

COVID Patient Recovery Alliance

AN ALLIANCE CONVENED BY LEAVITT PARTNERS

April 27, 2021

Frank Pallone
Chairman
House Committee on
Energy & Commerce

Cathy McMorris Rodgers
Ranking Member
House Committee on
Energy & Commerce

Anna G. Eshoo
Chairwoman
House Committee on
Energy & Commerce
Subcommittee on Health

Brett Guthrie
Ranking Member
House Committee on
Energy & Commerce
Subcommittee on Health

Dear Chairman Pallone, Ranking Member McMorris-Rodgers, Subcommittee Chairwoman Eshoo and Subcommittee Ranking Member Guthrie,

We applaud the Committee for holding the hearing “The Long Haul: Forging a Path through the Lingering Effects of COVID-19.” As co-convenors of the COVID Patient Recovery Alliance, we see the importance of working together to provide care for patients with long-COVID.

As part of our national response to the COVID-19 pandemic, we need to better understand long-COVID and how its effects may impact our health care system, our communities, and our path on the road to recovery. The Alliance we lead seeks to support the energy and innovation of public-sector and private-sector leaders as they ensure care for individuals experiencing long-COVID. The Alliance is developing national strategies to link diverse data sources, inform the development of models of care, and ensure adequate payment for the care of these patients.

While much is not yet fully understood about long-COVID, the needs patients are facing are real and the breadth of need is extensive. Published estimates suggest that somewhere between 10 to 30 percent of patients who recovered from COVID-19 may have long-COVID to some degree for some period of time. With researchers suggesting that during the public health emergency an estimated 100 million Americans have been infected with COVID-19, the size of the long-COVID patient population is quite significant.¹

To help understand and meet the needs of patients, our Alliance is comprised of leaders in business, health care, patient and consumer advocacy, research, academia, and data science. Through our members, the Alliance brings together technical expertise, experience, regulatory knowledge, and public policy understanding to achieve the following objectives:

¹ Estimate based on symptomatic confirmed cases and estimated asymptomatic cases. Centers for Disease Control and Prevention. Estimated disease burden of COVID-19 (updated January 19, 2021) of 83.1 million total infections from February – December 2020. <https://www.cdc.gov/coronavirus/2019-ncov/cases-updates/burden.html> website accessed February 27, 2021. And Institute for Health Metrics and Evaluation. COVID-19 Results Briefing (updated April 21, 2021) estimates 30 percent of people in the U.S. infected as of April 19, 2021. http://www.healthdata.org/sites/default/files/files/Projects/COVID/2021/102_briefing_United_States_of_America_15.pdf website accessed February 27, 2021

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- **Data Collection and Evidence Generation:** Coordinate federated studies to characterize long-COVID by leveraging members' individual robust data assets and analytic capabilities. The Alliance will use the data work to inform policy positions and advocacy efforts, such as the development of targeted federal policy solutions and potential best practices.
- **Care Model Development:** Inform the development of models of care to help optimize the use of resources and improve the care of patients with long-COVID based on evidence, best practices, and patients' needs and characteristics.
- **Payment Model Development:** Inform the development of payment strategies, tools, and policies to ensure patients with long-COVID receive adequate care and support based on evidence, best practices, and patients' needs and characteristics.

While many patients with long-COVID face needs, there are several different patient populations to which the Alliance is paying close attention. The Alliance is particularly interested in patients with long-COVID:

- Who served their communities and nation when called to duty as essential workers, frontline providers, and workers in other key sectors;
- Whose COVID-19-related costs are extraordinary and burdensome or who are underserved by existing programs or sources of coverage; and
- Who come from communities that have been disproportionately impacted during the public health emergency from disparities and inequities.

The reality of many Americans who suffered from COVID-19 but have not yet fully recovered has important ramifications for their ability to be restored to full health, return to work, and reengage in their families and communities. Many of the common long-COVID symptoms can negatively impact an individual's ability to return to work following infection and be productive while at work; these symptoms include brain fog, dizziness, inability to focus, fatigue, anxiety and depression, and inability to exercise or be active.² Press reports have noted how individuals with long-COVID are finding they need accommodations from their employers, including modified schedules and expectations for near-constant digital communication.³

We applaud Congress's appropriation of \$1.15 billion to the NIH to study long-COVID and other long-term effects of COVID-19. While it is critical to address many of these unanswered questions, the research will take time. Given the scope of the challenges, we believe there is also a need for near- and mid-term strategies to identify care gaps and ensure equitable care and coverage to patients with long-COVID. Collaboration amongst key stakeholders can help shape and support solutions to address long-COVID.

As Congress seeks to better understand and respond to long-COVID, the COVID Patient Recovery Alliance stands ready to engage policymakers and welcomes the opportunity to serve as a resource to you on these important issues on an ongoing basis. We are underway in identifying system gaps, data improvements, and actionable targeted approaches to help ensure quality care for patients with long-COVID and support our nation's road to recovery. We appreciate your interest and are ready to help inform the thoughtful bipartisan work for which the Committee is well-known.

Sincerely,

Governor Michael O. Leavitt
Co-convener

Nancy-Ann DeParle
Co-convener

² <https://pubmed.ncbi.nlm.nih.gov/33532785/>

³ <https://www.wsj.com/articles/the-challenges-of-getting-long-covid-patients-back-to-work-11613350801>

