HOUSE COMMITTEE ON ENERGY AND COMMERCE SUBCOMMITTEE ON HEALTH

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

April 28, 2021 at 11:00 A.M., Virtual Hearing via Cisco WebEx

PURPOSE

The purpose of this hearing is for the Subcommittee on Health of the Committee on Energy and Commerce to examine the long-term health impacts of the COVID-19 virus.

KEY TAKEAWAYS

- The National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC) are collaborating to conduct research on lasting health effects of the COVID-19 virus.
- Longitudinal, large studies are required to understand long lasting effects of COVID, termed “long COVID”.
- Preliminary findings show long COVID symptoms can include shortness of breath, brain fog, mental health conditions, and loss of taste and smell. Better evidence is required to understand the anatomical mechanisms of the virus on these effects.
- Witnesses and members expressed the importance of integrated health care services and including mental and behavioral health care delivery.

MEMBERS PRESENT

Chairwoman Eshoo, Ranking Member Guthrie, Chairman of the Full Committee Pallone, Ranking Member of the Full Committee Rodgers, Representatives Matsui, Castor, Sarbanes, Welch, Schrader, Rice, Cárdenas, Ruiz, Dingell, Kuster, Kelly, Barragán, Craig, Schrier, Trahan, Fletcher, Burgess, Griffith, Bilirakis, Bucshon, Carter, Dunn, Curtis, and Joyce

WITNESSES

Panel 1

Francis S. Collins, M.D., Ph.D.
Director
National Institutes of Health

John T. Brooks, M.D.
Chief Medical Officer, CDC COVID-19 Response
Centers for Disease Control and Prevention

Panel 2

Steven Deeks, M.D.

Professor of Medicine

University of California, San Francisco

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

Natalie Hakala
Patient
Eugene, OR

Lisa McCorkell
Patient
Oakland, CA

Chimere Smith
Patient
Baltimore, MD

OPENING STATEMENTS

Chairwoman of the Subcommittee Eshoo (D-CA) stated that the few formal, large sample studies hint at long term symptoms of COVID. 2 out of 3 patients with COVID paid at least one outpatient visit. Data show that brain fog, loss of smell and taste, and chronic pain are all symptoms of COVID. This research suggests that in the U.S., where there have been more than 32 million confirmed COVID cases, there could be millions of long haulers suffering from the long term effects of the virus. Swaths of the population across all communities will have had COVID-19, and because of this many long haulers struggle to be taken seriously by the medical system, namely black women and women of color. This uncovers failures in treating chronic disease and disability. Federal leadership is needed to coordinate the long-haul COVID patients. COVID patients are also finding gaps in safety nets in coverage and access. In the next few days, the National Institutes of Health (NIH) will announce millions of dollars for COVID researchers.

Chairman of the Subcommittee Guthrie (R-KY) said that many Americans are experiencing lasting symptoms weeks and months after being infected by COVID. At the end of last year, Congress came together to allocate money toward COVID research, but there are still many questions. A workshop on post-acute sequelae was hosted to learn more about the long term effects of COVID. People have reported that COVID prevented them from returning back to their jobs and returning back to normal. COVID can be avoided with vaccination, and it is imperative that all Americans get vaccinated.

Chairman of the Full Committee Pallone (D-NJ) said that the country has been battling COVID-19 for a year now. A growing number of individuals are experiencing the long term effects of COVID-19 and has been impacting otherwise healthy people. Symptoms lasting longer than 4 weeks after initial infection indicate long-term impacts of COVID. Long haulers have difficulty in managing these symptoms, which raises concern of the alarming trends. People with multiple symptoms are more susceptible to long lasting effects of COVID. The goal is to learn more about these long lasting COVID effects. Chairman Pallone stated that millions of people will require ongoing and interdisciplinary care, so it is imperative to learn more about these effects to prevent and treat those who suffer from long COVID.

Ranking Member of the Full Committee Rodgers (R-WA) said the long-term effects of COVID are incredibly concerning. Long-hauler symptoms are widespread, indicating a need for long-term treatment for "long COVID". The COVID vaccines are vital for prevention and stopping people from becoming long haulers. Unfortunately, there are no diagnostics or treatments for long COVID. COVID has had devastating impacts on Americans, and patients deserve answers and the best care possible.

TESTIMONY FROM PANEL 1

Dr. Francis Collins said that people are suffering months after having contracted COVID-19, with symptoms such as palpitations, muscle and joint pain, depression, loss of taste and smell, etc. Substantial research is needed to understand long COVID. To the patient community, many have been suffering for more than a year with no forecast on what the future may hold. He said that tens of thousands of patients need to be studied, and to do this rapidly, the NIH is launching a meta-cohort study. Dr. Collins stated that an important part of this is building on existing community-based cohorts or on the electronic health records of large hospital systems. These resources already include tens of thousands of participants who have already contributed years of medical data—many of whom suffer from long COVID. This approach will enable the NIH to hit the ground running, giving researchers access to existing data that can quickly provide valuable insights on who may be most at risk, how frequently symptoms occur, and how long symptoms last. Patients will be invited to take part in studies to understand the virus to develop therapies and test these therapies in patient volunteers. A cohort for children and adolescents is also needed to understand the virus's impact on their development. Dr. Collins stated intensive lab and imaging studies should be launched as well.

Dr. John Brooks said based on studies, the Centers for Disease Control (CDC) has distinguished three types of COVID conditions. The classifications, however, may change. The first is long COVID, which are symptoms that last for months. The second is comprised of long-term damage to body system or organs, and the third is complications from prolonged treatment or hospitalization. They will continue to investigate COVID through the lens of health equity, especially for disproportionately impacted communities. He stated the CDC launched studies to understand emergent conditions that follow recovery from infection and to assess the contribution to the burden of disease on survivors. Amongst these studies are prospective studies that follow patients up to two years to collect more information on the proportion of people who develop post-COVID conditions, as well as assess risk factors for their development. CDC is also working with multiple partners to develop online surveys about long term symptoms and using many de-identified electronic health record databases to examine healthcare utilization of patient populations after initial infection. Dr. Brooks stated that the CDC is also working on evidence-based guidelines to equip providers with informative guidance. CDC is also working on better understanding COVID as rooted in science and being as transparent as possible. Health equity will be at the forefront of their efforts.

QUESTIONS AND ANSWERS

Chairwoman of the Subcommittee Eshoo said the Biden Administration has developed responses to the pandemic, but there is not a response to the long-term impacts of COVID. It's a crisis for patients and has an effect on the healthcare system. She asked who is in charge of leading this effort. **Dr. Collins** said that there are partnerships that are working on this, but there is no top-level oversight on this initiative. He said that may get in the way of a more organic approach. **Dr. Brooks** said that they are collaborating intensively, which is necessary for a coordinated response. The NIH and CDC are working very well right now, and have been in touch with the Centers for Medicare and Medicaid Services (CMS) and Social Security. **Chairwoman Eshoo** asked when the meta-cohort will conclude and in the meantime, what members can tell constituents about what is attached to the condition. **Dr. Collins** said that applications for funding are being reviewed, so they can immediately start the research process of analyzing the underlying mechanism of the virus.

Chairman of the Subcommittee Guthrie said that people who have long-term symptoms feel improvement after being vaccinated and asked about this response. **Dr. Collins** said that it is hard to get accurate data on vaccination improvements on long COVID and this needs to be better understood. **Chairman Guthrie** asked how long COVID cases can be diagnosed earlier and what diagnostics are needed to identify these cases. **Dr. Brooks** said that there are people who have long COVID who have no prior history of testing. The most important thing is to get vaccinated and avoid developing the conditions in the first place. The symptoms and ways people present are very different, so this is important to keep in mind. It is also important to take patients for their word. **Chairman Guthrie** asked how the NIH is leveraging community-based cohorts and what more can be done. **Dr. Collins** said that volunteer consent to research is vital for historical information to identify developments of long COVID.

Chairman of the Full Committee Pallone asked more about the incidence and prevalence of long COVID. **Dr. Brooks** said that there have been cohort studies since last spring that has provided insight on post-COVID conditions. Long term impacts of COVID are common, with research suggesting 2 out of 3 COVID patients have made a scheduled visit to a provider. The data of this study will allow them to hone in on what the precise numbers looks like. **Chairman Pallone** wanted more information on the meta-cohort. **Dr. Collins** said that learning from long-standing studies is part of the meta-cohort. Looking at people in treatment trials is also important. Patient support groups are also highly motivated and have collected data, and the NIH wants to tap into these experiences as well.

Ranking Member of the Full Committee Rodgers said that understanding the origins of the pandemic is important and asked if it is in the public interest to have an investigation on origins of COVID. Collins said that an investigation to follow the original World Health Organization investigation is needed, and it should be science-based. The NIH will play a role in this follow-up investigation. **Ranking Member Rodgers** said that children are more protected from the more severe symptoms of COVID and asked about the research in children. **Dr. Collins** said that children can get long COVID and they are not immune to it. They must understand this as well. Children can also get multisystem inflammatory

syndrome in children (MIS-C), which is an autoimmune condition that can put children in the intensive care unit. **Ranking Member Rodgers** asked about what post-COVID conditions can be compared to. **Dr. Brooks** said that the complications in post-COVID conditions are similar to myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). He stressed that post-COVID differs, but shares common symptoms with these conditions. Anxiety and depression linger as well.

(The hearing experienced technological difficulties in this portion of the transcript. Representative Castor, Brooks, Griffith, Sarbanes, and Bilirakis's questions were not captured. Their statements will be made available by the Subcommittee at a later time.)

Representative Welch (D-VT) comment that with respect to long haulers, there is a necessity to come to consensus and agree upon what is the best methodology for treatment. **Dr. Collins** said that developing a case definition is important. **Dr. Brooks** said that machine learning is a new tool that is useful, as well as scanning data sets to analyze what types of visits are being made and what treatments are being described. They also bounce this information off of patient advocates to capture the experience. **Representative Welch** said that there is a challenge with obtaining accurate data from populations of Black, Indigenous, and people of color (BIPOC) communities. He asked if there needs to be additional data obtained from these communities. **Dr. Brooks** said that yes, he agrees that they need more data in these communities. They may also focus on communities not in the spotlight, such as those who are incarcerated.

Representative Bucshon (R-IN) stated that loss of smell and taste is a common symptom. **Dr. Brooks** said that the virus doesn't seem to target the olfactory nerves but does target more of the nerves around these areas that leads to neurologic injury. The good news is that most people will recover their smell and taste. In terms of treatment, smell training is a therapy that works and should be done early on. **Representative Bucshon** said that he is in support of enhancing funding for research. He asked what percentage of the NIH funding will be directed towards funding for COVID research. **Dr. Collins** said that they aim to initiate therapeutic interventions and researching anticoagulants for long COVID treatment. They must look into safe treatments. **Representative Bucshon** asked about other treatments. **Dr. Collins** said research into steroids and giving intravenous immunoglobulins may also help. It is easier to treat a patient if you know the underlying causes of the illness.

Representative Schrader (D-OR) questioned how they are ruling out other diseases among patients given the fact that long COVID mimics other disease state. **Dr. Collins** said that they must have clear definition of the positive viral test, but a year ago, the tests were not readily available. Now, patients may have the onset of other conditions that may be mistaken for long COVID. They must ensure that they are not merging together conditions. **Representative Schrader** asked if there are studies on long COVID impacts on chronic fatigue syndrome. **Dr. Collins** said that they must research these overlaps. With chronic fatigue, it is very difficult to catch the underlying infection that causes chronic fatigue. Researching similarities and differences is important to identify interventions that may work for both groups. **Representative Schrader** asked if cytokine secretion is a

biomarker of long COVID. **Dr. Collins** said that they see cytokines elevations and cytokine storms, but it hasn't been so obvious in those suffering months later. A study showed that there are abnormalities that occur in people with long COVID compared to those with no long-term symptoms of COVID.

Representative Dunn (R-FL) asked how long-haulers can get doctors to believe their symptoms of COVID and asked about scaling testing for T-cell immunity. **Dr. Collins** said that there are disagreements between the reliability of T-cell response. **Representative Dunn** asked about educational resources that he can direct patients to and what specialists are best equipped to treat these patients. **Dr. Brooks** said that they hold regular calls for patients to raise awareness and for providers to accept the illness. They also publish guidelines on how to manage patient conditions. He directed Representative Dunn to calls on the CDC website for clinician guidelines.

Representative Cárdenas (R-CA) asked about the relationship between social determinants of health and long COVID and how Congress can respond to these connections. **Dr. Collins** said that social determinants of health play a role in who is most likely to be impacted by the pandemic, which impacts their access to care. Underserved communities have been hit hard and people with long COVID from these communities are less likely to the get the proper quality of care. **Dr. Brooks** said that the pandemic has been unprecedented and structural racism has driven these health disparities. This is an opportunity to make changes to rectify these disparities. They must listen to these communities to find solutions that resonate with them.

Representative Curtis (R-UT) asked if there are trends among the patient population in developing long COVID. **Dr. Collins** said that those who stayed in the hospital have a higher risk of developing long COVID. They are also able to better predict who may develop long COVID. Risk factors are women, older age, high body mass index, and obesity. Beyond that, there are no other risk factors that have been identified. **Representative Curtis** asked from a patient's perspective, how do they determine whether to get treatment and where should they go for care. **Dr. Brooks** said that he would advise patients that if they have new symptoms they've never had before, documenting these symptoms is important. The temporal association is also important to note. While they are learning more about these symptoms, patients should go to a primary care physician (PCP) first and maybe seek out a post-COVID clinic. These clinics are largely affiliated with university institutions.

Representative Ruiz (R-CA) said he is concerned about the underserved communities being left behind. He applauds the initiatives of the Biden administration. He asked what the CDC is going to do to address barriers for communities to get the care they need. **Dr. Brooks** said that they've put about 3 billion dollars into building vaccine confidence, focusing on underserved communities. They have also created opportunities to address these disparities and increasing access. Finally, they are building a core of community health workers who can be trusted messengers. **Representative Ruiz** asked about initiatives to target underserved communities. **Dr. Brooks** said that they work with allied partners, community-based organizations, and other connections to be trusted

messengers. **Representative Ruiz** said that equity needs to be part of the design. He also asked about the rate of long COVID in children, as well as rates of MIS-C. **Dr. Brooks** said that they haven't seen a huge prevalence of long COVID in children and that early recognition is important for MIS-C.

Representative Joyce (R-PA) said that strep throat, when treated early, has a rapid recovery. But if left untreated without penicillin, it can be much more severe. He asked about the importance of monoclonal antibody treatment and the role of developing the necessary therapeutics to prevent long COVID. **Dr. Collins** said that as part of the meta-cohort, they are enrolling those who have enrolled in the therapeutic trials. Monoclonal antibodies are not universally successful. They are running master protocols on therapeutic agents, including more sophisticated designer drugs that interfere with the viral life cycle. **Dr. Brooks** said that the epidemiology shows that the greater the infection is, the higher risk of long COVID. Another area of research is looking at pre-exposure medications. Treating the infection as early as possible that lessens the severity of disease will be able to impact the number of people developing long COVID.

Representative Dingell (D-MI) inquired about how COVID has impacted primary care physicians and ensuring they have the tools they need to diagnose. **Dr. Brooks** said that providers must learn how to recognize the conditions and who they can refer the patient to. Building these specialties is necessary. Focusing on this condition will benefit other infectious diseases. **Representative Dingell** asked if the NIH and the CDC have the resources they need. **Dr. Collins** said that the funding is adequate for now, but is not sure what will happen in the future to examine interventions. **Dr. Brooks** said having this hearing is a good first step in raising awareness.

Representative Kuster (D-NH) said that having a coordinated effort is necessary to examine long COVID and asked what initiatives are being implemented to examine the impacts. **Dr. Collins** said that tapping into the post-COVID clinics and running trials on treatments are necessary. **Representative Kuster** asked about breathing techniques and other treatments that don't entail intervention, but have allowed people to live with long COVID. **Dr. Collins** said that cardiac rehabilitation and treatments to eliminate brain fog are being researched.

Representative Kelly (D-IL) stated that some of her constituents are unable to work due to long COVID and asked about discrimination against those with long COVID. **Dr. Collins** said that it is important to support people such as through social security and disability. They also aim to work with CMS. Employers will generally not be sympathetic on long COVID impacts. **Dr. Brooks** said those who are challenged with the medical illness must have support to continue to work and be employed. Providing guidelines with disability claims is necessary to ensure people are taken care of.

Representative Carter (R-GA) asked if there are any reasons on the vaccine improving COVID symptoms. **Dr. Brooks** said it may have something to do with getting the immune system back on track to combatting the virus. It is not an experience that every person will have, but may be helpful to address vaccine hesitancy. **Dr. Collins** said that there is

a small study on improvements of symptoms from the vaccine. There are only theories for now, and more research needs to be done on the impacts of vaccine on long COVID. **Representative Carter** asked if there are psychological impacts due to long COVID. **Dr. Collins** said that there is very little information on the anatomic mechanism of COVID-related psychological issues. **Dr. Brooks** said that mental health must be addressed alongside COVID.

Representative Barragán (D-CA) asked if there is information on why long COVID is impacting younger people more. **Dr. Brooks** said that amongst the people impacted by COVID are between the ages of 18 and 39. He said he hopes that people focus on the age differences more. **Dr. Collins** said that there are more young people getting affected, but older people are more likely to develop long-COVID symptoms. **Representative Barragán** said that addressing social determinants is necessary and asked if Congress should be doing more to address these. **Dr. Brooks** said that he will get an answer on funding at the CDC.

Representative Craig (D-MN) said that long COVID is a complex disease that may need extensive care, but may only be available at certain institutions. She asked with such complexities, where should people start in terms of the setting they are looking for to seek care for long COVID. **Dr. Brooks** said that he recommends care with a PCP and obtain a referral to a specialty. He said there are support groups that can offer resources for patients. **Representative Craig** asked what is happening at NIH to learn from academic medical centers to assist in developing models for long COVID. **Dr. Collins** said that pulling together multidisciplinary care at academic centers to gain access to multiple expertise is important.

Representative Schrier (D-WA) asked if they may be too complacent in managing long COVID in children and asked how it presents in children. **Dr. Brooks** said that pulmonary conditions and persistent fatigue are some symptoms. Brain fog is another symptom. **Representative Schrier** said that the best way to prevent long COVID is getting vaccinated and asked why they are not moving quickly with the approval to get vaccines to kids. **Dr. Collins** said that he is hopeful that the Food and Drug Administration (FDA) will approve vaccines for kids soon. **Representative Schrier** asked if there is collaboration with Israel on research on long COVID. **Dr. Brooks** said they follow the Israeli response closely and working with the WHO on working on the long-COVID effort.

Representative Trahan (D-MA) said that MIS-C research has largely gone underfunded. (Her statements were not entirely captured due to audio issues). **Dr. Collins** said that there has been a lack of understanding of similar conditions, but more funding can allow for better understanding of these conditions.

Representative Fletcher (D-TX) said patients have faced skepticism from providers and confusion on how to categorize their condition. She asked about ways to recognize symptoms and seek out care, especially for places that do not have a post-COVID clinic. **Dr. Collins** said this hearing is a good first step to be informed on long COVID. **Dr.**

Brooks said that developing guidance for patients to seek out primary care is necessary and referring them to specialists for long COVID.

Representative Schakowsky (D-IL) asked about affordability of treatments, especially for marginalized communities. **Dr. Collins** said that partnerships with the federal agencies is necessary to promote affordability of treatments. **Dr. Brooks** said establishing case definitions is vital.

Representative Doyle (D-PA) asked how researchers can widely disseminate research findings to the public. **Dr. Collins** said that researchers are avidly reading journals to stay up to date on the latest findings. **Representative Doyle** said that many doctors and patients have heard of ivermectin and asked about the utilization of this treatment. **Dr. Collins** said there are a number of studies on ivermectin and the NIH is interested in investigating this treatment.

Representative Rice (D-NY) asked about the CDC and Kaiser partnership and the limitations of long COVID research. **Dr. Brooks** said the main findings were people who were outpatient only, during the 1 months to 6 months, about 68% sought care for some condition, which was evenly distributed across most communities. When utilizing data, it is difficult to understand the patient's journey. **Representative Rice** asked how best to inform decisions for those with long COVID. **Dr. Brooks** said to listen to and take the patient seriously is important. He also said enough representation for certain populations is also necessary to gather enough data.

TESTIMONY FROM PANEL 2

Ms. Hakala said she contracted COVID last year, and following her quarantine, her fatigue got worse and she developed pneumonia. She tried to work half days and went to urgent care and was placed on some medications to help with pain. In August, she was bedridden and had to catch her breath during conversations. She said she had overall inflammation and started cardiac rehab. By the end of January, she got her vaccine and did her first jogging. In February, she got her second dose and felt improvements. Now, she can jog longer and her energy levels are higher.

Ms. Smith said she is living as a black disabled woman living with long-COVID. There were many black women who suffer from chronic conditions. Black women were already abused and disadvantaged. They are not new to this and long-COVID is another burden. They have been gaslit by doctors. Long-COVID has impacted black women mentally and physically, and they need comprehensive unemployment guidance and disability benefits. It is imperative they create equitable research standards. There are no studies that focus on black people with COVID. Black people delay care because they are distrustful of doctors. Post-COVID clinics cannot work alone, which is why she is developing initiatives to advocate for black women suffering from long COVID.

Ms. McCorkell said that her symptoms began last year and was not able to access a test. Symptoms such as memory loss and impaired cognitive function were common amongst survey respondents. Long COVID is complex and patients e experiencing

barriers to care. Those who are experiencing real symptoms must wait months for treatment and incur medical costs. Having medical leave and workplace benefits are necessary to support COVID patients. Clinics continue to gaslight COVID patients and their symptoms.

Dr. Possick stated a comprehensive evaluation to care for patients was done to untangle complex symptoms. Patients were front line and essential workers, and their quality of life has been impacted. Some have even cut costs on rent and utilities to pay for medical bills. Consensus practice supports patients, but the demand outpaces availability. Looking ahead, the magnitude of the challenge is daunting. They do not know what kind of care is needed to treat long-COVID patients. Increasing awareness of long COVID is necessary, as well as ensuring early and equitable care. Patients need access to various services to treat symptoms.

Dr. Deeks said there is not universal consensus of what is going on with COVID. Some believe the vaccine is making the virus worse, and there are many different mechanisms that could be contributing to this. Disabling disease is fortunately not that common, but is something that needs be focused on. The epidemiology is complex. People are getting acute COVID in a society of isolation and stratified socioeconomic status. There is no known mechanism yet, but the NIH is working on establishing research on this. There must be more engagement in industry for drug development, as well as representatives from all other members at the table.

QUESTIONS AND ANSWERS

Chairwoman Eshoo asked if community health clinics can sustain post-COVID clinics. **Dr. Possick said** that many clinics are grassroots efforts and ensuring no communities are left behind is necessary. **Chairwoman Eshoo** asked for more clarification on certain long-hauler studies, particularly on the spike protein. **Dr. Deeks** said that inflammation impacts methylation on the virus, but cannot provide more information on the studies. Eshoo said that long COVID patients have not been listened to, and asked what the most important thing Congress should understand about COVID. **Ms. Smith** said that understanding the history of what black women and other communities face in terms of health equity. They are racially profiled and underserved, and it is important for Congress to provide comprehensive care**. Ms. Hakala** said raising awareness and emphasizing this is a reoccurring problem is necessary. **Ms. McCorkell** said making sure there is equitable access to care is vital, as well as having the ability to rest, especially at the beginning stages of the condition.

Ranking Member Guthrie asked about cognitive bias and challenges with post-COVID conditions. **Dr. Possick** said that physicians are unsure of what to look for in diagnosis, but taking steps to get more clarity is important. Guthrie asked about dissemination of COVID information. **Dr. Possick** said the CDC calls and bringing physicians to the table has been vital. **Dr. Deeks** said clinicians like to be able to measure and quantifying conditions, but there is not a diagnostic tool for COVID.

Representative Matsui (D-CA) said COVID has impacted mental health, and patients with long COVID have added challenges. She asked what strategies practices took to address the symptoms COVID patents were facing. **Dr. Possick** said that an interdisciplinary approach was taken to care for patients. They built collaboration between social workers and psychiatry workers. **Representative Matsui** asked how mental health fits into integrated approaches to care. **Ms. McCorkell** said many long COVID patients may present with symptoms, but doesn't mean that they are causing COVID symptoms. In terms of integrated care, it is important that the mental health treatment is available. **Representative Matsui** asked if integrated care is the best approach to treating long COVID. **Dr. Deeks** said yes, clinics with integrated care are necessary.

Ranking Member Rodgers asked what can be done to educate patients and providers on long-COVID. **Ms. Smith** said that she will be working with patients who need additional supports and working with other partners to educate patients on COVID. **Ranking Member Rodgers** asked about emphasizing the mild, acute, and long-term impacts of COVID, especially for young people. **Dr. Possick** said that the patient population has been shifting towards younger patients and were taken by surprise on how much they are struggling now. They must also understand what fuels vaccine reluctance.

Representative Dingell said the patient-centered research has been very impressive and getting patient voices together. She asked how patient-centered research has been utilized. **Ms. McCorkell** said that the patient-centered research has filled gaps, and teams have been formed to bring long COVID to light.

Representative Burgess asked about barriers to reaching long COVID patients. **Dr. Possick** said that there are barriers to telehealth and geography to accessing COVID care.

Representative Cardenas asked if racism exists in America and if it stops at the door of health care. **Ms. Smith** said absolutely yes, it exists, and it extends into healthcare. She hopes that they can change the narrative of long-COVID. **Representative Cardenas** said it is important to recognize that racism exists and to constantly check yourself to recognize racism.

Representative Griffith asked what the treatment and rehabilitation look like for patients. **Dr. Possick** said that approaching statements about rehabilitation must be done with caution. The appropriate solution for each patient requires assessment. **Representative Griffith** said that must be hard for providers to treat long COVID because it presents differently in patients. **Dr. Possick** said that this is common in many cases and that recovery is not linear.

Representative Kelly asked what can be done to improve the system. **Ms. Smith** said that notes that are written on patients must be accurate, and patients must be able to trust doctors. **Representative Kelly** asked what barriers exist for receiving long COVID treatments. **Dr. Possick** said there are many, such as trust in the health care system,

stigma associated with reporting symptoms, engaging therapy, etc., are all barriers to access.

Representative Bilirakis asked if there was a definition for long COVID. **Dr. Deeks** said there is no standardized definition or name for long COVID. **Representative Bilirakis** asked how this can be addressed to standardize long COVID. **Dr. Possick** said each provider codes in different ways, it is very hard to capture the phenotypic diversity. **Representative Bilirakis** asked what the most common long-term symptoms of COVID and why asymptomatic people develop long COVID. **Dr. Possick** said the most common symptom is shortness of breath, as well as mental health symptoms.

Representative Schrier said working with CMS on getting a specific code is important. She asked how they can differentiate the different mechanistic pathways, which can make it difficult to treat. **Dr. Deeks** said that various clinics have different brands of treatment and clinicians must continue to share their knowledge with one another.

Representative Carter said many patients are young adults or adolescents. **Dr. Possick** said it may reflect many things, but there is a large number of younger people in patient profiles. There may be different perception to changes to health and many young people are getting newly infected. **Representative Carter** asked how they can ensure that there is no stigma that develops from long COVID. **Dr. Possick** said that having this hearing is a big step in raising awareness. **Dr. Deeks** said those with HIV have stigma and it doesn't go away. Establishing a name, providing funding, and other initiatives covering this condition is important. Stigma is constantly being fixed, but having a hearing discussion is important.