



PATIENT PERSPECTIVES ON LONG COVID

HOSTED BY **Pandemic Patients & COVID Survivors for Change**

WHAT IS LONG COVID?

INTERIM WORKING DEFINITION OF LONG COVID

Long COVID is broadly defined as signs, symptoms, and conditions that continue or develop after initial COVID-19 or SARS-CoV-2 infection. The signs, symptoms, and conditions are present four weeks or more after the initial phase of infection; may be multisystemic; and may present with a relapsing–remitting pattern and progression or worsening over time, with the possibility of severe and life-threatening events even months or years after infection. Long COVID is not one condition. It represents many potentially overlapping entities, likely with different biological causes and different sets of risk factors and outcomes.
NATIONAL ACADEMIES OF SCIENCES, ENGINEERING, AND MEDICINE (NASEM)

WHAT DO WE KNOW ABOUT LONG COVID?

According to the most recent data collected by the U.S. Census Bureau, over 38 million Americans have had a prior COVID-19 infection with symptoms lasting over 3 months.

HOUSEHOLD PULSE SURVEY*

Severe COVID-19 infections increase the risk of cardiac arrest, death, diabetes, heart failure, pulmonary embolism, and stroke. COVID-19 also increases the risk of developing myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) dysautonomia, among many other conditions.

LONG COVID: MAJOR FINDINGS, MECHANISMS, AND RECOMMENDATIONS*

Vaccination before infection with COVID-19 provides only partial protection in the post-acute phase of the disease: vaccinated people with COVID-19 infection have a 15% lower risk of developing long COVID symptoms compared to unvaccinated people.

LONG COVID AFTER BREAKTHROUGH SARS-COV-2 INFECTION*

Reinfection further increases risks of death, hospitalization and sequelae in multiple organ systems in the acute and postacute phase... The risks were evident regardless of vaccination status... Compared to noninfected controls, cumulative risks and burdens of repeat infection increased according to the number of infections.

ACUTE AND POSTACUTE SEQUELAE ASSOCIATED WITH SARS-COV-2 REINFECTION*

David Cutler of Harvard University estimates that the total cost of long COVID is \$3.7 trillion, which represents roughly \$11,000 per capita or 17% of the 2019 GDP of the United States. These costs represent lost quality of life, reduced earnings, and increased medical spending. The enormity of these costs implies that policies to address long COVID are urgently needed. With costs this high, virtually any amount spent on long COVID detection, treatment, and control would result in benefits far above what it costs.

THE ECONOMIC COST OF LONG COVID: AN UPDATE*

**Scan the QR code for additional information.*

WHAT DO WE KNOW ABOUT LONG COVID? (cont.)

An estimated 2-4 million Americans have left the workforce due to long COVID. This translates to \$168-230 billion in lost wages annually.

NEW DATA SHOWS LONG COVID IS KEEPING AS MANY AS 4 MILLION PEOPLE OUT OF WORK*

Claims associated with long COVID are rising for disability insurance, workers compensation, and group health insurance. Those higher claims could increase costs for insurers and eventually, employers.

WHAT ARE THE IMPLICATIONS OF LONG COVID FOR EMPLOYMENT AND HEALTH COVERAGE?*

**Scan the QR code for additional information.*

WHAT CAN THE GOVERNMENT DO ABOUT LONG COVID?

STOP IT AT THE SOURCE

The costs associated with long COVID are significant, and the risk of developing long COVID following each COVID-19 infection is substantial. Preventing the spread of COVID-19 is the most effective strategy for reducing the prevalence of long COVID.

- Improve ventilation and air quality in the workplace, and in educational, transportation, and health care settings.

SUPPORT PATIENTS' RECOVERY

Treatment approaches to long COVID are as diverse as the symptoms patients experience. Long COVID patients need access to complex specialty care, diagnostics, and therapeutic interventions to successfully manage their health and symptoms.

- Allow medical providers to practice telehealth across state lines.
- Develop and disseminate educational resources regarding long COVID for medical practitioners and their staff.
- Provide funding for interdisciplinary long COVID clinics where patients can receive comprehensive care and support services.
- Reduce health disparities among marginalized communities by ensuring equitable access to comprehensive care.

PROMOTE WORKFORCE PARTICIPATION

Long COVID can manifest as disabling symptoms that diminish patients' ability to provide for themselves and their families, which reduces tax revenue and strains safety net programs. Policies that bolster long COVID patients' participation in the workforce will help alleviate the economic burden of the disease.

- Develop and disseminate educational resources regarding the rights of people with disabilities related to long COVID and strategies to accommodate employees with long COVID.
- For those who cannot work, streamline the application process for SSDI and increase the Social Security Administration's capacity for claims adjudication.
- Eliminate the 5-month mandatory waiting period for SSDI benefits and the additional 24-month waiting period for Medicare coverage.

INVEST IN RESEARCH

A cure for long COVID does not yet exist and clinical trials for treatments are lagging behind. Patients are relying on the federal government's ongoing investment in biomedical research to accelerate the discovery of treatments and a cure for long COVID.

- Continue investing in patient-centered research at the NIH and prioritize patient engagement in the biomedical research enterprise.
- Continue investing in the development of innovative tools to advance the diagnosis and treatment of long COVID.