EXECUTIVE SUMMARY

WHO WE ARE

The COVID Patient Recovery Alliance is a multi-sector group of organizations whose mission is to define, develop, and assist in implementing a national strategy to characterize, diagnose, ensure care for, and sustainably fund the full recovery of individuals with the clinical syndrome of Post-Acute Sequelae of COVID-19 ("PASC," but more commonly referred to as "long-COVID"). New data estimates that 100 million Americans have been infected by the virus causing COVID-19,[1] and published studies indicate 10-30 percent of people diagnosed with COVID-19 may have ongoing symptoms after acute infection, many of which can impact return to work and life.

To address these unprecedented and long-term health consequences of COVID-19, the Alliance is developing national solutions that link diverse data sources, inform the development of models of care, and ensure adequate payment for the care and full recovery of these patients. The Alliance is particularly interested in helping people who served their communities or nation when called to duty; whose COVID-19-related costs are extraordinary and burdensome; or who are underserved by existing programs, including those racial and ethnic minorities and communities experiencing health disparities.

There is a pressing need to restore this group of COVID-19 survivors to health, and to assure an organized, evidence-based, and holistic approach to helping them across all of American society. Leaders in business, health care, research, academia, science, and other sectors face an opportunity to marshal a coordinated effort to collect evidence, analyze data, and develop a strategy and array of resources aimed at each facet of this challenge, including patients, health care delivery system, public and private payers, communities, and businesses. Many agencies, companies, ad hoc groups, and institutions have begun to recognize the need for action, but no single organization can tackle this project alone. This need and opportunity led to the creation of the COVID Patient Recovery Alliance.

WHAT WE ARE DOING

The work of the COVID-19 Patient Recovery Alliance falls into three main categories: Data Collection and Evidence Generation; Care Model Development; and Payment Models.

Data Collection and Evidence Generation

Drawing upon the expertise of key Alliance members and their own data collection efforts, research, and analyses, the Alliance is rapidly defining clinical subgroups of the long-COVID survivor population in order to establish a critical foundation for developing targeted pathways for clinical management. This multi-sector approach will afford the Alliance the ability to aggregate multiple data sources to form a more complete picture of COVID-19 survivors, their clinical needs, and likely sources of health care coverage. This picture will evolve and be continually refined as new data and information become available.

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[1] http://www.healthdata.org/sites/default/files/files/Projects/COVID/2021/102_briefing_United_States_of_America_15.pdf

Care Model Development

To address the lack of standards of care for individuals suffering from long-COVID, Alliance members are identifying models of care, drawing on the expertise of Alliance members and nationally recognized experts in comprehensive COVID-19 interventions. By curating best practices, this cohort of COVID-19 survivors, payers, providers, health systems, and benefits coordinators will have access to evidence-based, expert-developed, and scalable care management solutions.

Payment Models

The ultimate success of any COVID-19 care pathway may be accelerated by the development of a payment model structured to incentivize its adoption and successful deployment. The Alliance is considering new payment models for public and private payers, which could build on existing payment systems. For example, some targeted payment approaches could support fee-for-service payments for remote monitoring or home care, or better assess the degree to which current risk-adjustment mechanisms are adequate considering changes in care utilization and patient acuity.

WHAT IS LONG-COVID?

While millions of Americans have been diagnosed with COVID-19 and have completely recovered, a significant number of individuals continue to experience after-effects from the disease. Recent data suggests that 10 percent of COVID-19 patients end up suffering from long-COVID.[2] For these patients, being at home after "recovery" is the start of a new and protracted period of uncertainty as they wrestle with ongoing clinical needs that seem to be chronic.

The National Institute of Health (NIH) recently launched a new initiative to study long-COVID, known as the PASC Initiative. Congress has allocated over $1.15 billion in funds over a four-year period to support new and ongoing research on long-COVID-related research topics, including how to prevent and treat long-COVID symptoms.[3] It is hoped that this dedicated funding to study long-COVID will generate fresh insights to inform the nation's response. The Alliance will generate information and insights far in advance of these studies, and be integrated into testable plans for health care delivery, payment, and rehabilitation and economic recovery.

While a precise number of total cases has yet to be determined, published studies find that 10-30% of COVID-19 survivors may have ongoing symptoms. Based on that percentage, out of roughly 30 million reported COVID-19 cases, an estimated 3 to 9 million individuals could have persistent symptoms over some period. This number could be even larger, as analyses from CDC and Institute for Health Metrics and Evaluation suggest that the number of COVID-19 cases in the U.S. may be as high as 100 million.[6,7,8]

Long-COVID Symptoms

While a standardized definition has not been adopted in the U.S., the U.K.'s National Institute for Health and Care Excellence defines long-COVID as "signs and symptoms that develop during or following an infection consistent with COVID-19, continue for more than 12 weeks and are not

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[2] https://health.ucdavis.edu/coronavirus/covid-19-information/covid-19-long-haulers.html
[3] https://www.nih.gov/about-nih/who-we-are/nih-director/statements/nih-launches-new-initiative-study-long-covid

explained by an alternative diagnosis."[4] The most commonly reported long-COVID symptoms include fatigue, muscle or body aches, shortness of breath or difficulty breathing, cough, and joint and chest pain. However, more serious long-term complications related to cardiovascular, respiratory, neurologic, and psychiatric health have been reported.[5]

In a survey of more than 1,500 COVID-19 patients, nearly 100 different long-term symptoms of COVID-19 were reported. Many of these issues lie well beyond the range of typical COVID-19 symptoms recognized by the CDC; for example, they include difficulty concentrating, dizziness, memory problems, difficulty sleeping, and hair loss.[6] This same survey found that 26.5% of symptoms experienced by long-COVID patients were described as painful.

Long-COVID Impact on Return to Work

Many of the common long-COVID symptoms described above can negatively impact an individual's ability to return to work following infection and to 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.[10] Many individuals with long-COVID are requesting accommodations at work as a result of these symptoms, such as shortened schedules, adjusted expectations for constant digital communication, and even maximizing possible disability benefits.[11]

Disparities Among Long-COVID Patients

The hospitalization and death rates of COVID-19 are significantly higher for Black, Hispanic/Latino, and American Indian/Native Alaskan communities. Contributing factors for increased risk of getting sick, being hospitalized, and dying from COVID-19 include lack of health care access, discrimination, occupation, education, income, wealth gaps, and crowded living circumstances.[12] What is currently unknown, however, is the risk of long-COVID among various racial and ethnic minority groups, and their access to treatment, both of which are areas this Alliance is exploring through data collection and evidence generation.

Health Care Costs and Utilization

Recent data suggests that health insurers are anticipating increased health costs in 2021 as a result of deferred care or avoided preventative care for chronic conditions during social distancing lockdown periods, and health care complications following recovery from severe cases of COVID-19. However, there is no comprehensive and holistic study concerning the types of health care coverage long-COVID patients currently have, nor are there estimates around their future health care costs and utilization following acute COVID-19 infection.[13]

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[4] https://www.nice.org.uk/guidance/ng188/documents/final-scope
[5] https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects.html
[6] https://static1.squarespace.com/static/5e8b5f63562c031c16e36a93/t/5f459ef7798e8b6037fa6c57/1598398215120/2020+Survivor+Corps+COVID-19+%27Long+Hauler%27+Symptoms+Survey+Report+%28revised+July+25.4%29.pdf
[7] https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2776560
[8] https://jamanetwork.com/journals/jama/fullarticle/2771111
[9] https://www.cdc.gov/coronavirus/2019-ncov/cases-updates/burden.html
[10] Ibid.
[11] https://www.wsj.com/articles/the-challenges-of-getting-long-covid-patients-back-to-work-11613350801
[12] https://www.cdc.gov/coronavirus/2019-ncov/community/health-equity/race-ethnicity.html
[13] https://www.kff.org/private-insurance/issue-brief/2021-premium-changes-on-aca-exchanges-and-the-impact-of-covid-19-on-rates/

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