



American Academy of
Physical Medicine and Rehabilitation

**TESTIMONY FOR THE WRITTEN RECORD
FROM THE**

AMERICAN ACADEMY OF PHYSICAL MEDICINE & REHABILITATION (AAPM&R)

**COMMITTEE ON HEALTH, EDUCATION, LABOR, AND PENSIONS
UNITED STATES SENATE**

**A COMPREHENSIVE FEDERAL RESPONSE TO ADDRESS POST-ACUTE SEQUELAE
OF SARS-COV-2 INFECTION (PASC), OR “LONG COVID”**

HEARING ON

AN UPDATE FROM FEDERAL OFFICIALS ON EFFORTS TO COMBAT COVID-19”

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Chairwoman Murray, Ranking Member Burr, and Members of the Health, Education, Labor, and Pensions Committee:

Thank you for the opportunity to submit testimony today regarding Post-Acute Sequelae of SARS-CoV-2 infection, also known as “PASC” or “Long COVID.” On behalf of the American Academy of Physical Medicine and Rehabilitation (“AAPM&R” or the “Academy”), I am grateful for the Committee’s attention to this dire and complex issue. I would also like to take this opportunity to thank Congress for the \$1.15 billion in funds allocated to the National Institutes of Health (NIH) in the recently passed Consolidated Appropriations Act of 2021, Public Law 116-260, as well as the work Congress and the federal government has undertaken over the past year to respond to the COVID-19 pandemic.

I am a physiatrist, working at Penn Medicine and an Assistant Professor at the University of Pennsylvania, as well as a member of the AAPM&R. The Academy is the national medical specialty organization representing more than 9,000 physicians who are specialists in physical medicine and rehabilitation (PM&R). PM&R physicians, also known as physiatrists, are medical experts in treating a wide variety of conditions affecting the brain, spinal cord, nerves, bones, joints, ligaments, muscles, and tendons. PM&R physicians evaluate and treat injuries, illnesses, and disabilities, and are experts in designing comprehensive, patient-centered treatment plans. Physiatrists utilize cutting-edge as well as time-tested treatments to maximize function and quality of life.

Physiatrists, as trained physician experts in rehabilitation, have played and continue playing a unique role in helping American patients recover from the acute phase of COVID-19. As you know, COVID-19 can be a devastating virus that affects pulmonary, cardiac, and neurological function. On top of recovering from the disease itself, necessary treatments for dire cases of COVID-19, such as prolonged time on

mechanical ventilation, can result in impaired swallowing, difficulty speaking, muscular weakness, and pain. Physiatrists are uniquely able to devise rehabilitation programs aimed at restoring function and maintaining optimal health for these patients to return to their lives and work after their lives were upended by the novel coronavirus. Physiatrists have been working on the front lines of the pandemic since the beginning of this public health emergency. In the spring of 2020, we were working on the front lines in inpatient rehabilitation facilities to help decompress the massive surge of patients being admitted to acute care hospitals. This soon evolved to treating recovering COVID-19 patients who had been in the intensive care unit and suffered multi-system organ failure and complications (such as strokes and critical illness polyneuropathy). These patients required rehabilitation to regain their previous functional abilities and independence. While we continue to treat these patients, over the past ten months our outpatient practice also began treating patients suffering from the prolonged effects of COVID-19, often called PASC, “post-covid syndrome,” or “Long COVID.”

Due to the nature of our specialty and our experience working with and coordinating care for people with complex disabilities and chronic conditions, physiatrists have been recognized as one of the leading specialties for assessing and treating patients experiencing Long COVID. It is currently estimated that 10-30%¹ of people who had COVID-19 will experience prolonged effects related to previous COVID-19 infection. Even considering the conservative estimate of 10%, this represents well over 8 million people² given the infection rate of this virus. Additionally, these symptoms can appear in patients who were asymptomatic and may have never even known they were infected with COVID in the first place.

¹ Rubin R. As Their Numbers Grow, COVID-19 “Long Haulers” Stump Experts. JAMA. 2020;324(14):1381–1383. doi:10.1001/jama.2020.17709.

² Estimated Disease Burden of COVID-19. Centers for Disease Control and Prevention. January 19, 2021. <https://www.cdc.gov/coronavirus/2019-ncov/cases-updates/burden.html>



Over the past six months, psychiatrists and other clinicians have come together to address Long COVID by opening multi-disciplinary Long COVID clinics, in addition to our existing physician duties. These multi-disciplinary clinics serve as a “one-stop shop” to help this population address their new, varied, and debilitating symptoms, such as cognitive impairment (often called “brain fog”), shortness of breath, fatigue, pain, and mobility difficulties. These clinics convene different physician specialists, therapists, social workers, and sometimes researchers who are gathering vital data from patients with PASC. I currently lead such a clinic, the Penn Medicine Post-COVID Assessment and Recovery Clinic. AAPM&R has gathered 26 of these institutions to create a Multi-Disciplinary PASC Collaborative of experts to develop clinical guidance to improve quality of care, formal education, and resources to improve the experience of care and health equity. These collaborative discussions have illuminated the consistent infrastructure and access barriers we are seeing across the various multi-disciplinary clinics that have organically started across the country. Additionally, the needs of Long COVID patients are already spreading far beyond the clinical sphere, as patients face difficulties in returning to work and school, receiving necessary workplace accommodations, and accessing Social Security, disability, and other benefits. **AAPM&R has called on the Administration and Congress to develop a comprehensive federal plan to defeat the national Long COVID crisis.** To develop such a plan, to assess the varied policy considerations and far-reaching impacts of Long COVID, and to obtain meaningful input from a wide range of stakeholders, AAPM&R recommends the immediate formation of a federal commission (or other similarly empowered coordinating body) with a diversity of expertise to develop priority recommendations for addressing infrastructure needs and other gaps in access to timely and appropriate clinical care for all individuals with PASC.

Access Barriers

Not all insurers and health plans cover rehabilitation services, specialty home services, or post-acute care for neurorehabilitation and often end up needing to fight with their insurers to be seen and treated. These services are vitally important for this population experiencing the breadth of Long COVID symptoms and who often have difficulty organizing and traveling to many different doctors' offices. Because there is not adequate coverage, many patients cannot access these services as chronic symptoms are typically not considered as acute or emergencies. Many patients are simply unable to afford the costs of Long COVID treatment out of pocket, especially given the wide range of services required for adequate treatment and the long-lasting, potentially even permanent, effects of this condition.

In addition to financial barriers, individuals experiencing Long COVID are subject to the same systemic barriers to care that individuals with other complex, chronic conditions experience. For instance, when a patient visits their primary care provider to discuss their PASC symptoms, they are often provided with several referrals to specialists to address the confluence of their symptoms. Such patients may receive a referral to a cardiologist, pulmonologist, neurologist, psychiatrist, and orders for various labs and other tests. This puts the patient in the position of coordinating their own complex care and having to attend many different appointments, if they are even able to secure appointments in a timely manner. This is particularly difficult for patients with Long COVID who are suffering new physical and cognitive impairments. The multi-disciplinary clinic approach, to the contrary, creates a hub where a patient can see a physiatrist, consult with other specialists, complete their testing, and meet with needed therapists through a comprehensive, coordinated approach. It is one of the reasons these clinics have months-long waiting lists just to be evaluated for the first time.



The PASC clinics that are emerging across the country are typically part of an academic medical center or other health system that has the resources and capacity to develop these clinics quickly. These systems have significant financial reserves, physical space, and existing networks of specialists to erect these multi-disciplinary clinics quickly. In addition, practitioners leading these clinics can be given the leeway to devote their time and energy to developing a new model of care for their patients with PASC. For the vast majority of health care providers across the nation, these capabilities will not be available to adequately support such multi-disciplinary clinics without some form of financial assistance to jumpstart their development, even as they are proving highly effective in meeting the needs of patients with Long COVID. To put it plainly, the need for these clinics far outstrips the resources available in many areas of the country. Currently, the patients we are seeing in our clinic are not representative of the likely Long COVID population. Our patients are more likely to be middle/upper-middle class, middle-aged, and white than the typical COVID-19 patient. This demonstrates the ongoing problem with equitable access to COVID-related care. We do not believe that the population we are seeing is more severely affected by Long COVID, but rather this population has adequate access to this care. The disparate care evidenced in acute COVID in cases of Long COVID.

Payment Issues for Patients and Providers

Typically, clinical visits to evaluate, diagnose, and coordinate treatment for patients with Long COVID symptoms take an hour or more. Such complex and lengthy visits are simply not in sync with the typical reimbursement models for medical practice and the existing Evaluation and Management (E&M) codes are not equitable for the work required to treat these patients. Existing E&M codes are based upon a standard 15-minute patient visit, which is not a reasonable amount of time to evaluate complex PASC patients. This discrepancy in reimbursement and the time expended may be why more doctors are not able to adequately care for these patients. Improved reimbursement policies, such as a Long COVID add-on

code, are desperately needed to ensure that physicians can dedicate the time and resources necessary to provide appropriate care to Long COVID patients. Such reforms will make it feasible for physicians to provide this care, increasing the supply of providers offering Long COVID treatment and reducing wait times and other barriers to accessing care for patients. Currently, the physicians working in these clinics are doing so as an adjunct to their existing clinical responsibilities, making it difficult for many physicians to participate in this new model of care. A relative dearth of physicians in many cases has resulted in wait times beyond four months for patients to see the specialists necessary to treat their Long COVID symptoms.

Multi-disciplinary clinics are proving to be successful and a sorely needed model for addressing the multi-disciplinary clinical needs associated with Long COVID, but as described, there are several barriers to patients accessing such care. Funding or grants to establish these clinics would help create more of these clinics, streamline care, and help patients optimize their health and function faster.

Other Access Issues

Telemedicine has rapidly evolved over the past year and has been widely adopted throughout the pandemic. For safety reasons and the nature of Long COVID, telemedicine has been vital in treating patients with PASC. It allows patients access to a multi-disciplinary clinic that may not exist in their geographic area, a common concern for many patients nationwide, especially those residing in rural areas. However, many individuals in rural and low-income neighborhoods and across the country still do not have access to critical broadband internet and other technological requirements to appropriately access virtual care. This needs to be rectified for patients enduring the effects of Long COVID and all patients seeking virtual health care during the pandemic and beyond.

Many patients experiencing PASC may not have been specifically tested for COVID-19 nor exhibit antibodies, which results in some providers not knowing to refer them to a PASC clinic. There have been barriers to accurate testing throughout the pandemic for different populations, especially communities of color and people with disabilities. As treatments and reimbursement for Long COVID patients evolve, it is crucial that we not create additional barriers to access, such as a requirement for a positive COVID-19 test to gain access to a multi-disciplinary clinic.

The nature of Long COVID also means that many patients present with symptoms that do not appear in a normally recognized test. For example, patients may complain of shortness of breath, but show no discernible physical issues in imaging of their lungs. This has been a longstanding problem for patients with other long-term, chronic, and not clearly delineated conditions, such as chronic fatigue syndrome and other complex disease states. We hope that the efforts to improve multi-disciplinary care for patients with Long COVID can also benefit individuals with other complicated medical conditions. This underscores the need for research on PASC to be conducted rapidly and translated to providers so that this new population can be recognized for the symptoms they are suffering, instead of being dismissed for not fitting existing medical paradigms.

The infrastructure and access issues encountered by these multi-disciplinary PASC clinics are not new issues. Patients with disabilities and complex conditions have experienced these same barriers in our health system for years. The influx of people into the disability and chronic illness community from the rapidly growing population of people with Long COVID has shone a light on these barriers and gaps in care for so many patients. Long-term, ongoing support for multidisciplinary care is desperately needed.



Additional Needs of Long COVID Patients

The significant and time sensitive clinical needs of Long COVID patients only reflect one aspect of the impacts of Long COVID on the country. As we continue to develop a deeper understanding of Long COVID, some patients are likely to experience long-term or even permanent Long COVID symptoms, potentially impacting their ability to function independently for years to come. As a result, we expect that many Long COVID patients will become members of the disability community in the coming months and even years. These individuals will face significant additional barriers because of their symptoms. It is critical to consider how individuals with Long COVID will be able to access disability benefits, including Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI); the accommodations these individuals may need to return to work, if they are able; the availability of Long-Term Services and Supports (LTSS) that may be necessary; the education these individuals may need to understand the services available to them and their rights under the Americans with Disabilities Act and other federal statutes; and much more. There are many facets to the Long COVID crisis, and the need for policy solutions is likely to only grow over the coming months. In order to coordinate the federal response to Long COVID, and to ensure that recommendations for statutory and regulatory changes can be made through a unified, recognized body with the imprimatur of the federal government, AAPM&R strongly recommends the formation of a commission, task force, or other federal interagency entity, led by the White House or at senior levels within the Department of Health and Human Services, and tasked with development of a crisis plan to address the immediate and long-term impacts of Long COVID-19. We encourage the subcommittee to consider this need and offer our assistance in any way we can to advance policy for those living with Long COVID.



We thank the committee for its leadership in recognizing this critical issue for individuals across the country and appreciate the opportunity to submit this written testimony. As the subcommittee, Congress, and the federal government continue to consider policies to address the Long COVID crisis, we offer our support as an organization and on behalf of the physiatry profession and urge the subcommittee to consider AAPM&R and the Multi-Disciplinary PASC Collaborative as a resource. We look forward to working with you to serve the needs of the millions of patients nationwide experiencing the debilitating effects of Long COVID.

Sincerely,

A handwritten signature in black ink, appearing to read "Ben Abramoff". The signature is written in a cursive, somewhat stylized font.

Benjamin Abramoff, MD, MS
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Co-Chair of AAPM&R's Multi-Disciplinary PASC Collaborative

Appendix I: Current List of Institution Members Participating in the Multi-Disciplinary PASC Collaborative

- University of Washington
- Icahn School of Medicine at Mount Sinai
- UT Health San Antonio
- Rusk Rehabilitation, NYU Langone Health
- UT Southwestern Medical Center
- Shirley Ryan AbilityLab
- Penn Medicine
- Beth Israel Deaconess Medical Center
- OHSU - Oregon Health & Science University
- Johns Hopkins Medicine
- University of Kansas Health System
- Ascension Medical Group
- Mayo Clinic
- Cedars Sinai – LA
- GW Medical Faculty Associates
- JFK Johnson Rehabilitation Institute at Hackensack Meridian Health
- UNC-Chapel Hill
- University of Colorado
- UC Davis Health
- Vanderbilt University Medical Center
- Kennedy Krieger Institute - Pediatric Post COVID-19 Rehabilitation Clinic
- Montefiore-Einstein COVID-19 Recovery (CORE) Clinic
- Hartford HealthCare's COVID Recovery Center
- Tulane Neurology Post COVID Care Clinic
- Northwestern Medicine Comprehensive COVID-19 Center
- MetroHealth Post-COVID Clinic