members of their own racial and ethnic background tend to have better outcomes. APTA is committed to ensuring that we are recruiting providers who reflect the diversity of the patient populations we serve to help address health inequities. In the 116th Congress, Rep. Bobby Rush and Rep. Cathy McMorris Rodgers introduced the Allied Health Workforce Diversity Act (H.R. 3637) that would create student scholarships or stipends for individuals underrepresented in the professions of physical therapy, occupational therapy, audiology, respiratory therapy, and speech-language pathology, including racial and ethnic minorities and those from disadvantaged backgrounds. The Allied Health Workforce Diversity Act is expected to be introduced in the 117th Congress in the near future; if enacted, it would boost the number of minorities in the health profession workforce and correct the underrepresentation in these fields.

Conclusion

We appreciate the opportunity to provide the subcommittee with our perspective on the role of physical therapy and long-haul COVID-19 recovery. Physical therapists and physical therapist assistants help people with impairments and challenges maximize their quality of life. People with PASC need our expertise and care; APTA stands ready to collaborate with Congress, and our health professional colleagues to promote their recovery. Should you have any questions, please do not hesitate to contact David Scala, APTA congressional affairs senior specialist, at davidscala@apta.org. Thank you for your consideration.

615 Westlake Avenue N
Seattle, Washington 98109
206.548.7000 phone

ALLEN INSTITUTE for IMMUNOLOGY

April 27, 2021

The Honorable Cathy McMorris Rodgers
Ranking Member
Energy and Commerce Committee
Washington, D.C. 20515

Dear Ranking Member McMorris Rodgers,

In preparation for the Subcommittee on Health's hearing on April 28, 2021 entitled "The Long Haul: Forging a Path Through the Lingering Effects of COVID-19", we write regarding COVID-19 immunity, specifically understanding diversity and addressing disparity in health care research.

As you know, the Allen Institute located in Seattle, Washington is one of the nation's premier research institutes dedicated to unlocking the complexities of bioscience and advancing our knowledge to improve human health. Using an open science, multi-scale, team-oriented approach, the Allen Institute focuses on accelerating foundational research, developing standards and models, and cultivating new ideas to make a broad, transformational impact on science.

Today, we have over 148 million confirmed cases of COVID-19 documented globally, which has resulted in over 3.12 million deaths with serious morbidity effects and ongoing health concerns in a much broader global population. A heartfelt statistic is that the United States alone has had over 572,000 deaths during this pandemic. An astonishing statistic which does not get enough attention is that the burden of the deaths and accompanying morbidity across the nation are in underserved populations including indigenous Americans, African Americans, Pacific Islanders and Hispanic/Latino Americans. Recent research suggests that approximately 500 plus deaths occur in these populations for about every 100 deaths in the white American population per 100,000 subjects.

There are many socioeconomic and cultural reasons that are often cited to explain these staggering statistics including lack of access to health care, the extensive use of public transportation, crowded living conditions including multigenerational families and occupations that involve frequent face to face interactions. As highlighted by many in the federal government since the beginnings of the pandemic, the presence of racism in our health care system poses a significant problem as well. While we believe that many of these conditions clearly contribute to negative COVID-19 outcomes; these underserved populations are profoundly understudied.

In the tens of thousands of scientific publications published and/or posted in reprint servers surrounding the COVID-19 pandemic, surprisingly few are focused on studying people of color in the U.S. population. Therefore, in collaboration with our partners, the Allen Institute for Immunology has successfully completed initial deep immune profiling studies in Seattle-Tacoma residents who acquired the virus in the community, including first responders and volunteers from the region over many months of follow-up. These studies revealed a rich heterogeneity of the mild to moderate disease category, differential paths to convalescence/wellness and in a subpopulation, a skewed immune dysfunction associated with long hauler symptoms. Specific results are in the process of being submitted for a peer review publication on key disease signatures from deep immune profiling of mild to moderate disease volunteers in these longitudinal studies.

These successful pilot studies have demonstrated a proven pipeline to ascertain immune dysfunction and outcomes applicable to any human condition or population. As the immune system is emerging as a key predictor of either good or bad outcomes in the pandemic, extending this scalable model for immune system profiling to local underserved populations is both timely and informative to detect and prevent a downward spiral of vulnerable patients in this pandemic and into the future. **Therefore, we encourage this Committee to support further federal investment dedicated to expanding this important research to ensure equality for our nation's underserved communities in regard to COVID-19 research leading to subsequent optimized, personalized care for our diverse population.**

We greatly appreciate your attention to this important issue, and look forward to working with you and your colleagues to address research gaps in immunology related to COVID-19 and future pandemics. Should you have any questions, please do not hesitate to reach out to me directly at tomb@alleninstitute.org.

Sincerely,



Thomas F. Bumol, Ph.D.
Executive Vice President and Director
Allen Institute for Immunology

STATEMENT FOR THE RECORD

HEARING BEFORE THE SUBCOMMITTEE ON HEALTH
COMMITTEE ON ENERGY AND COMMERCE

April 28, 2021

"Survivor Corps PASC Research Brief"

Submitted by Survivor Corps

Natalie Lambert, Ph.D., Survivor Corps Medical Advisory Board, Indiana University School of Medicine, Department of Biostatistics and Health Data Sciences
Diana Berrent, J.D., Founder
Karen Harris, J.D., Director of Science and Policy
Suzanne Pincus, Director of Communications

Chairwoman Eshoo, Ranking Member Guthrie, Chairman Pallone, Ranking Member McMorris-Rodgers, and distinguished members of the Subcommittee:

Thank you for the opportunity to submit testimony today. In this brief we summarize the research findings of Survivor Corps and our research collaborators regarding patients' experiences with Post-Acute Sequelae of SARS-CoV-2 infection (PASC).

Key research findings about PASC:

- People suffering from PASC experience a wide range of long-lasting COVID-19 symptoms (over 100 symptoms identified by our research)[1]
- In our study of COVID-19 patients' electronic health records, 27% of COVID-19 positive patients reported symptoms after 60 days. Being asymptomatic at onset of COVID-19 was the strongest predictor of developing PASC[2], which indicates that large numbers of people who did not know they had COVID-19 are likely to develop PASC
- While the impact of COVID-19 on the lungs and vascular system is becoming well known, our research found that brain, whole body, eye, skin, and dental symptoms are also frequently occurring health problems for people suffering from PASC
- On average, our research participants with PASC reported 21.4 symptoms and the number of symptoms ranged from 1 to 93[3]
- The most commonly reported long-lasting COVID-19 symptoms found by our research are: fatigue (79.0%), headache (55.3%), shortness of breath (55.3%), difficulty concentrating (53.57%), inability to exercise or be active (49.6%), cough (49.0%), changed sense of taste (44.9%), diarrhea (43.9%), muscle or body aches (43.5%), difficulty sleeping (41.8%), and memory problems (40.1%)
- The PASC symptoms that survivors reported most impacted their ability to work included the relapsing/remitting nature of illness (described by survivors as "changing symptoms"), inability to concentrate, fatigue, and memory problems, among others
- Patients reports suggest that PASC symptoms occur in waves, from neurological and cardiovascular manifestations with some indicators of a strong immune response, followed by microvascular consequences, and then impact on endocrine (thyroid) function

[1] https://www.survivorcorps.com/s/2020-Survivor-Corps-COVID-19-Long-Hauler-Symptoms-Survey-Report-revised-July-254.pdf
[2] https://www.medrxiv.org/content/10.1101/2021.03.03.21252086v1
[3] https://www.medrxiv.org/content/10.1101/2021.03.22.21254026v2

FIGURE 1. PERCENTAGE OF RESPONDENTS REPORTING EACH PASC SYMPTOM (OUT OF 5,163)

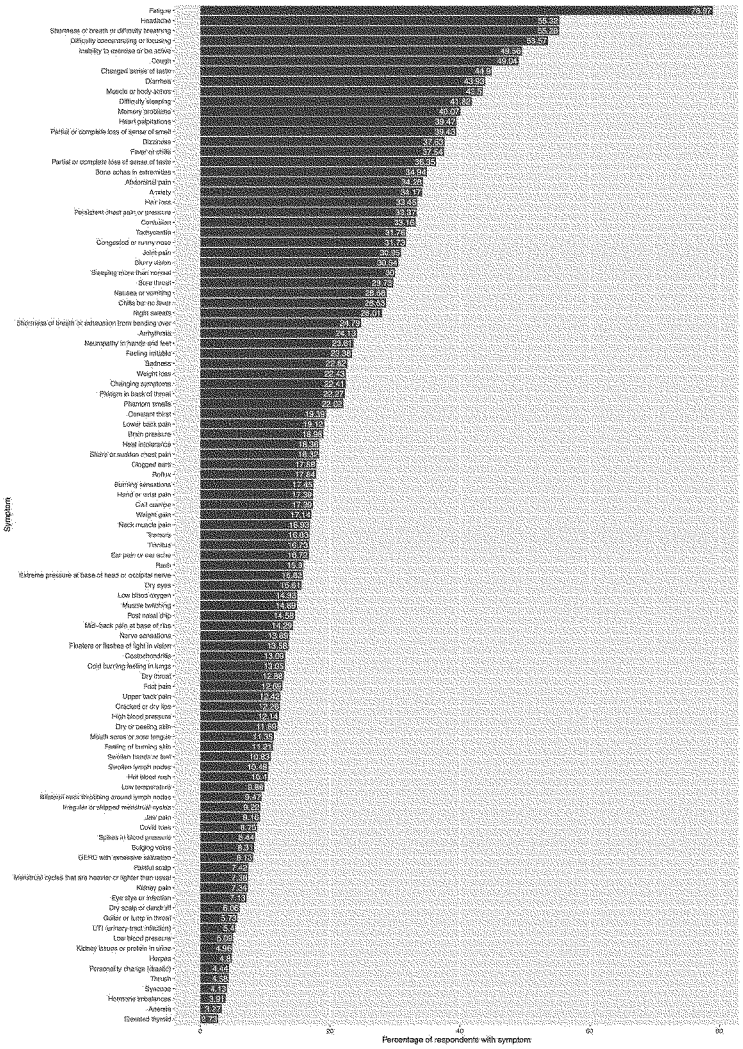

FIGURE 2. NUMBER OF COVID-19 SYMPTOMS EXPERIENCED BY PASC SURVIVORS

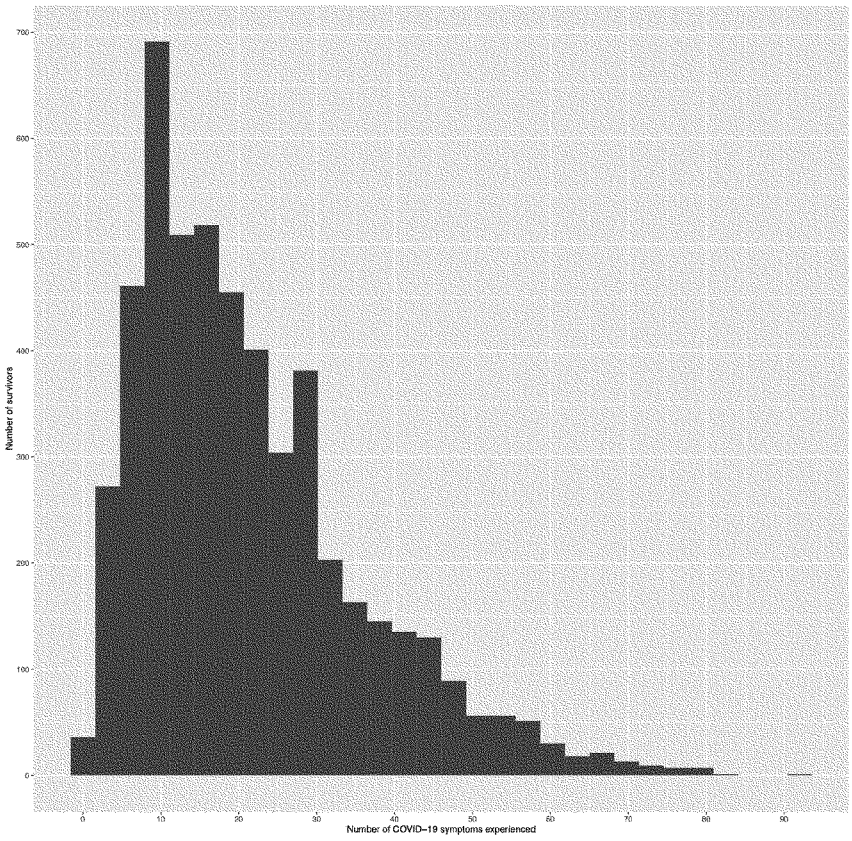

FIGURE 3. THE SYMPTOMS OF PASC AND THEIR IMPACT ON SURVIVORS' ABILITY TO WORK

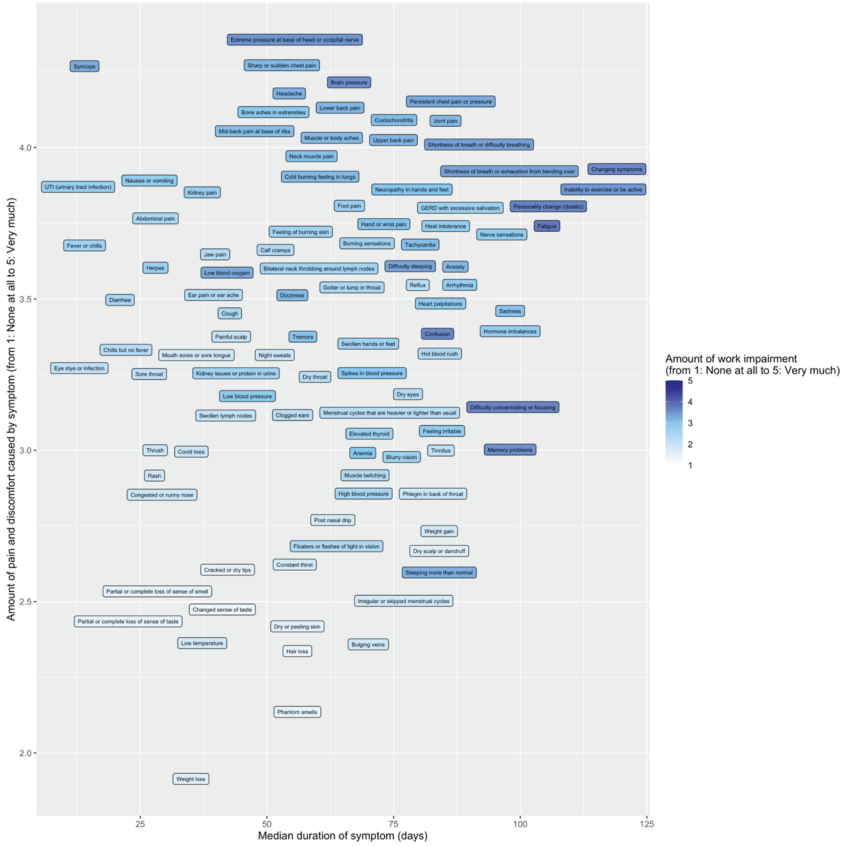

FIGURE 4. PASC INDICATING WAVES OF SEQUELAE IN PLOT OF MEDIAN SYMPTOM ONSET AND DURATION

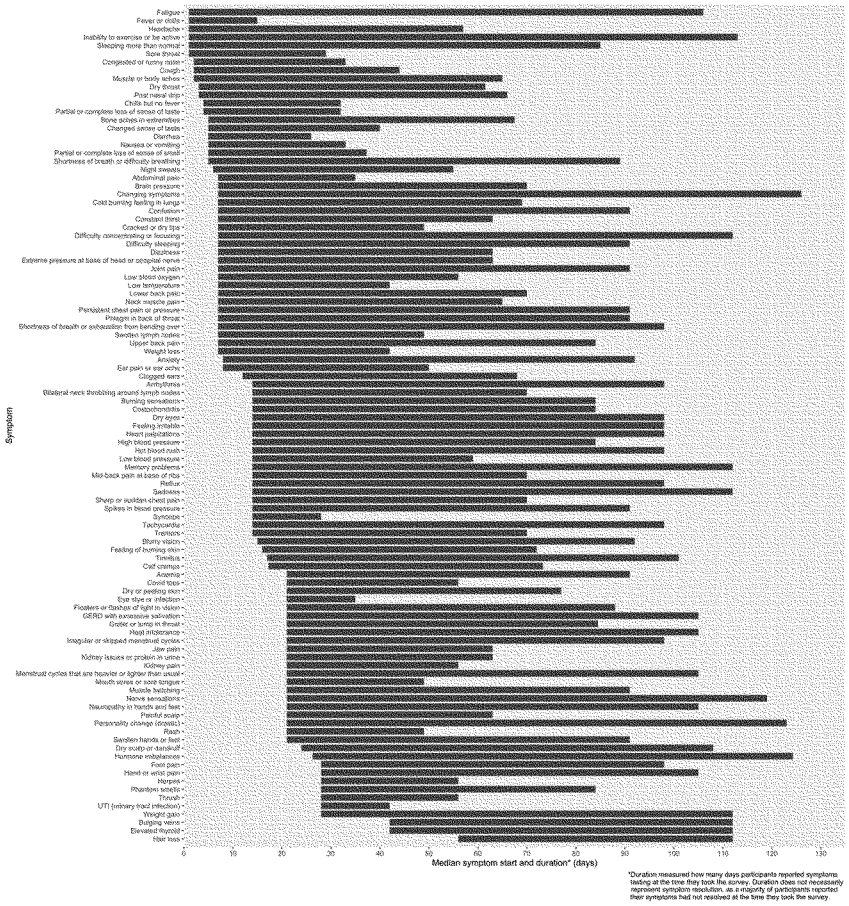

TABLE 1. PASC SYMPTOMS AND THEIR HEALTH IMPACTS

Symptom	Number of patients reporting symptom	Percentage of patients reporting symptom (%)	Median start date (days)	Median duration (days)	Average pain/discomfort of symptom (1-5)	Average work impairment of symptom (1-5)	Average social impairment of symptom (1-5)	Percentage afflicted reporting symptom as ongoing (%)	Percentage afflicted reporting symptom as intermittent (%)
Fatigue	4077	78.97	1	105	3.77	3.79	3.68	83.25	53.74
Headache	2856	55.32	1	56	4.15	3.22	3.07	65.90	76.68
Shortness of breath or difficulty breathing	2854	55.28	5	84	4.04	3.40	3.26	72.04	66.40
Difficulty concentrating or focusing	2766	53.57	7	105	3.14	3.66	3.18	83.41	69.99
Inability to exercise or be active	2559	49.56	1	112	3.84	3.48	3.60	84.25	32.00
Cough	2532	49.04	2	42	3.48	2.46	2.39	52.41	57.23
Changed sense of taste	2318	44.90	5	35	2.50	1.32	1.63	53.71	31.58
Diarrhea	2268	43.93	5	21	3.50	2.49	2.39	44.22	63.62
Muscle or body aches	2246	43.50	2	63	4.05	3.12	2.98	64.07	61.62
Difficulty sleeping	2159	41.82	7	84	3.59	3.35	3.16	80.45	50.58
Memory problems	2069	40.07	14	98	3.00	3.55	3.10	86.52	63.80
Heart palpitations	2038	39.47	14	84	3.51	2.90	2.74	76.55	84.69
Partial or complete loss of sense of smell	2036	39.43	5	32.25	2.50	1.47	1.71	48.33	22.94

Dizziness	1943	37.63	7	56	3.53	3.14	2.92	68.76	82.86
Fever or chills	1938	37.54	1	14	3.68	2.60	2.47	27.19	57.28
Partial or complete loss of sense of taste	1877	36.35	4	28	2.46	1.44	1.71	45.07	24.08
Bone aches in extremities	1804	34.94	5	62.5	4.12	2.97	2.88	73.61	69.90
Abdominal pain	1770	34.28	7	28	3.77	2.47	2.56	61.07	80.51
Anxiety	1764	34.17	8	84	3.60	3.15	3.39	88.72	83.84
Hair loss	1727	33.45	56	56	2.34	1.40	1.74	76.03	15.98
Persistent chest pain or pressure	1723	33.37	7	84	4.12	3.30	3.15	66.69	67.38
Confusion	1712	33.16	7	84	3.38	3.65	3.33	78.62	77.10
Tachycardia	1640	31.76	14	84	3.62	3.09	2.94	70.49	76.77
Congested or runny nose	1638	31.73	2	31	2.86	1.89	1.83	57.39	53.79
Joint pain	1598	30.95	7	84	4.06	3.15	3.04	76.47	62.08
Blurry vision	1577	30.54	15	77	2.98	2.69	2.21	79.71	71.85
Sleeping more than normal	1549	30.00	1	84	2.63	3.25	3.16	68.82	38.80
Sore throat	1535	29.73	1	28	3.28	2.09	2.02	43.06	52.44
Nausea or vomiting	1481	28.68	5	28	3.88	2.84	2.77	45.78	70.02
Chills but no fever	1478	28.63	4	28	3.30	2.24	2.19	42.69	77.13
Night sweats	1446	28.01	6	49	3.29	1.93	1.88	49.03	69.16
Shortness of breath or exhaustion from	1280	24.79	7	91	3.80	3.37	3.15	76.17	55.55

bending over									
Arrhythmia	1246	24.13	14	84	3.53	2.84	2.77	79.86	87.72
Neuropathy in hands and feet	1219	23.61	21	84	3.71	3.04	2.86	79.66	68.33
Feeling irritable	1207	23.38	14	84	3.06	2.85	3.36	79.45	77.96
Sadness	1168	22.62	14	98	3.44	3.04	3.48	79.54	69.26
Weight loss	1158	22.43	7	35	1.91	1.55	1.53	36.01	18.05
Changing symptoms	1157	22.41	7	119	3.93	3.61	3.61	83.49	82.45
Phlegm in back of throat	1150	22.27	7	84	2.86	1.90	1.85	71.83	54.87
Phantom smells	1137	22.02	28	56	2.14	1.43	1.54	64.82	81.71
Constant thirst	1001	19.39	7	56	2.63	1.74	1.66	67.43	43.96
Lower back pain	987	19.12	7	63	4.10	3.17	2.99	65.96	63.32
Brain pressure	980	18.98	7	63	4.22	3.56	3.42	73.16	78.27
Heat intolerance	948	18.36	21	84	3.70	2.83	3.03	83.23	51.58
Sharp or sudden chest pain	946	18.32	14	56	4.25	3.15	2.95	59.83	79.49
Clogged ears	923	17.88	12	56	3.12	2.19	2.17	70.21	63.06
Reflux	921	17.84	14	84	3.56	2.23	2.23	73.07	72.42
Burning sensations	901	17.45	14	70	3.71	2.64	2.58	70.26	81.69
Calf cramps	898	17.39	17.25	56	3.69	2.37	2.28	71.38	84.97
Hand or wrist pain	898	17.39	28	77	3.78	3.05	2.47	77.17	67.37
Weight gain	885	17.14	28	84	2.72	1.81	2.11	82.94	15.14
Neck muscle pain	874	16.93	7	58	4.00	3.07	2.85	66.48	58.81

Tremors	869	16.83	14	56	3.35	3.05	2.75	66.28	76.18
Tinnitus	864	16.73	17	84	3.01	2.13	2.08	75.35	60.19
Ear pain or ear ache	863	16.72	8	42	3.51	2.35	2.23	58.98	69.06
Rash	821	15.90	21	28	2.91	1.84	1.87	46.41	46.04
Extreme pressure at base of head or occipital nerve	817	15.82	7	56	4.36	3.51	3.32	66.10	71.73
Dry eyes	806	15.61	14	84	3.16	2.32	1.99	74.81	54.59
Low blood oxygen	771	14.93	7	49	3.61	3.30	3.18	54.22	58.75
Muscle twitching	769	14.89	21	70	2.92	2.32	2.21	68.14	79.32
Post nasal drip	753	14.58	3	63	2.77	1.80	1.75	67.60	53.25
Mid-back pain at base of ribs	738	14.29	14	56	4.05	3.09	2.91	63.01	63.96
Nerve sensations	707	13.69	21	98	3.72	2.89	2.81	76.38	74.82
Floaters or flashes of light in vision	701	13.58	21	67	2.67	2.38	2.06	74.04	72.18
Costochondritis	676	13.09	14	70	4.11	3.10	2.93	67.01	60.06
Cold burning feeling in lungs	674	13.05	7	62	3.93	3.13	3.07	64.39	70.62
Dry throat	665	12.88	3	58.5	3.26	2.24	2.14	68.42	58.80
Foot pain	655	12.69	28	70	3.80	2.72	2.62	80.61	68.09
Upper back pain	641	12.42	7	77	4.03	3.17	3.02	69.11	62.25
Cracked or dry lips	633	12.26	7	42	2.60	1.46	1.46	60.98	36.02

High blood pressure	627	12.14	14	70	2.89	2.55	2.41	68.58	55.34
Dry or peeling skin	614	11.89	21	56	2.42	1.56	1.55	66.61	29.97
Mouth sores or sore tongue	586	11.35	21	28	3.30	1.84	1.85	46.93	47.10
Feeling of burning skin	579	11.21	16	56	3.69	2.59	2.49	60.28	72.54
Swollen hands or feet	559	10.83	21	70	3.35	2.62	2.40	73.35	63.69
Swollen lymph nodes	541	10.48	7	42	3.12	2.07	1.98	52.87	43.81
Hot blood rush	537	10.40	14	84	3.34	2.38	2.36	70.02	80.63
Low temperatur e	510	9.88	7	35	2.39	1.82	1.87	53.33	68.63
Bilateral neck throbbing around lymph nodes	489	9.47	14	56	3.66	2.58	2.54	68.92	74.03
Irregular or skipped menstrual cycles	476	9.22	21	77	2.50	1.79	1.84	66.39	42.44
Jaw pain	473	9.16	21	42	3.63	2.30	2.20	58.14	67.23
Covid toes	452	8.75	21	35	3.00	1.96	1.85	50.00	44.91
Spikes in blood pressure	436	8.44	14	77	3.25	2.98	2.76	63.53	74.77
Bulging veins	429	8.31	42	70	2.36	1.84	1.75	73.43	62.00
GERD with excessive salivation	420	8.13	21	84	3.80	2.68	2.70	77.38	65.48
Painful scalp	383	7.42	21	42	3.35	2.04	2.02	54.57	57.96

Menstrual cycles that are heavier or lighter than usual	381	7.38	21	84	3.09	2.22	2.24	69.55	44.88
Kidney pain	379	7.34	21	35	3.86	2.74	2.60	49.34	67.28
Eye stye or infection	368	7.13	21	14	3.28	2.12	1.93	33.70	32.61
Dry scalp or dandruff	313	6.06	24	84	2.64	1.56	1.71	79.23	28.75
Goiter or lump in throat	296	5.73	21	63.5	3.57	2.45	2.37	65.54	50.68
UTI (urinary tract infection)	279	5.40	28	14	3.87	2.75	2.74	31.54	38.71
Low blood pressure	263	5.09	14	45	3.21	2.92	2.77	61.22	59.70
Kidney issues or protein in urine	256	4.96	21	42	3.28	2.58	2.51	58.59	37.89
Herpes	248	4.80	28	28	3.60	2.71	2.68	52.82	50.40
Personality change (drastic)	229	4.44	21	102	3.78	3.69	3.98	68.12	48.91
Thrush	226	4.38	28	28	3.00	1.95	2.05	33.63	30.09
Syncope	213	4.13	14	14	4.27	3.29	3.15	38.03	62.44
Hormone imbalances	202	3.91	26.25	98	3.42	2.82	2.88	68.32	45.54
Anemia	169	3.27	21	70	3.00	3.01	2.90	73.96	23.67
Elevated thyroid	141	2.73	42	70	3.02	2.67	2.52	68.79	17.73

Thank you, Madame Chair and members of the Subcommittee. We appreciate the opportunity to present what we have learned about PASC from those suffering from the disease.

Thank you for the opportunity to submit this testimony today.

STATEMENT FOR THE RECORD

HEARING BEFORE THE SUBCOMMITTEE ON HEALTH
COMMITTEE ON ENERGY AND COMMERCE

April 28, 2021

"Advocating for Answers: Health Care and Research Needs
that Support Individuals with Long COVID-19"

Submitted by Survivor Corps

Diana Berrent, J.D., Founder
Karen Harris, J.D., Director of Science and Policy
Harlan Krumholz, M.D., S.M., Survivor Corps Medical Advisory Board, Yale-New Haven Hospital
Natalie Lambert, Ph.D., Survivor Corps Medical Advisory Board, Indiana University School of Medicine, Department of Biostatistics and Health Data Sciences
William W. Li, M.D., Survivor Corps Medical Advisory Board, The Angiogenesis Foundation
Suzanne Pincus, Director of Communications

Chairwoman Eshoo, Ranking Member Guthrie, Chairman Pallone, Ranking Member McMorris-Rodgers, and distinguished members of the Subcommittee:

Thank you for the opportunity to submit testimony today. Providing a voice to those suffering from Long COVID-19 is an essential first step in addressing the abundance of new and challenging issues facing the medical and research communities who seek to work with patients to find successful health care strategies to address the Post-Acute Sequelae of SARS-CoV-2 infection ("PASC"), sometimes referred as "long hauler's syndrome."

Survivor Corps is the largest grassroots movement in America dedicated to actively ending the COVID pandemic. With over 165,000 members we are continually connecting, supporting, educating and motivating those affected by COVID-19, including colleagues, families and friends. We aim to mobilize as many as possible to support all ongoing scientific, medical and academic research. As we look to the second year of this pandemic, our mission includes:

- Supporting COVID-19 survivors in their recovery from acute and long COVID;
- Assisting with the advancement of research, data collection and analysis, and the development of health care practices;
- Encouraging government backed interventions such as coordinated care, improved access, the launch of registries and the development of benefit programs providing insurance, disability and financial assistance;

- Bringing patient voices to the forefront of scientific research, thereby redefining citizen science so that citizens and scientists work in collaboration to honor the needs of patients and accelerate the pace of scientific discovery; and,
- Memorializing the national reaction to COVID in order to maintain a record of best practices to help ensure that an equitable plan is developed to better prepare us for pandemic challenges we may face in the future.

As of April 27, 2021, SARS-CoV-2 has infected more than 148 million people worldwide, with over 32 million cases and 569,000 deaths occurring in the United States. Some states still struggle with double-digit positivity rates and caseloads equal to or greater than those experienced in October 2020. The acute manifestations of this devastating pandemic have taken lives, disabled our economy, and disrupted our communities. However, the long-term sequelae of infection may be just as daunting, with implications for massive numbers of people left with chronic conditions totaling in the millions. Initial studies suggest that anywhere from 30 to 60% of people infected with SARS-CoV-2 exhibit mild to disabling long-term symptoms.[1,2] Many studies indicate that PASC can involve multiple organ systems[3], spanning the range of fatigue, tachycardia, memory problems, difficulty concentrating, blurry vision, and severe headaches, among more than 100 symptoms. The medical specialists who are involved with care of people suffering from PASC include cardiologists, pulmonologists, endocrinologists, neurologists, nephrologists, gastroenterologists, radiologists, dermatologists, psychiatrists, pain specialists, rehabilitation specialists, general practitioners and specialists from other disciplines.

The need for a multi-disciplinary care for PASC patients has been shown in numerous research studies. Survivor Corps surveyed 5,163 COVID-19 survivors reporting symptoms more than 21 days following SARS-CoV-2 infection.[4] Participants reported an average of 21.4 symptoms and the number of symptoms ranged from 1 to 93. The most common symptoms were fatigue (79.0%), headache (55.3%), shortness of breath (55.3%), difficulty concentrating (53.6%), cough (49.0%), changed sense of taste (44.9%), diarrhea (43.9%), and muscle or body aches (43.5%). The timing of symptom onset varied and was best described as happening in waves. The longest lasting symptoms on average for all participants (in days) were "frequently changing" symptoms (112.0), inability to exercise (106.5), fatigue (101.7), difficulty concentrating (101.1), memory problems (100.8), sadness (99.2), hormone imbalance (99.1), and shortness of breath (96.9). Many symptoms presented with pain. These symptoms can be severe enough to make it difficult or impossible for many people to return to work or perform necessary, everyday activities without assistance.

Additional studies building on Survivor Corps' findings have been and are being carried out. One study looked at electronic data sets and reported symptoms experienced by those with PASC.[5] Twenty-seven percent of subjects reported persistent symptoms after 60 days. Presenting symptoms included palpitations, chronic rhinitis, dysgeusia, chills, insomnia, hyperhidrosis, anxiety, sore throat, and headache. Of great concern was the finding that roughly 32% of those reporting symptoms at day 61+ were initially asymptomatic at the time of SARS-CoV-2 testing. The public health implications of PASC infection are vast. At this time there are no guidelines for diagnosis, case management, assessment or

[1] https://jamanetwork.com/journals/jama/fullarticle/2771581
[2] https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2776560
[3] https://bmjopen.bmj.com/content/11/3/e048391
[4] https://www.medrxiv.org/content/10.1101/2021.03.22.21254026v1
[5] https://www.medrxiv.org/content/10.1101/2021.03.03.21252086v1

care. Additional studies are urgently needed that focus on the physical, mental, and emotional impact of long-term COVID-19 survivors who suffer from PASC infection.

For the millions experiencing long-term symptoms, there needs to be a home in the government for information regarding their condition and care. This central office must be tasked with driving and coordinating scientific information and research, distilling information about clinical patient experiences, developing guidance to the medical community on best clinical practices, advancing policies, and supporting the people's interests. We advise that patient-centered, social scientific research be supported on equal footing with clinical studies of PASC. PASC causes a wide range of sequelae and each individual's experience with the disease can vary to an extraordinary degree. Because of this, a true understanding of PASC can only be developed by conducting research that can characterize the patterns of experiences and health impacts of diverse groups of people suffering from PASC and using these findings to create hypotheses that guide clinical and translational research. Just as good clinical research is the pathway to understanding the biological underpinnings of PASC, nationally funded, social scientific research is essential for understanding what clinical research and which federal policies will best enable PASC survivors to recover and return to work and daily activities.

Government leadership is essential to prevent an American crisis caused by COVID's unique long-term pathology. Presently, there is no coordinating entity taking charge of collecting data on all people suffering from PASC, developing practices in the health care field, and leading the development of solutions from prevention to treatment to recovery. The NIH has issued a call for research and identified the most pressing research questions related to PASC and Congress has earmarked $1.15 billion in funding over four years to support this work. This is a good first step, but more support for research is needed. In addition, financial support is essential for those with PASC infection who now struggle with the high cost of healthcare, therapeutics and medical testing, as well as increased debt, loss of employment, and housing and food insecurity. Additional funding also is needed to support patient-centered stakeholder research that assesses the physical, mental, occupational, and social impacts of PASC, as well as research to develop diagnostic and therapeutic tools, medical and nutritional interventions, mental health support programs, and work policies that address these impacts. Industries in the health and recovery fields, from insurance to fitness to rehabilitation, are floundering without leadership as they seek to plan how to serve affected individuals best and move forward in a post-COVID economy.

Many governmental departments have launched programs and efforts on COVID-19 recovery. These programs exist in offices in the Department of Defense, Veterans Affairs, Labor, Social Security and Education, and Health and Human Services, including the FDA, NIH, CDC, ONC, AHRQ, CMS, and HRSA. Still, to be most effective, they require coordination. The wealth of information on PASC grows daily, but it does not currently have a home base from which it can be used for prevention, intervention, and guiding policy. We urge Congress to find a home from which information can be captured and disseminated to the medical and research communities and to the general public, and from which a roadmap to recovery for individuals who suffer from the condition can be designed and implemented.

Leadership is needed to promote partnerships and convene discussions between medical societies, patient advocacy groups, research institutions, international coalitions, and policymakers. As other Departments and Agencies focus on vaccinations, acute treatments, opening the economy, school re-opening, and other aspects of the pandemic, efforts must be led that address the needs of people whose experience with the illness has not ended.

The list of to-dos in the arena of PASC ranges from the basic to the complex, including refining the definition of the condition so that the medical and insurance industries can coordinate care and monitor recovery. Multidisciplinary Post-COVID Care Centers need to be established nationally, with uniform standards, coordinated intake, screening, care and monitoring strategies. In addition, at-home patient care recommendations need to be developed to assist those who do not yet have access to these centers, or who experience economic or healthcare insecurity. These centers could establish a 'gold standard' of care, bringing together new technologies that would elevate America's healthcare strategies, as we adopt holistic, transparent and more efficient systems. In the absence of this, millions of Americans will compete for scarce openings at expensive care centers that will have different approaches for PASC, amplifying health care inequalities, and bolstering health disparities that leave the most disadvantaged groups behind. Systematically monitoring the effectiveness of PASC care strategies will help set a standard for post-pandemic management in preparation for future health disasters.

PASC's impact on disability and workforce policies are also in great need of attention. Without significant investment today in diagnosis, treatment and health management strategies, COVID-19's long-term economic impact will go unchecked. Not since World War II has America faced the challenge of supporting such a potentially large chronically disabled population in need of care. Only economic investment today can protect our national workforce and economy tomorrow.

PASC needs a champion and a home where it will not be lost amid decades-long analyses. Americans need a coordinated movement that brings together patients, re-builds trust in the government's ability to care for its citizens, coordinates the efforts of medical scientists, public health workers, and policy makers, and helps to fast-track a pathway to recovery for the tens of millions of Americans who have survived COVID-19 and suffer from its aftermath. We urge Congress and the Administration to:

1. Champion this effort,
2. Require and support leadership and coordination between individuals, organizations and agencies working on these issues, and
3. Adequately fund all of the efforts and entities mentioned above.

Thank you, Madame Chair and members of the Subcommittee. We appreciate the opportunity to address the personal, public health, economic and societal problems brought about by long COVID. Leadership, planning and coordination of efforts are desperately needed as we learn more about PASC infection. How America responds today will define who we are in the decades to come and will prepare us to respond more effectively to health care crises we may face in the future.

We look forward to working collaboratively to address both the immediate challenges of this pandemic and the challenges associated with long COVID conditions. Thank you for the opportunity to submit this testimony today.

SURVIVOR CORPS

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Survivor Corps Overview

April 2021

Survivor Corps
The Epicenter of Hope

Survivor Corps is the largest grassroots movement in America dedicated to actively ending the COVID pandemic. Our mission is to connect, support and educate those affected by COVID-19. We aim to mobilize as many as possible to support all ongoing scientific, medical and academic research.

Our work is influencing the development of new therapeutics for those with COVID and improved care for those suffering from Long COVID/PASC. As of April 2021, there are over 165,000 members of Survivor Corps.

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Research

Survivor Corps has redefined what it means to be a citizen scientist. By working and collaborating with researchers and clinicians around the world, the organization and its members have participated in groundbreaking and critical research in the fight against COVID-19.

Studies Include:

- Indiana University School of Medicine/Survivor Corps Symptom Survey Publications
- Columbia University Dept of Medicine, Division of Digestive and Liver Disease
- Long term COVID studies (CDC Inspire, Stanford autonomic dysfunction, JHU symptoms and recovery, UI/Mayo Brain Health, etc.)
- University of Michigan Institute for Social Research
- Stanford Healthcare Innovative Lab
- Adaptive Biotechnology T-Detect

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Original Research:
Survivor Corps/Indiana University School of Medicine

Overview

Indiana University School of Medicine and Survivor Corps designed and conducted studies with members in the Survivor Corps Facebook group. Recruitment was also done through newsletters and other social media platforms.

Results

- 2 White papers - posted on our website: A Long Hauler Symptom report, An assessment of preventative screening methods based on symptoms reported
- medRxiv preprints: Timing, Duration and Health Impacts of PASC, & Symptom Clusters, and Predictors for Becoming a Long-Hauler
- See: www.survivorcorps.com/reports

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Insights from Survivor Corps Research

- Range of long-term sequelae, their timing, duration, and health impacts in terms of social impact, family impact, and ability to work
- Many PASC sequelae are intermittent, and this quality of sequelae makes it difficult for many survivors to return to work
- Symptoms arise in waves, which suggests neurological and cardiovascular manifestations, followed by microvascular consequences and then possible impact on endocrine function
- This finding can help to guide research on the biological processes underpinning PASC
- Process: SC polls have been essential for generating hypotheses about new sequelae, health impacts, barriers to care, the financial impacts of PASC, and health outcomes related to covid vaccines
- Future: Currently analyzing data to gain insights into effective care, symptom management and outstanding patient needs

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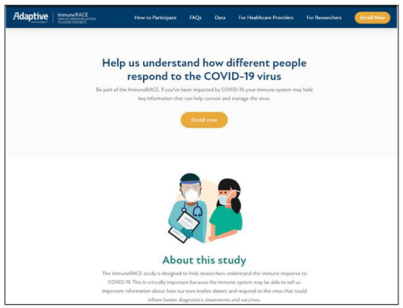
Contributions To Science:
Adaptive Biotechnologies T-Detect

From Bench to Bedside: Contributions to Clinical Research

Survivor Corps contributions to Research: ImmuneRACE



- Clinical study participation
  - Several key members of Survivor Corps participated, and drove patient participation in the prospective ImmuneRACE study
  - Contribution to the largest public database of immune response to the virus (ImmuneCODE)
- Ongoing patient education
  - Two webinars to educate patients on the basics of the immune system and T cells
- Informed development of the first clinical T-cell test to detect past COVID-19 infection (EUA authorized)
  - T cells last longer than antibodies, therefore a T-cell test is an important tool for people who want to know if they had COVID-19 and may help them to understand and address ongoing health issues

"Survivor Corps has been leader in encouraging patient participation in research, enabling direct contributions to scientific breakthroughs during this public health crisis. Because of these contributions, patients around the world are already benefiting from advances made in the diagnosis and treatment of COVID-19."

- Lance Baldo, Chief Medical Officer, Adaptive Biotechnologies

1

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Adaptive biotechnologies

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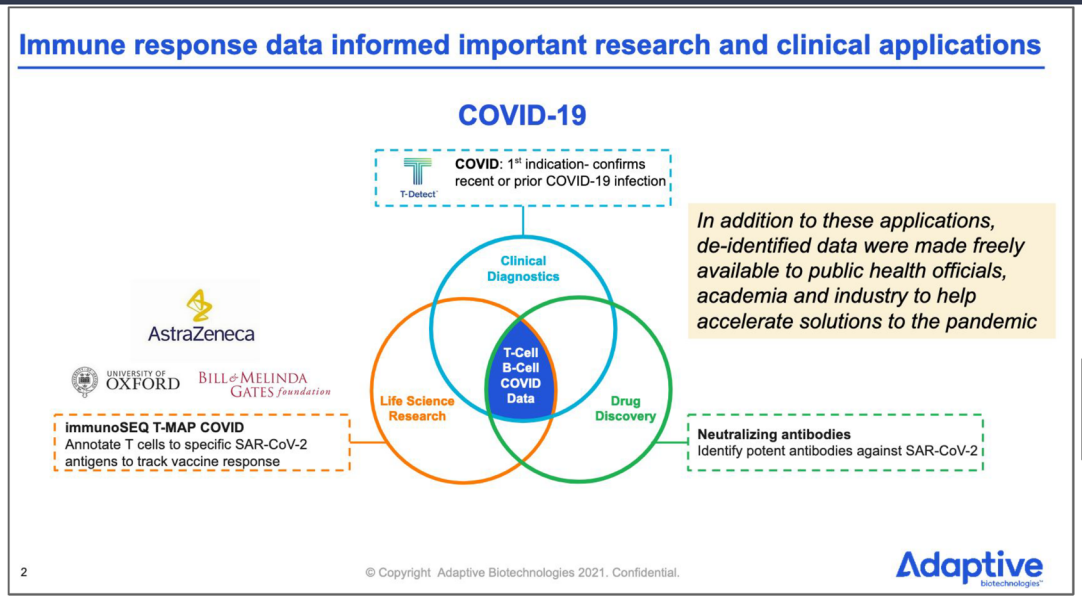
Source:
Adaptive Biotechnologies

Contributions To Science:
Adaptive Biotechnologies T-Detect



Source:
Adaptive
Biotechnologies

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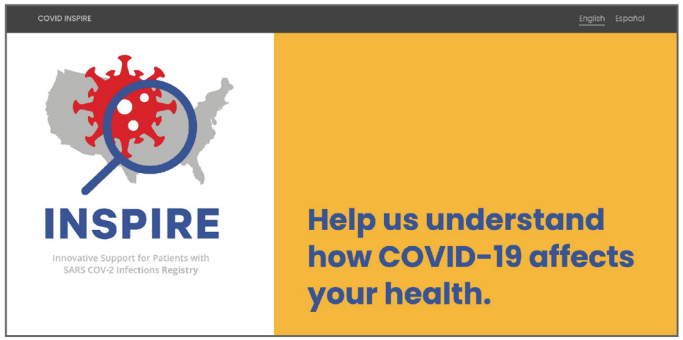
Contributions To Science:
Inspire Study

Overview

Example: CDC Inspire Study



Results

- Survivor Corps conducted question review for study
- Assessed user interface
- Promoted on social media (in English and Spanish)
- Drove recruitment

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Future Studies
Long COVID focused studies submitted to the NIH for consideration

Overview

Survivor Corps is collaborating with researchers to support the development of new studies focused on understanding Long COVID.

Potential Studies

- Children with Long COVID
- Multi-state longitudinal studies on PASC
- Localized PASC studies combining surveys, bio-specimens, testing, and treatment success
- Focused biological (blood, saliva) collection studies to understand the underlying mechanisms of PASC
- Scanning studies to identify organ health in PASC patients
- Studies targeting treatment potential for specific symptoms (for example: headaches, GI issues, sleep disturbance and fatigue)

SurvivorCorps.com

The Survivor Corps website (www.SurvivorCorps.com) is a central hub for information for those affected by COVID-19, including patients, caretakers and physicians.

The United States Library of Congress selected the Survivor Corps website for inclusion in the nation's historic Coronavirus Web Archive.

Website Topic Areas:

- Research and Clinical Study Opportunities
- Therapeutics
- Educational Resources
- News and Media
- Post COVID Care Center Guidelines and Locations
- Physician Resources
- Digital Resources for Social Media
- FAQs

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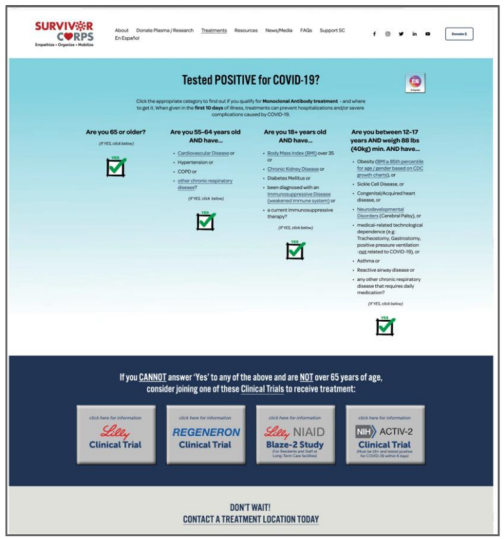
GotCOVID.org

Overview

- Portal on the Survivor Corps website dedicated to assisting those who are newly diagnosed with COVID-19 on assessing their potential eligibility for monoclonal antibodies and accessing treatment
- Links to HHS & National Infusion Center resources
- Information on clinical trials for those who do not qualify under the current EUA
- Comprehensive FAQ section
- Medical Facility and Physician Resources
- Content is available in English and Spanish



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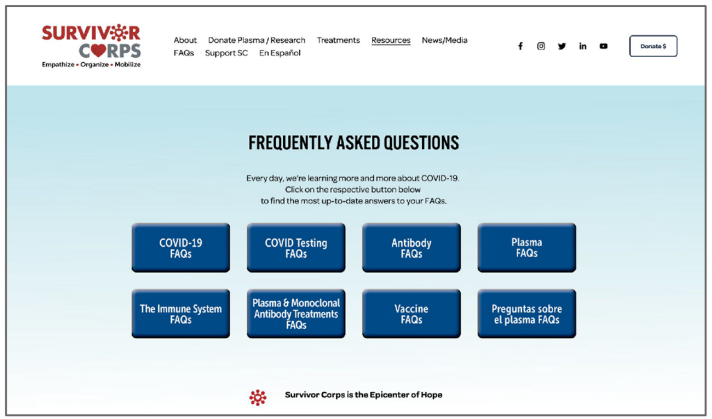
SurvivorCorps.Com
FAQ Section

Overview

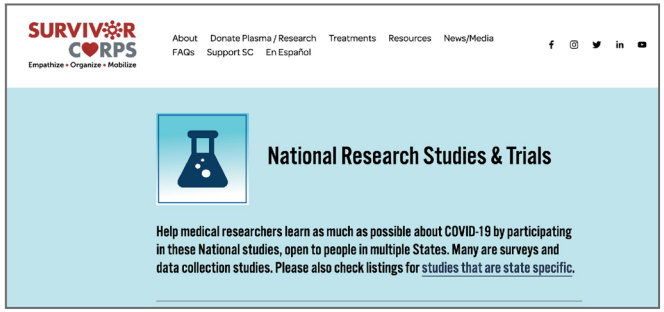
The FAQ section acts as a guide for users to get their questions answered on multiple topics.



SurvivorCorps.Com
Research Opportunity Library

Overview

Survivor Corps promotes research studies relating to COVID-19. Topics include therapeutics, Long COVID, vaccines, patient narratives and equity in care.



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SurvivorCorps.Com
Physicians Resources Page

Overview

In an effort to fill a communication gap caused by the overwhelming demands on the healthcare industry during the pandemic, Survivor Corps has developed resources for physicians and healthcare facilities.



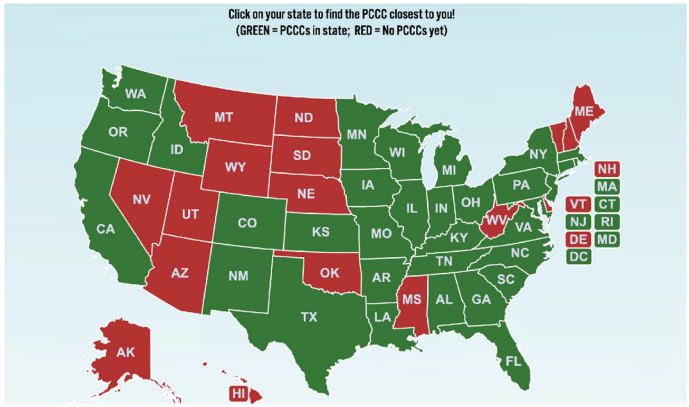
SurvivorCorps.Com
Post COVID Care Centers

Overview

The Survivor Corps website offers a comprehensive location map and listings of Post COVID Care Centers, Rehabilitation Facilities and Acute Care Centers around the country.

In addition, suggested guidelines are provided to those facilities seeking to set up healthcare programs for those with Long COVID.

www.survivorcorps.com/pccc



SurvivorCorps.Com

COVID Live Webinars: We Bring The Experts To You

Topics Have Included:

- Long COVID
- Plasma
- Mental Health
- Monoclonal Antibody Treatments
- Symptom Specific Discussions
- Timely Update on COVID
- T-Cells and Immunity
- Vaccines

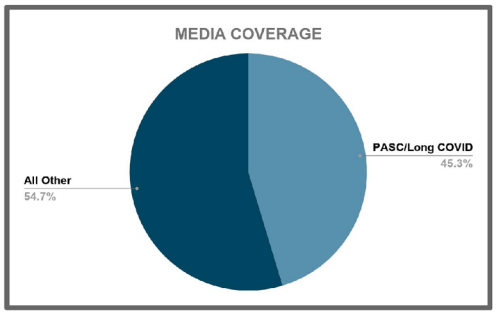
Expert Panelists Have Included:

- Dr. Anthony Fauci
- Dr. Andrew von Eschenbach
- Dr. Michael Joyner
- Dr. Kavita Patel
- Dr. Daniel Griffin
- Dr. Vin Gupta
- Dr. Lance Baldo
- Dr. Emma Guttman
- Dr. David Putrino

Survivor Corps Media Reach

In the 13 months since its founding, Survivor Corps has been featured in over 4,000 media pieces with a reach of over 13.6 Billion.

Coverage on PASC/Long COVID makes up over 45% of coverage. "All other" coverage includes vaccines, therapeutics, personal testimony and equity.



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Survivor Corps
The Epicenter of Hope

Communications Contact:
Suzanne Pincus Shidlovsky
suzanne@survivorcorps.com

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Attachment—Additional Questions for the Record

Subcommittee on Health
Hearing on
"The Long Haul: Forging a Path through the Lingering Effects of COVID-19"
April 28, 2021

Francis Collins, M.D., Ph.D., Director, National Institutes of Health

The Honorable Robin Kelly (D-IL)

1. How do we help employers understand the plight of their employees experiencing long COVID to ensure they are not discriminated against in the workforce and are able to remain productive citizens, if they choose to?

NIH Response:

NIH-funded research helps provides a critical evidence base to inform health-related policies and patient protections, including protection against employment discrimination. Ongoing research, as well compelling, credible patient testimonials, tell us that the long-term effects of coronavirus disease 2019 (COVID-19) are real. While most people recover quickly and fully from infection with severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), some experience symptoms lasting weeks or months after the acute infection has passed—also known as post-acute sequelae of SARS-CoV-2 infection (PASC). These symptoms can range from mild to debilitating and may include fatigue, shortness of breath, "brain fog," sleep disorders, heart palpitations, fever, gastrointestinal symptoms, anxiety, and depression. PASC is most often reported as persistent symptoms after acute COVID-19 (or long COVID) but can occur even among those who tested positive for the virus but never had acute symptoms. PASC has been reported in all age groups and demographics. The prevalence of PASC is unclear, but it is estimated that 10-30 percent of those who have had acute SARS-CoV-2 infection will experience persistent symptoms lasting at least one month.

NIH's Researching COVID to Enhance Recovery (RECOVER) initiative seeks to understand, and ultimately to prevent and treat, long COVID and other forms of PASC. At the heart of the Initiative is an observational study that will include adults and children recruited from ongoing studies of COVID-19, long COVID clinics, and other cohorts. The RECOVER Initiative is designed to significantly expand our knowledge about PASC, including helping to define the full spectrum of PASC, its prevalence, and outcomes over several years, and its underlying biology. Through RECOVER, NIH is also working to educate the public about PASC, including through a new website that will launch in early June 2021, recovercovid.org. The website will include a fact sheet about PASC that has been disseminated widely in partnership with medical and scientific societies. NIH leadership is also spreading the word about long COVID and PASC

through media interviews and town hall-style events, often in partnership with Members of Congress, to reach those communities hit hardest by COVID-19 and thus most vulnerable to long COVID.

The Honorable Cathy McMorris Rodgers (R-WA)

1. I have been hearing from individuals in my district who are unable to be accepted into a COVID-19 long-hauler clinic even though they are clinically similar to COVID-19 long-hauler patients, but for whatever reason were unable to obtain a positive COVID-19 test. What is being done to address this problem? How can we provide better access to care for these patients?

NIH Response:

The NIH RECOVER Initiative is supporting research to understand, and ultimately to prevent and treat, long COVID and other post-acute sequelae of SARS-CoV-2 infection (PASC). Patients are involved at every feasible step in planning and implementing this research. NIH believes that engaging people affected by PASC, and understanding their experience, needs, and priorities, are critical to the Initiative's success. In letters, emails, and calls—as well as a RECOVER virtual listening session to be held on June 2, 2021—a significant number of people have shared their frustration in being unable to receive a confirmed diagnosis of long COVID based on SARS-CoV-2 testing.[1] Many became acutely ill with COVID-19 when testing was not yet available to them; others had no acute illness but developed symptoms later. In either situation, these individuals tend to share a similar array of symptoms—including but not limited to fatigue, shortness of breath, and "brain fog"—that have persisted long after the virus would have been expected to clear from their bodies. Clinicians caring for patients with long COVID have shared similar accounts, including in published reports.[2]

One of the goals of the RECOVER meta-cohort study is to develop core defining characteristics and diagnostic criteria for long COVID and other forms of PASC. RECOVER is considering the use of alternative approaches to classify and diagnose long COVID in the absence of a positive SARS-CoV-2 test as it recruits study participants. Furthermore, in coordination with the NIH Rapid Acceleration of Diagnostics (RADx) program, RECOVER will explore the use of innovative tests for detecting past SARS-CoV-2 infection. For example, rather than seeking to detect the virus or antibodies to the virus, such tests could be designed to detect cellular responses to the virus that persist long after infection.

The Honorable Gus Bilirakis (R-FL)

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[1] videocast.nih.gov/watch=42174
[2] pubmed.ncbi.nlm.nih.gov/33780290/

1. One thing the hearing did not touch upon in any great detail was the role of early diagnosis in the treatment and prevention of progression of long-COVID-19. Could you elaborate on that in more depth?

NIH Response:

The NIH RECOVER initiative will increase our understanding of the early signs and symptoms of long COVID, as well as help lead to intervention strategies. At the heart of RECOVER will be a large diverse cohort that will include patients from, for example, long COVID clinics, NIH's COVID studies and trials, and other long-standing cohort studies. This meta-cohort will include tens of thousands of adults and children with acute infection as well as those experiencing PASC long COVID and other post-acute sequelae of SARS-CoV-2 infection (PASC). Understanding the acute phase of SARS-CoV-2 infection, its trajectory, and the factors that lead to full recovery or prolonged symptoms, are critical to early diagnosis, treatment, and prevention of PASC.

NIH released the first funding opportunities for RECOVER in February 2021, and in June 2021, the initiative will fund a Clinical Science Core that will assemble the meta-cohort, and will work to identify key clinical features of PASC, establish early diagnostic criteria, investigate mechanisms of disease, and identify potential targets for drug therapies or other interventions. As this information evolves, the initiative will support interventional trials. In addition, it is hoped that many of the ongoing clinical trials currently focused on treating acute COVID-19 will point to potential interventions for long COVID.

2. I was impressed by how patient-centric your and Dr. Brooks' remarks were. It is obvious patients are at the center of what both your agencies are doing to solve the many mysteries of long-COVID-19. I understand that you are working with the Social Security Administration and others to determine a case definition for long-COVID which I assume would be for disability determinations. But before that, if a patient suspects he or she has long-COVID, what steps will their primary care provider go through to make a determination that it is, in fact, long COVID?

    a. And related to that, we touched briefly on the role of diagnostics at the hearing. What diagnostic methods exist to help diagnose long-COVID?

NIH Response:

While there is much to learn about long COVID and other post-acute sequelae of SARS-CoV-2 infection (PASC), current diagnostic protocols generally include physical, cognitive, and psychological assessments. A growing body of scientific literature reports a constellation of common yet variable symptoms—such as fatigue, shortness of breath, brain fog, and heart palpitations—that also have been associated with other syndromes theorized to have a viral origin, including chronic fatigue syndrome. NIH's RECOVER Initiative seeks to understand the full spectrum of PASC, is supporting a long-term cohort study of tens of thousands of individuals

who have experienced SARS-CoV-2 infection and/or PASC symptoms to help establish diagnostic criteria. A positive test for SARS-CoV-2 infection can be helpful in making a determination of PASC. However, NIH recognizes the need to consider alternative diagnostic criteria, especially because many patients experiencing PASC did not have access to testing during the time that the virus or antibodies would have been detectable.

With respect to neurological sequelae, there is high variability in both the type of symptoms associated with long COVID and in their severity. NIH supports a Neuro Databank/Biobank that is being leveraged to investigate the full range of neurological outcomes associated with PASC.

Finally, NIH supports the Medical Imaging and Data Resource Center (MIDRC), which is harnessing artificial intelligence (AI) and medical imaging to respond to COVID-19. This project can translate scientific findings into practical imaging tools expected to benefit patients with acute COVID-19 and long COVID. For example, MIDRC is creating a repository of chest images combined with clinical symptoms and other clinical data that will be used to develop AI to assess COVID-19 status, including post-acute sequelae.

3. You mentioned that NIH intends to "bring in the insights of small businesses" on long-COVID. What will that process be?

    a. If a small business wanted to follow up on that, whom would they contact?

NIH Response:

The NIH RECOVER initiative will assemble a meta-cohort of individuals with acute SARS-CoV-2 infection, as well as individuals with post-acute sequelae of SARS-CoV-2 (PASC), to understand the full clinical spectrum and potential causes of PASC, including long COVID. In June 2021, NIH will begin funding the RECOVER Clinical Science Core (CSC), which will take the lead in building the meta-cohort, harmonizing and coordinating data, and developing study protocols, including regular laboratory and clinical tests to monitor patients' health status and to identify potential biomarkers of PASC.

The CSC will establish a vetting process for proposals from small businesses and other organizations engaged in long COVID research. NIH encourages such researchers to check the RECOVER website (recovercovid.org) as well as the COVID-19 Open Funding Opportunities webpage (covid19.nih.gov/funding/open-funding-opportunities) for updates. RECOVER will soon solicit proposals for the use of mobile health apps and digital health strategies to recruit individuals from community settings and collect real world data from participants.[3] Small businesses focused on mobile and/or digital health are eligible to apply.

[3] covid19.nih.gov/sites/default/files/2021-04/NOITP_Data_Rep_MHP_FINAL_4-19-21.pdf

NIH points of contact for small businesses include the Small Business Innovation Research (SBIR) and Small Business Technology Transfer (STTR) programs,[4] as well as the NIH RADx program; this initiative to speed innovation in COVID-19 testing has supported companies ranging from small start-ups to publicly held corporations.[5]

[4] sbir.nih.gov/

[5] www.nih.gov/news-events/news-releases/nih-delivering-new-covid-19-testing-technologies-meet-us-demand

Attachment—Additional Questions for the Record

Subcommittee on Health
Hearing on
"The Long Haul: Forging a Path through the Lingering Effects of COVID-19"
April 28, 2021

John T. Brooks, M.D., Chief Medical Officer, CDC COVID-19 Response, Centers for Disease Control and Prevention

The Honorable Cathy McMorris Rodgers (R-WA)

1. **I have been hearing from individuals in my district who are unable to be accepted into a COVID-19 long-hauler clinic even though they are clinically similar to COVID-19 long-hauler patients, but for whatever reason were unable to obtain a positive COVID-19 test. What is being done to address this problem? How can we provide better access to care for these patients?**

   CDC Response: Primary care providers are generally able to diagnose and manage most cases of post-COVID conditions, and they may refer patients to post-COVID care clinics, where available. CDC does not recommend requiring a positive COVID-19 test for a patient to be considered for treatment of post-COVID conditions. CDC recognizes that some people may have been unable to obtain testing because of concerns related to access to care and testing. Individuals infected with the virus that causes COVID-19, but who were asymptomatic or exhibited only mild symptoms, may not have been aware that they had contracted COVID-19, and so may not have sought testing. Antibody testing may be helpful in establishing a history of infection in asymptomatic or mildly symptomatic people, but such testing is not required.

   At this time, there is no single laboratory test that can confirm post-COVID conditions, in part due to the diversity of post-COVID symptoms. Consequently, the absence of abnormal laboratory test results alone should not preclude an individual from treatment for post-COVID conditions.

   Health care professionals should communicate clearly with their patients about the information available on post-COVID conditions and set goals through shared decision-making. Additionally, clinicians should encourage patients to report any new symptoms and changes to their routines. Each treatment plan should be tailored to a patient's symptoms and personal circumstances. CDC worked on interim guidance for health care providers on post-COVID conditions, with a focus on equiping primary care providers with availble information on diagnosis and management. Providing guidance for front-line providers is critical to improve diagnosis, management, and patient care.

Additionally, CDC provides and reguarly updates information on post-COVID conditions via webpages for both healthcare providers and the public. CDC also disseminates information through partners and multiple other channels, including Clinical Outreach and Communication Activity (COCA) calls targeting healthcare providers, as well as publications on the topic in CDC's Morbidity and Mortality Weekly Report (MMWR) and other scientific journals.

The Honorable Gus Bilirakis (R-FL)

1. **One thing the hearing did not touch upon in any great detail was the role of early diagnosis in the treatment and prevention of progression of long-COVID-19. Could you elaborate on that in more depth?**

   CDC Response: Preventing infection with the virus that causes COVID-19 — SARS-CoV-2 — through vaccination and mitigation of transmission minimizes the chance of contracting COVID-19 and the possibility of developing post-COVID conditions. Post-COVID conditions can occur in patients with varying degrees of acute illness, including those who had mild or asymptomatic infections. Due to the variable symptomology and potentially low observability of post-COVID conditions, early diagnosis is critical if patients are to obtain immediate and proper treatment for their illness. This is one reason CDC recommends that health care providers inquire about a broad range of mental and physical symptoms potentially related to COVID-19, such as cognitive impairment, chest pain, diarrhea, difficult or labored breathing, fatigue, joint or muscle pain, and loss of smell or taste.

   To promote early diagnosis of post-COVID conditions, health care professionals are encouraged to follow up with COVID-19 patients one to two weeks after they are discharged from hospital for assessment of post-COVID symptoms. For infected patients who were not hospitalized, but who experience COVID-like symptoms, clinicians should consider arranging follow-up three to four weeks after a patient's initial infection. Health care providers should also consider monitoring patient symptoms during the first four to twelve weeks after initial infection, and expanding care if symptoms persist beyond twelve weeks.

FRANK PALLONE, JR., NEW JERSEY
CHAIRMAN

CATHY McMORRIS RODGERS, WASHINGTON
RANKING MEMBER

ONE HUNDRED SEVENTEENTH CONGRESS

Congress of the United States

House of Representatives

COMMITTEE ON ENERGY AND COMMERCE

2125 RAYBURN HOUSE OFFICE BUILDING
WASHINGTON, DC 20515-6115

Majority (202) 225-2927
Minority (202) 225-3641

June 8, 2021

Ms. Chimére L. Smith
Long COVID Patient Consultant for Urban Communities
4303 Davis Avenue
Baltimore, MD 21229

Dear Ms. Smith:

Thank you for appearing before the Subcommittee on Health on Wednesday, April 28, 2021, at the hearing entitled "The Long Haul: Forging a Path through the Lingering Effects of COVID-19." I appreciate the time and effort you gave as a witness before the Committee on Energy and Commerce.

Pursuant to Rule 3 of the Committee on Energy and Commerce, members are permitted to submit additional questions to the witnesses for their responses, which will be included in the hearing record. Attached are questions directed to you from a member of the Committee. In preparing your answers to these questions, please address your response to the member who has submitted the questions in the space provided.

To facilitate the printing of the hearing record, please submit your responses to these questions no later than the close of business on Tuesday, June 22, 2021. As previously noted, this transmittal letter and your responses, as well as the responses from the other witnesses appearing at the hearing, will all be included in the hearing record. Your written responses should be transmitted by e-mail in the Word document provided to Meghan Mullon, Policy Analyst, at Meghan.Mullon@mail.house.gov. To help in maintaining the proper format for hearing records, please use the document provided to complete your responses.

Thank you for your prompt attention to this request. If you need additional information or have other questions, please contact Ms. Mullon with the Committee staff at (202) 225-2927.

Sincerely,

Frank Pallone, Jr.
Chairman

Attachment

cc: The Honorable Cathy McMorris Rodgers
Ranking Member
Committee on Energy and Commerce

The Honorable Anna G. Eshoo
Chairwoman
Subcommittee on Health

The Honorable Brett Guthrie
Ranking Member
Subcommittee on Health

[Ms. Smith did not answer submitted questions for the record by the time of publication.]

Attachment—Additional Questions for the Record

Subcommittee on Health
Hearing on
"The Long Haul: Forging a Path through the Lingering Effects of COVID-19"
April 28, 2021

Ms. Chimére L. Smith, Long COVID Patient Consultant for Urban Communities

The Honorable Robin Kelly (D-IL)

1. Can you describe some of the events where you felt as if your concerns were not taking seriously? Tell us how you were feeling and areas of opportunity in which our health care system could have supported you more.

Attachment—Additional Questions for the Record

Subcommittee on Health
Hearing on
"The Long Haul: Forging a Path through the Lingering Effects of COVID-19"
April 28, 2021

Jennifer Possick, M.D., Associate Professor, Section of Pulmonary, Critical Care and Sleep Medicine, Yale School of Medicine, Director, Post-COVID Recovery Program, Winchester Center for Lung Disease, Yale-New Haven Hospital

The Honorable Robin Kelly (D-IL)

1. During your testimony you state, "We must ensure early and equitable access to care for individuals with post-COVID-19 disease." COVID-19 disproportionately impacted Black and Brown communities which is evident in that data of infection rates and mortality rates. Are you seeing this trend in the Long-COVID disease population? What barriers are keeping people from receiving the equitable post-acute care that you state is necessary for all to receive?

The demographics of patients with post-COVID-19 complications at our clinic appear to mirror the demographics of the patients treated for acute disease in our local community. We do not know whether there are independent demographic risk factors for the development of persistent symptoms or complications. Moreover, based on anecdotal reports from the patients under our care in the past two years, we are concerned that disparities in care access as well as unconscious biases may contribute to under-recognition of post-COVID-19 complications and delays in diagnosis for vulnerable populations.
The most fundamental barrier to care for post-COVID-19 conditions is the mismatch between resources for these services and the sheer number of individuals who need either primary diagnostic evaluation or ongoing care. Insurance disparities, cost of care, language barriers, technologic disparities (in the case of telehealth-based services) contribute expected barriers as well. In addition, most multidisciplinary post-COVID-19 clinics are centered in areas around academic medical centers, contributing to geographic disparities. Specific therapeutic interventions, such as physical therapy and mental health services, are unevenly supported by insurance carriers and financially untenable for some patients to continue for more than a short period.

