

Good afternoon. I'm Commander Ibad Khan, and I'm representing the Clinician Outreach and Communication Activity, COCA, with the Emergency Risk Communication Branch at the Centers for Disease Control and Prevention. I would like to welcome you to today's COCA Call, Evaluating and Caring for Patients with Post-COVID Conditions. All participants joining us today are in listen only mode.

Free continuing education is offered for this webinar. Instructions on how to earn continuing education will be provided at the end of the COCA Call. In compliance with continuing education requirements, CDC, our planners, our presenters, and their spouses/partners wish to disclose they have no financial interests or other relationships with the manufacturers of commercial products, suppliers of commercial services, or commercial supporters, with the exception of Dr. Michael Saag, who would like to disclose that he is the principal investigator on two studies with Gilead and ViiV. And Dr. Alex Vosooney, who would like to disclose that she owns 10 shares of stock in 3M.

Planners have reviewed content to ensure there is no bias. This presentation will not include any discussion of the unlabeled use of product or a product under investigational use. CDC did not accept commercial support for this continuing education activity.

At the conclusion of today's session, participants will be able to accomplish the following— Describe the symptoms and conditions associated with post-COVID conditions. Determine which clinical assessments and tests are needed for a patient while reducing burden from excessive testing and medical encounters. And describe the medical home approach and how it can be used to optimize patient care.

After today's presentations, there will be a Q&A session. You may submit questions at any time during today's presentation. To ask a question using Zoom, click the Q&A button at the bottom of your screen, then type your question in the Q&A box. Please note we receive many more questions that we can answer during our webinars.

If you are a patient, please refer your questions to your healthcare provider. If you're a member of the media, please contact CDC Media Relations at 404-639-3286 or send an email to media@CDC.gov.

I would now like to welcome our presenters for today's COCA Call. We are pleased to have with us Dr. Jennifer Chevinsky, who is an Epidemic Intelligence Service Officer working in the Post-COVID-19 Conditions Unit as part of CDC's COVID-19 Response. Dr. Alex Vosooney who is the chair for the Subcommittee on Clinical Recommendations and Policies at the American Academy of Family Physicians. And Dr. Michael Saag who is a professor of medicine at the University of Alabama, Birmingham and the Director of the UAB Center for AIDS Research.

Please note that during Dr. Vosooney and Dr. Saag's presentations, the slides will not advance as they do not have slides for their portion of the presentation. It is now my pleasure to turn it over to Dr. Chevinsky.

Dr. Chevinsky, please proceed.

Thank you. Hi, I'm Jennifer Chevinsky, and I'm a preventive medicine and lifestyle medicine physician and an Epidemic Intelligence Service Officer with the Post-COVID Conditions Unit at CDC. And today I'll be presenting information about the new interim guidance for healthcare professionals, Evaluating and Caring for Patients with Post-COVID Conditions. Next slide, please.

CDC's interim guidance was informed by individual expert opinion and feedback from large medical organizations and patient advocacy groups, in addition to the most current data. We coordinated discussions during March and April 2021 with 13 US medical professionals providing care to patients with post-COVID conditions and with expertise in a range of clinical specialties, including adult and pediatric pulmonary medicine, critical care medicine, infectious disease, physical medicine and rehabilitation, neurology, psychiatry, rheumatology, nephrology, hematology, and cardiology.

In today's presentation, I'll highlight key points from the background, general considerations, suggested workup, management, clinical and public health recommendations, and future directions. Next slide, please. We're going to start with the background. You can continue to the next slide.

Post-COVID conditions is an umbrella term for the wide range of physical and mental health consequences experienced by some patients that are present four or more weeks after SARS-CoV-2 infection, including by patients who had initial mild or asymptomatic acute infection. Next slide.

Post-COVID conditions are heterogeneous. For some patients, post-COVID conditions may involve continuing, recurrent or new symptoms and clinical findings that persist for weeks, months, or longer. There are multiple possible onset patterns for post-COVID conditions that have been identified, which further exemplifies their heterogeneity. And these different patterns include persistent symptoms and conditions that begin at the time of acute COVID-19 illness, new onset late sequelae following asymptomatic disease or a period of acute symptom relief or remission. An evolution of symptoms and conditions that include some persistent symptoms like shortness of breath with the addition of new symptoms or conditions over time, like cognitive difficulties. And post-COVID conditions may be attributable to different underlying pathophysiological processes like organ damage from acute phase infection, complications from a persistent hyperinflammatory state, ongoing viral activity associated with the interhost viral reservoir, and inadequate antibody response or other potential causes.

Factors that may further complicate the presentation of post-COVID conditions include physical deconditioning at baseline or after a prolonged acute disease course that can be nonspecific to COVID-19, pre-COVID comorbidities, or other physical and mental health consequences of a potentially life-threatening illness with a long or complicated disease course, as well as lifestyle changes due to the COVID-19 pandemic. Some presentations may share similarities with other post-viral syndromes, such as myalgic encephalomyelitis, chronic fatigue syndrome, dysautonomia, such as POTS, or mast cell activation syndrome.

Some of these types of conditions were also reported in patients who recovered from severe acute respiratory syndrome and Middle East respiratory syndrome, two other life threatening illnesses resulting from coronavirus infections. Next slide.

Post-COVID conditions also may affect millions of Americans. At present, robust longitudinal surveillance data on post-COVID conditions are lacking, and the prevalence is challenging to estimate. The frequency of long-term symptoms and conditions following SARS-CoV-2 infection varies widely in the literature, ranging from 5% in some studies to 80% in others.

Evidence suggests that post-COVID conditions occur in children and adolescents, as well as adults, but the true frequency and severity are unknown. There are challenges estimating the exact prevalence, including the prevalence in some groups that could be at higher risk. Next slide. Post-COVID conditions are associated with a spectrum of physical, social, and psychological consequences, as well as functional limitations that can present substantial challenges to patient wellness and quality of life. And the persistence, severity and disability associated with these symptoms and conditions was diagnostic in management challenges for patients, healthcare professionals, employers, and to the US healthcare system. Next slide.

We'll move into general considerations. Next slide.

Overall, it is important for healthcare professionals to listen to and validate patients' experiences, recognizing that symptoms and conditions can substantially impact their quality of life functioning, and ability to return to school or work. Healthcare professionals should partner with patients to identify achievable health goals, setting expectations with patients and their families that outcomes from post-COVID conditions differ among patients, and with transparency that there's much more to learn about post-COVID conditions.

Most post-COVID conditions can be diagnosed and managed by primary care providers, and a patient-centered medical home model could be helpful with coordinated comprehensive care and open communication among a core group of specialty care providers and support services, like occupational therapy, physical therapy and social work to maximize functional improvement and rehabilitation efforts. Healthcare professionals may also consider referral to multidisciplinary post-COVID care centers, where available and accessible, for additional care considerations. Healthcare professionals may consider using a stepwise approach to other specialist referrals, while being mindful of the additional financial, time, and psychological burden that multiple specialist visits may put on patients, and the possibility of fragmentation of care that can increase risk of contradictory medical advice. Many post-COVID conditions may be diagnosed clinically based on history and physical exam findings. Others might require directed diagnostic testing, with the understanding that potential harms could arise from excessive testing, such as increased risk for incidental findings, image-related radiation exposure and cost.

For most patients with post-COVID conditions, healthcare professionals might choose a conservative diagnostic approach in the first four to 12 weeks following SARS-CoV-2 infection, as evidence suggests that for some patients symptoms may improve or resolve during the first few months. However, workup and testing shouldn't be delayed when signs and symptoms of urgent clinical conditions are present, such as life-threatening conditions like pulmonary

embolism, myocardial infarction, pericarditis, epifusion, stroke, or renal failure. And symptoms that persist beyond three months should prompt further evaluation. Next slide. So now we'll move into the suggested workup. Next slide.

Commonly reported symptoms are shown on this slide and include symptoms such as dyspnea, fatigue, post-exertional malaise and brain fog. Post-exertional malaise, a commonly reported symptom, is the worsening of symptoms following even minor physical or mental exertion, with symptoms typically worsening 12 to 48 hours after activity, and lasting for days or even weeks. When possible, healthcare professionals should establish a timeline of when symptoms emerge during acute illness and afterwards. The history of present illness should also include the patient's COVID-19 disease course, severity of illness, and treatments received.

The broad spectrum of signs and symptoms reported, as seen on this slide, warrants a broad approach to the review of symptoms. Next slide. For patients with clinical features warranting further evaluation, healthcare professionals might consider the broad range of possible post-COVID conditions. Additional system-based conditions that have been reported following SARS-CoV-2 infection are included on this slide, such as myocarditis, chronic kidney disease, pulmonary embolism, dysautonomia, and others. Next slide.

Post-COVID conditions involve multiple organ systems, thus a thorough physical exam should be completed. For patients who report previous infection with SARS-CoV-2, in addition to standard vital signs and BMI, healthcare professionals should evaluate ambulatory pulse oximetry for individuals presenting with respiratory symptoms, fatigue, or malaise. And orthostatic vital signs should be evaluated for individuals reporting postural symptoms -- dizziness, fatigue, cognitive impairment, or malaise. Next slide.

At this time, no laboratory tests can definitively distinguish post-COVID condition from other ideologies, in part due to the heterogeneity of post-COVID conditions. A positive SARS-CoV-2 viral test or serologic antibody tests can help assess for current or previous infection. However, these laboratory tests are not required to establish the diagnosis of post-COVID conditions. RTPCR and antigen testing are not 100% sensitive, and further, testing capacity was limited early in the pandemic, so that some infected and recovered persons had no opportunity to obtain laboratory confirmation of SARS-CoV-2 infection. Before ordering other laboratory testing for post-COVID conditions, the goal of testing should be clear to the healthcare professional and to the patient. Laboratory testing should be guided by the patient history, physical exam, and clinical findings.

A basic panel of laboratory tests might be considered for patients with ongoing symptoms, including testing for other non-COVID conditions that may be contributing to illness between four and 12 weeks of infection to assess for conditions that may respond to treatment, until more information and evidence is available for specific laboratory testing for post-COVID conditions. And more specialized testing may not be needed in patients who are being initially evaluated for post-COVID conditions. However, expanded testing should be considered if symptoms persist for 12 weeks or longer. Next slide. Laboratory tests should be ordered in the context of suggestive findings on history physical exam, like testing for rheumatological conditions in patients experiencing ongoing arthralgias.

You'll find this table of basic and more specialized diagnostic tests in the interim guidance as a place to start or test to consider depending on a patient's presentation. Next slide.

Symptom inventories and assessment tools can help evaluate and monitor the status of post-COVID conditions. Functional testing can also be helpful to quantitatively document clinical status over time. A selection of some available assessment tools is shown on this slide and on the next slide. These and other measures can be also found in the guidance document. Next slide, please.

Healthcare professionals should use caution when conducting exercise capacity testing in some patients, especially those with post-exertional malaise. Exercise capacity tests should be scheduled for a dedicated follow-up appointment so that patients can prepare additional home supports, ensuring that the testing circumstances best support the patients to perform maximally. And then documenting this performance can create an effective, reliable record of functional status and may be needed for assessment for other services or disability. Next slide.

More evidence is needed to support the utility of specific imaging tests for evaluation of post-COVID conditions. Additional diagnostic testing should be guided by findings from patient history and physical exam and results of previous diagnostic testing, and may include a chest X-ray, pulmonary function tests, electrocardiogram, echocardiogram for persistent or new respiratory or cardiac concerns, although more evidence is needed to support the utility of these tests for post-COVID conditions. In patients with normal chest X-rays and normal oxygen saturation, CT imaging of the chest might have lower yield for pulmonary pathology. In patients without an elevated D-dimer and compatible symptoms, CT pulmonary angiogram may be lower yield within the context of a pulmonary embolism workup. And in patients with brain fog symptoms and without other focal neurological deficits, MRI of the brain might not be revealing. Further caution may be exercised in ordering imaging in children without a high index of suspicion of [inaudible]. More specialized imaging tests like cardiac MRI might merit consultation with specialists. Next slide.

We're going to move into the suggested management. Next slide.

For most patients, the goal of medical management of post-COVID conditions is to optimize function and quality of life. Healthcare professionals in partnership with patients and their families, and in consultation with the appropriate specialist, should develop a comprehensive management plan based on their patient's presenting symptoms, underlying medical and psychiatric conditions, personal and social situations, and their treatment goals. Transparency is important for the process of both. Healthcare professionals should advise patients that post-COVID conditions are not yet well understood, and assure them that support will continue to be provided as new information emerges.

Patient diaries and calendars may be useful to document changes in health conditions and symptom severity, especially in relation to potential triggers such as physical and cognitive exertion, foods, menstruation, and treatments or medications. Such diaries and calendars can provide greater insight into patient symptoms and lived experience. For some patients, comprehensive rehabilitation might include physical and occupational therapy, speech and

language therapy, vocational therapy, as well as neurologic rehabilitation for cognitive symptoms. A conservative physical rehabilitation plan might be indicated, and consultation with psychiatry for cautious initiation of exercise and recommendations about pacing may be useful. Symptoms not explained by or out of proportion to objective findings are not uncommon after COVID-19, and shouldn't be dismissed even if there's not yet a full understanding of their etiology or their expected duration.

Many post-COVID conditions can be improved through already established symptom management approaches like breathing exercises to improve symptoms of dyspnea. FDA-approved or other over-the-counter medications as well as vitamins or electrolyte supplements may be helpful for indicated illnesses like treating a headache or documented deficiencies like a vitamin deficiency. Some treatments have been offered that lack evidence of efficacy or effectiveness, and could be harmful to patients. Healthcare professionals should inquire about any unprescribed medication, herbal remedies, supplements or other treatments that patients may be taking for their post-COVID conditions. Patients with post-COVID -- patients with post-COVID conditions may share some of the symptoms that occur in patients who experience MECS, fibromyalgia, post-treatment Lyme disease syndrome, dysautonomia, and mast cell activation syndrome.

Symptom management approaches that have been helpful for these disorders may also benefit some patients with post-COVID conditions. For example, activity management or pacing for post-exertional malaise. Evidence indicates that holistic support for the patient throughout their illness course can be beneficial. Healthcare professionals can provide information on peer support resources, like patient support groups and online forums. When material, employment or other social support needs are identified -- such as housing, access to food, family illness, bereavement, caregiving, or disability -- healthcare professionals should consider referral to applicable services.

And if needed, consider engaging a social worker or similarly trained professional to assist. Next slide. There are some patient groups that may require special considerations. Persons who belong to racial and ethnic minority populations have experienced a higher burden of COVID-19, in part because of structural racism and longstanding disparities in social determinants of health, which could reasonably lead to a higher incidence of post-COVID conditions in these same populations. Deploying resources to these communities can help ensure disproportionately affected residents are aware of post-COVID conditions and have access to needed services that may be lacking there.

People with disabilities may require close follow-up for impact on severity of existing functional limitations. People experiencing homelessness or housing instability, as well as people in correctional facilities, may experience particular challenges in consistent access to healthcare and other support services. People with preexisting substance use disorder may be at risk for relapse. Telemedicine visits may be helpful for patients who live in rural areas with access to broadband. People with barriers to accessing healthcare due to lack of health insurance, access to healthcare professionals who accept their health insurance, or lack of transportation, childcare, or paid sick leave may face additional challenges accessing healthcare.

Tools for cross-cultural communication and language access, including translated materials on post-COVID conditions and interpreter services could help address health literacy and improve communication effectiveness. Lastly, patient advocacy groups have raised concerns that some post-COVID conditions have been either misdiagnosed as or misattributed to psychiatric causes, particularly among persons who belong to marginalized or vulnerable groups. Sensitivity to and awareness of stigma, completing a full clinical evaluation, and maintaining an attitude of empathy and understanding can help address these issues. Next slide.

We'll move to the clinical and public health recommendations. Next slide, please.

Documentation of post-COVID conditions is critical for accurate public health surveillance. The World Health Organization has developed coding guidance for healthcare encounters related to post-COVID conditions based on ICD-10 CM codes. WHO has recommended U09. 9 post-COVID-19 condition unspecified. This code is not currently available in the US and is under review by the US ICD-10 Coordination and Maintenance Committee. In the meantime, CDC recommends use of B94. 8, sequela of other specified infectious and parasitic diseases for post-COVID conditions. Next slide.

People with post-COVID conditions should continue to follow CDC's recommended COVID-19 prevention measures, including wearing a face mask when and where indicated, maintaining the appropriate physical distance for people who are not from their household, avoiding crowds and poorly ventilated indoor spaces, washing hands, and when vaccinated, following the general recommendations for vaccinated people.

COVID-19 vaccination should be offered to all eligible people, regardless of their history of SARS-CoV-2 infection. Although anecdotal reports indicate that some patients with post-COVID conditions have experienced improvements in their symptoms after COVID-19 vaccination, research is ongoing to establish the extent of this effect if verified. Next slide. Patients with post-COVID conditions might benefit from a review of their current preventive care practices, including age-appropriate preventive health screenings and vaccinations that may have been delayed due to the pandemic, and other discussions regarding nutrition, physical activity, sleep, stress management, interpersonal relationships, and optimizing management of underlying medical conditions. During the pandemic, fewer routine childhood vaccine doses were administered, leaving children at risk for vaccine preventable diseases. Next slide.

We'll move to future directions. Next slide, please.

Knowledge of post-COVID conditions is likely to change rapidly with ongoing research. Research is underway to define the post-acute and long-term phases of COVID-19. The natural history of SARS-CoV-2 infection and COVID-19 related illnesses is a current area of investigation. And the prevalence, type, duration, and severity of persistent symptoms following resolution of acute SARS-CoV-2 infection, as well as risk factors associated with their development, continue to be studied. CDC has also partnered with NIH, aligning efforts within the federal government to support the task initiative. CDC will continue to work in collaboration with federal, state, local, academic, and community partners to better understand the long-term effects of SARS-CoV-2 infection. And this guidance will be updated as new information

emerges. Healthcare professionals and patients should continue to check for updates on evolving guidance for post-COVID conditions. Next slide.

Next slide.

And we'll move to the acknowledgments. Next slide.

So I would like to thank you my co authors from the Post-COVID Conditions Unit, as well as our external experts, our post-COVID condition experts, the medical associations that provided feedback, as well as the patient advocacy organizations that provided feedback through the course of this process. We thank you. Next slide.

Next slide.

Next slide.

And one more. Next slide. And one after that. I'm sorry. Perfect.

So this is our disclaimer, and I just wanted to say thank you. And we'll take questions after all of the speakers. And now I'd like to pass it on to Dr. Vosooney.

And Dr. Vosooney, before you begin -- this is the moderator. I just have a quick announcement. We have been made aware that due to a technical problem with Zoom beyond our control, the Q&A box might not be visible to all our attendees. If that is the case, please insert your question for the presenters in the chat box. You will find the chat box either on the bottom or the top of your screen in the menu ribbon. Please insert your questions to the presenters in the chat box, and we will attempt to answer them during the Q&A session. Thank you. Dr. Vosooney, please proceed.

Thank you. Thank you, Dr. Chevinsky. As they mentioned, my name is Alex Vosooney, and I'm the AAFP chair of the Subcommittee on Clinical Recommendations and Policies. I'm also a family physician from Minnesota practicing full spectrum family care, working in a fairly diverse neighborhood near downtown St. Paul. I'm fortunate to work with a health group that really values the relationships that primary care and specialty care have with each other, and fosters good communication between those groups.

While my patients are locally enough, they don't have to deal with one to three hours of travel to get their care, many of them still prefer to be seen in their home clinic by their regular primary care clinician, because they really value the longitudinal relationship they've built up with their provider. Knowing how valuable that primary care patient relationship can be is one of the reasons I was so pleased that the CDC guidance called out the importance of involving primary care, as well as their emphasis on utilizing a medical home approach, aiming for whole person patient care with an emphasis on individualized testing and workup. I'd also like to mention I do not have any slides, so you will not see slides advanced during my presentation. It will likely stay where it is right now.

For those of you not familiar with a medical home model, let me provide you a brief overview. Those of us in primary care may feel fairly familiar with it. But medical homes fulfill five key functions. They provide access to and continuity of care, meaning that patients are able to see the same clinician for the vast majority of their chronic and acute care needs in a timely fashion.

They can have access to their patients via potentially a medical messaging portal, 24-hour, after hours call number. It also gives clinicians the benefits of being able to see some of the same patients and to really again develop that longitudinal relationship. Medical homes also provide planned and population care. They often build registries to help coordinate care based on specific diseases and conditions. They offer care management.

This may be in the area of patient education, medication management, coordinating care transitions, and care planning through a variety of support services. They engage the patient and the caregiver. They use shared decision making, motivational interviewing, and other things to help make sure that patients really feel they're having a voice and a choice in their care plans. Medical homes are also comprehensive and provide coordination of care. They help coordinate those transitions across specialties and settings, making sure that patients are getting both safe and efficient experiences for their care.

For those of you who'd like to get more information on medical homes, the AAFP has information on our website, as does ACP. You could also look at the information available on the Primary Care Collaborative's Principles of Advanced Primary Care. Even if a primary care office doesn't fulfill all the criteria of a medical home, it's likely going to provide many of those services to patients. So how does this mean that a primary care clinician can help a patient experiencing post-COVID symptoms? Clinicians can meet patients where they're at, in terms of both location, cost, and symptom severity. While some patients may need and be willing to go to a multidisciplinary post-COVID clinic, others may prefer to be seen in their regular clinic, whether due to cost, transportation limitations, or the confidence they have in the relationship with the provider that they know.

If patients are going to go to a multidisciplinary center, or are seeing several other specialists, primary care providers are going to provide a bird's eye view of the care that's being given to that patient, helping that patient navigate their care seamlessly, and offering insight if there's potentially disagreement or lack of clarity on how patients should be proceeding. When looking at how long COVID can present, COVID in general has really amazed me in the variety of symptoms it causes and the various severity levels patients present with, and in the different ways that they recover. PCPs should feel empowered to manage and facilitate the care of their patients. Clinicians know their patient. They have the benefit of being able to provide continuity for them and to advocate for them.

They also have the experience to provide that insight and background on a patient, such as who's going to be minimizing their symptoms and going to need a little bit of coaxing to be fully up front about what they may be experiencing, who might need a call from a staff member between visits with reminders for medication or to ensure that they're going to follow up at their next in person visit. Primary care clinicians can also help set up expectations and guidance for patients right when they're diagnosed. If that's at an office visit, you may let them know what you kind of

expect their disease of course to potentially be like, and to let them know that if they're having symptoms after four weeks, that is something that may occur and that you'd want to see them back to discuss what they're experiencing. If patients are hospitalized, primary care clinicians can also ensure that those patients have an appropriate post-hospital follow up within one to two weeks of discharge. Clinicians are also in a great position to determine if your patients are going to be able to follow up in person or if telehealth might be appropriate for their follow up -- whether from an office visit to discuss their post-COVID symptoms, or ongoing work on that area.

So when seeing a patient with post-COVID symptoms, determine if these symptoms could be attributed to another chronic condition they have. Some people were not coming in for regular care during the pandemic. So for example, in a patient who's had COVID, is the shortness of breath they're experiencing now due to their asthma, which was poorly controlled prior to getting COVID? Is it a function of the COVID, or is it a new health issue? How severe are the symptoms? If they're severe and urgent, appropriately initiate testing. For example, if your patient who recently had COVID is having shortness of breath that's mild and slowly improving, it's a different care plan than if they present with new chest pain, tachycardia, and hypoxia. If symptoms are not severe, be sure that you're having that conversation with a patient about what the goals that they're trying to achieve with testing are.

Are they looking for an answer? Are they looking for how long this is going to take for them to get back to feeling the way they did before they had COVID? Or do they have a fear of another disease process that they really want to make sure we're ruling out? A conservative approach to testing may be very appropriate within the first four to 12 weeks. Be transparent with patients. Admit that there is a lot that we don't know about post-COVID symptoms and recovery. We are really the champions of evidence-based care. And I think it's important to admit to patients as well when we don't necessarily have a lot of evidence about something, but where we feel that there's reasonable expert opinion guiding our decisions and our pathway.

Adhere to our oath as clinicians to do no harm for our patients. Validate what your patient is experiencing. It's a frustrating process for your patient to feel unwell and not like themselves, but not necessarily have a visible problem that they can show the world. Whether that's with something as simple as saying, "I feel a little short of breath," and I may reassure them that they're not hypoxic. But it's still a frustrating thing to not be able to function the way they were prior to getting COVID.

Make sure that you're again offering that reassurance and ruling out things that are reasonable to rule out. Again, with that overview that primary care clinicians can have with that longitudinal relationships, it just behooves us to look at the whole picture. Again, is your patient losing weight because they're still missing their sense of taste? Food isn't good, and so the 15 to 20 pounds they've lost because of that and is now causing lightheadedness -- it might actually just be that they need to decrease their blood pressure medication. When sending a patient out to see a specialist, whether it's a one-time visit with a specialist or whether it's being sent to a multidisciplinary care clinic, be sure to be clear to the patient that your expectation is the specialist is going to communicate back to you as the primary clinician. You need to be aware of the plan so that you can continue to offer your patient the best and most appropriate care.

It's so appreciated when specialists send those notes back to primary care clinicians or if they think it's warranted, make a phone call, make that personal connection so that we can really ensure we're doing the best for our patients each and every time. If your group is looking to set up a multidisciplinary center, have a discussion about how you're going to expect that center to communicate with the primary care clinicians in your area. When we look at holistic support of the patient, we want to make sure that we're recognizing social determinants of health. Many primary care clinicians are doing work like this or may be familiar with some of the challenges our patients have faced in the past, whether it's with financial challenges, housing challenges, a challenging home environment. There are several options available for how to screen for social determinants of health.

The AAFP Everyone Project has training and equity resources. Some of those can include websites like findhelp.org, nowpow.org, the 211 helpline. Those resources are listed again on the Everyone Project.

Another simple thing a clinician can do is to ensure that they have their county's Health and Human Service Department phone numbers to be able to give patients. Standardizing how we ask patients if they're lacking in an area or needing extra support can be helpful and help remove stigma for people to feel that they are being isolated because of other factors. In our own clinic, we do a social determinants of health screening, and I have been surprised by how many of my patients have been very open and honest with me about many topics, including some of their social determinants of health have sometimes needed to have new referrals for extra support. Consider providing that information in multiple languages. Consider having it be a part of a standard language that you put into an after-visit summary for where patients can turn to if they feel they need extra resources or support.

If your patient or health system is looking to set up a multidisciplinary COVID clinic, consider how accessible it may be for patients. Is it near a bus line? Is there paid parking nearby? Are the hours accessible? Those factors can really go a long way in making sure we support our patients. Briefly, I just want to mention some of the work that we've done in my neck of the woods that's been helpful for our patients. We were caring for a pregnant patient who did develop COVID. She needed to go into the ICU. She was thankfully not intubated, but did need to be there for quite some time with quite a significant amount of oxygen support. We were able to discharge her from the hospital. And we partnered with pulmonology, primary care, and perinatology to ensure that we took good care of both she and her baby throughout the rest of their pregnancy.

In seeing that family for care after they delivered, we were able to keep track with mom to say, you know, "That fatigue you're feeling, does it feel similar to what you've experienced with prior pregnancies? Does it feel more significant? And how should we evaluate this? Does it feel like something that we can give time to? Do we need to be rechecking your hemoglobin knowing that you were a little bit anemic during the pregnancy? How can we coordinate this care for you?"

I also had a pediatric patient who, shortly after they developed COVID, had significant shortness of breath that brought them to the ER several times. The patient was always stable and safe and able to be discharged home.

However, when I was able to get them into clinic about a month and a half after their initial diagnosis, they still kept saying, "I'm short of breath. " And we were able to further clarify that patient really meant that they were having stomach pain and acid reflux. But when the reflux came up, they had discomfort in their chest. And that's really how they meant they were experiencing shortness of breath. Getting that clarity with the patient really allowed us to start readjusting how we were looking at what their symptoms were caused by, and making sure we're getting them on the right care path.

In our neck of the woods too, we're also getting great feedback from patients that they're really appreciating the validation of their symptoms. And that's been a tremendous asset to them as they've gone through this recovery process. Thank you for your time today and I will turn it over to Dr. Michael Saag.

Thanks very much, Alex. Good to be with everybody today. As you heard on the introductions, my background is that I'm a physician. I graduated medical school 40 years ago, and I've been a researcher, investigator, clinician in HIV/AIDS, also hepatitis C. But I'm not here today formally in my official capacity.

I'm here today as a patient. And I want to tell you briefly about my story and then circle back to long COVID. So I became infected on March 13th. It was a Friday the 13th in 2020. My son is a physician in New York.

We drove back 20 hours together in a car not wearing masks. And he, unbeknownst to us, had picked up COVID in the Manhattan environment. I'm not sure if it was in the hospital. More likely, I think it was in the community. And in 20 hours in a car without wearing masks with recycled air is a pretty good way to pick up COVID if the other person's infected.

Two days after I got back, I started running symptoms. The symptoms were mild to begin with, but by the sixth day, they accelerated to in the evening include shaking, chills, fever, cough, shortness of breath, headache, body aches, as well as a sensation of fear, because I wasn't sure where it was going. In the next 15 minutes, I watched my pulse oximeter drop from 90 to the high 80s. And just kept wondering, "Okay, when do I head to the hospital? And what is this going to mean?" By the next morning, I was okay. But then that cycle, starting in the evening, around 5:00 to 7:00 PM, exactly the same symptoms that night, resolving by the morning.

And this Groundhog Day experience continued for another eight days, until it finally disappeared in the morning, and didn't return, gratefully to me. I never had to go to the hospital, never really left my room, what I called Rikers Island, for 15 days straight. I slowly got back into activities. I experienced a fair amount of brain fog, again, pretty good in the morning, but towards the afternoon, even just responding to emails became quite difficult, and I just had to stop, rest, take a nap, or just relax my brain in whatever way that I could. The other thing I experienced was what I would call deconditioning.

But in retrospect, it could have been a part of the POTS syndrome of postural hypotension and tachycardia syndrome. A little bit of activity, just walking up one flight of stairs, I would have to stop, catch my breath, my heart rate would be elevated. These symptoms continued on for about

six weeks, and then thankfully resolved. And during that time, I returned to work and I volunteered to staff our COVID clinic. I was in clinic usually three, maybe four afternoons a week, seeing people with acute COVID.

It was actually a good experience, because not only was I able to provide some advice, but the fact that the patient was being taken care of by someone who had experienced what they're going through, I think made me a much more effective provider. And I think it helped the patients in that way. As we were moving into the late May, June, July time period, I started noticing that some of the patients who we had taken care in let's say April were coming back, not because they had a new episode of COVID, but because the original symptoms didn't resolve. And they had gone to their providers who said, "This is in your head, or this is not something to be worried about." But it was pretty profound, and all the things that Jennifer had described in various forms.

But the number one symptom that I noticed among people was fatigue. And then depending on which organ system was involved, it could have been brain, lung, heart, or other GI disorders that were persistent. It was highly variable. It was unpredictable. Some people did seem to get better. Others lingered, and we set up what was called -- I think a lot of you have done this -- a long COVID clinic that was subdivided into specialties based on neurology, pulmonary, cardiology, GI. And that's been a real help for patients. But I've got to say that, unfortunately, there's no diagnostic test that says, "Yep, you've got long COVID, or, "No, you don't. " It's a syndrome. There's no specific treatment other than symptomatic treatment.

There's a lot of theories and hypotheses about whether there's viral remnants that are causing the persistence of symptoms that the immune system is still reacting to, or that maybe in some sanctuary sites, there's some degree of viral replication that could still be ongoing. I don't personally think that's likely, but that needs to be evaluated. And antiviral therapy, Remdesivir, that type of thing is really not indicated nor helpful. There are no immune modulators that have worked, although we have used some inhaled steroids for those who have respiratory symptoms that could be on the bronchospasms sort of spectrum. But the bottom line is for the patients, for sure, and also for the providers, it is a very frustrating experience.

In my case, outside of the potential POTS and the brain fog that fortunately cleared, I did have hearing loss -- not complete, but partial. And that is not really cleared too much. So I'm wearing hearing aids now. It's frustrating. What's interesting, the delta variant that we're hearing about more and more that came out of India that's now penetrating pretty aggressively in Great Britain -- and we have about 6-7% in the US, has much more of an effect on hearing loss.

We all know about smell and taste with the original COVID strain, but that's something to keep on the watch for. I think I'll stop there. And we have about seven minutes for questions. I see a lot in the chat box. So Ibad, I'll turn it back over to you. And we'd love to hear from the participants about questions.

Thank you so much, Dr. Saag. Presenters, thank you for providing our audience with this timely information, especially your personal perspectives. We appreciate it. We will now go into our Q&A session.

As I mentioned, due to technical issues beyond our control, the Q&A box may not be available to you. So please input your questions into the chat box. And we will now ask those questions of the presenters. The first question that I would like to ask is, can you talk about the incidence of post-COVID symptoms in patients with mild or asymptomatic COVID infections?

This is Jennifer Chevinsky, and I can start on that one and then others can add. What I would say is that for those that had mild or asymptomatic illness, we are understanding that those individuals, a number of them do go on to also experience post-COVID conditions. There have been some studies that have come out that say that it might even be at similar rates to those that had more moderate or severe illness. However, as I had mentioned somewhat earlier, getting good prevalence data, really understanding the number and percent of individuals that are going on to experiences is really challenging. And there are different studies that are presenting different numbers.

At the CDC, we have a number of different studies that are ongoing to try and better understand the numbers, the prevalence, the incidence. We have cohort studies where we're looking at the natural history, from the point of experiencing COVID-19, or SARS-CoV-2 infection and then onward. So this is something that we're definitely interested in understanding better, and knowing what percent of people. There was a new study that came out that was reported on in the New York Times. So there's different estimates that are out there.

And it'll probably take a little bit longer, some more studies, to really come to more conclusive evidence about what that number or prevalence incidence percent is. Just to jump in, from my experience in the clinic -- and I've seen a lot of folks over the last year and a little bit. The mild symptoms -- I haven't seen that many people with asymptomatic infection, but those with mild symptoms on the initial certainly do develop long COVID. And sometimes the long COVID is actually worse than their original acute illness. The second thing I'll caution everyone about is that for patients who got severely ill when in the ICU, especially if they were on a ventilator, it's kind of hard to distinguish between long COVID pulmonary symptoms in those people who have scarring or other damage to their lung from the acute illnesses that's really causing the pulmonary symptoms.

So some folks in that category, it may not be long COVID per se, but a post-ICU, post-intubation, if you will, syndrome that we see in folks who've been on ventilators for a long time anyway.

Thank you very much. Our next question asks, is there an age or gender predisposition for post-COVID conditions?

This is Mike Saag again. I meant to say this in my last answer. And that is at least -- and Jennifer can give us the data -- but in my anecdotal experience, this is where the age differences don't seem to matter as much. We know that older patients especially early on were more likely to have to moderate to severe disease and be in the hospital or the ICU. For long COVID, it appears to be evenly distributed, or maybe even a little bit more of a tendency for younger folks who had mild symptoms initially to have persistent symptoms going on, which is different than the acute syndrome.

This is Jennifer. And I can also come in and say that this is something that we are interested in finding out more about. There have been some initial reports that have found perhaps more long COVID, or post-COVID conditions reported in women. However, we're trying to better understand whether there is actually a difference based on demographics in post-COVID conditions. And it's not completely clear yet whether there might be a difference based on sex or gender.

And then similarly to what Dr. Saag had mentioned, in terms of age, where we are seeing symptoms of post-COVID conditions in different age groups from children up to adults.

Thank you very much. Our next question asks, after an initial diagnosis of COVID-19, at what point do you consider symptoms presented by a patient to be technically post-COVID?

This is Jennifer. And if I'm understanding the question correctly, the way that we're looking at it is four or more weeks from the time of acute infection, you know, if that's known. That would be considered post-COVID conditions. Of course, it can be a little bit blurry when, you know, the acute phase turns into the post-acute sort of phase, for instance, for those that have extended hospitalizations or ICU stays. However, when we're talking about post-COVID conditions, we're looking at the four or more weeks from initial infection.

Thank you very much. Our next question asks, do you have any recommendations for cardiac rehab or similar programs for patients with post-COVID conditions that were cardiac in nature?

This is Mike Saag. I might take that to start. I think it really depends on the nature of the cardiac condition. And the thing we're seeing the most of is POTS, which is postural hypotension orthostasis with tachycardia. It can be quite debilitating.

A lot of times beta blockers are used. But I think the cardiac rehab is very important. Physical therapy, slow increase in exercise tolerance is helpful. It's in a lot of ways just kind of what I would call common sense medicine or symptomatic treatments. That's pretty much all we have right now.

But it does make sense to get into physical programs and increase exercise tolerance as the patient can tolerate.

Thank you very much. Next question asks, have you seen cases of vasculitis post-COVID specifically to hepatic and gastroduodenal arteries?

This is Mike Saag. I've not seen that.

Thank you. Next question asks, are there certain chronic conditions that serve as risk factors for post-COVID conditions?

That's a great question. This is Jennifer Chevinsky. It's something we're very much interested in finding more about. What we do understand is there are certain chronic conditions that might be associated with more severe COVID-19 disease with the acute disease, and therefore I guess

sequelae following the acute disease might be connected in some way to those underlying conditions. But more research is certainly needed on underlying chronic conditions and how or if they're associated with what's considered post-COVID conditions.

And this is Mike Saag. I've been struck by how many people have no underlying conditions. In fact, a couple of marathon runners that are young, in their 20s and 30s, who show up had COVID -- wasn't terrible. And then they come back with post-COVID conditions that they have trouble sometimes just standing in the shower or walking to the mailbox. And these are people who in the months before COVID had run marathons.

This is a very unpredictable thing has -- as we all are because of this webinar and other things, we're taking very seriously and have to figure out what's going on.

Thank you very much. On a different note, this question asks, Dr. Chevinsky mentioned that some patient groups may require special considerations. And some of those patient groups in her list would normally have preexisting conditions that may be confused with COVID-19 conditions. Are there some ways to differentiate that effectively? And what recommendations do you have for providers regarding that?

This is Jennifer Chevinsky. And I did mention that there are certain groups that we might need to pay special attention to. And the same, I would imagine, as Dr. Vosooney was mentioning about social determinants of health. They play a role in chronic conditions, underlying conditions, as well as post-COVID conditions.

Right now, in terms of differentiating between underlying chronic medical conditions and post-COVID conditions, there could be challenges there in trying to tease those apart, particularly if somebody say -- they didn't have, you know, continuity of care prior to their SARS-CoV-2 infection. And I'd like to pass it on to Dr. Vosooney who might have some more insight, as I'm sure she's seeing patients who both have chronic medical conditions and also have experienced post-COVID conditions.

Thank you. This is Alex Vosooney. I think the biggest thing is just again talking with the patient about what were we doing to manage those chronic conditions before they got COVID. Were they noticing any difficulties in their treatment plans? Were their symptoms well controlled? I also like to ask patients, what does this feel like to you? Patients are generally fairly good about saying, gosh, this feels like my typical asthma exacerbation. Or this feel differently, or this feels like when I had my heart attack.

Always something that is something that will make you pay attention when they say things like that. So listening to your patients about, especially if it's a chronic condition they've lived through for a while, how does this compare to what they typically experienced with that?

Thank you, that's very helpful. A follow up question along the same lines, perhaps for Dr. Vosooney, is, can you share if you know of recommended social determinants of health screening tool, like a screening tool to help determine social determinants that you can share or recommend?

That's a great question. There's no standard of care that I know of to say that this is the ideal social determinants of health screening tool. There are some different tools out there, some of which I think you do have to pay for as an organization, some of which may be free, but not quite as easy to complete. Nowpow.org is one that I've seen used in practice.

And that kind of goes based on patient responses to a questionnaire, and then with their zip code, gives them a list of information that may be helpful to them, whether it's in the area of transportation repair, food insecurity, housing issues. Other things that you can access pretty easily is the FindHelp.org. That one won't necessarily be specifically tailored to what your patient needs, but if you put in a zip code, it does give you a variety of supports in a variety of areas. So that may be information where it's simply easier to give it to the patient and let them explore.

There's also the 211 helpline, which should be available I believe in every state and in Puerto Rico, which is a number patients can call, and they can be connected to a variety of resources for a number of different areas.

Thank you very much. And the last question that I like to end with is something that Dr. Saag was referring to earlier when he shared the story of the marathon runners and other fit folks without any underlying conditions having debilitating post-COVID conditions. We've had questions in the chat box about various demographics and patient populations, clinical presentations, and if there are any differences. So to try and sum that up as one question, can you talk about if there are any clinical presentations specific to any age group, gender group, or folks with underlying conditions that can be attributed when it comes to post-COVID conditions? Or can this be across the board the same sort of post-COVID conditions regardless of underlying conditions or age?

Yeah, this is Mike Saag. I'll take the first shot at that. In some ways, if you've see one case of long COVID, you've seen one case of long COVID. There's so much variability and that's what makes it hard to even begin to characterize the syndrome, because it's so variable and the underlying conditions or the situation for the patient can range from these very fit marathon runners to people who are older with debilitating conditions. I'll finish with the comment that a lot of times I look at the patients with long COVID and flash back to Buffalo Springfield and their song For What It's Worth.

And the opening line is, "There's something happening here, what it is ain't exactly clear." And that's exactly the case with this. And that's a mandate for us to study this intensively and try to find answers to the questions, which the questions in the chat box have been fabulous. We just don't have the answers yet.

Okay, well, I want to thank everyone for joining us today, with a special thanks to our presenters Dr. Chevinsky, Dr. Vosooney, and Dr. Saag.

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