

Flash Report **EU-US Conference on Long COVID**

13 December 2022

DG SANTE hosted an online conference with over 800 participants to highlight the latest news and developments on long COVID¹ in the European Union and the United States of America. Experts from medical, public health, and health economics disciplines as well as representatives of patient organisations and policymakers shared their experiences and insights on long COVID. Emerging evidence suggests that as many as 1 in 8 people who recover from COVID-19 will experience long COVID with a wide range of debilitating symptoms lasting weeks or months after the initial infection.

The main objectives of the conference were to exchange experiences and knowledge between the EU and the US in long COVID research, treatment and health systems' responses, and also to identify key challenges and knowledge gaps in these areas.

Introduction and keynote addresses

Opening the conference, **Sandra Gallina**, Director-General for Health and Food Safety, European Commission, said there was an urgent need for a concerted and coordinated international response to the challenges posed by long COVID.

A recently published Opinion of the Expert Panel on effective ways of investing in health² had underscored the need to adapt national health systems to dealing with long COVID as well as addressing multimorbidity in the context of caring for patients with the condition. Millions of people in Europe and the United States have been affected by long COVID and they need targeted clinical care, better treatments, and support in dealing with the condition on a daily basis.



Admiral Rachel Levine, the Assistant Secretary for Health at the United States Department of Health and Human Services, highlighted the work being done by US authorities, across 14 different federal agencies, to respond to the challenge of long COVID. Two important reports on long COVID had recently been published³ and the government was funding research and fostering international collaboration as a central focus of its strategy.

Professor Peter Piot, Special Advisor to the President of the European Commission, highlighted the need to support people affected by long COVID and to ensure that they have access to targeted care and support. As someone who had been personally affected by long COVID, he considered it important to challenge the misconception that the condition was not real. He stressed the need for better education and more research into the origins, clinical syndromes, diagnosis, treatment and prevention of the condition, as well as its economic impact.

Dr Ashish Jha, White House COVID-19 Response Coordinator for the United States, noted that the mechanisms behind long COVID were not fully understood but progress was being made on identifying potential causes. He said that the US government was taking an all-of-government and all-of-society approach to managing long COVID, which included research and development, expanding the healthcare workforce, and providing support for those with long COVID.

¹ Long COVID, also known as post-COVID syndrome or long-haul COVID, refers to the ongoing symptoms and health effects experienced by some individuals after recovering from COVID-19, the illness caused by the SARS-CoV-2 virus.

² https://health.ec.europa.eu/publications/facing-impact-post-covid-19-condition-long-covid-health-systems_en

³ https://www.hhs.gov/about/news/2022/08/03/biden-harris-administration-releases-two-new-reports-long-covid-support-patients-further-research. html

Patient perspectives on long COVID

Representatives of Long COVID patient organisations said that without effective treatments, many people with long COVID would never recover, and the illness would significantly disrupt the global economy. It was also important to improve education to counteract the stigma that patients with long COVID experience and take due account of the complex and evolving nature of the disease and its symptoms. The European patient organisation, Long COVID Europe, therefore called for an emergency fund for research and clinical trials on long COVID and associated health conditions, at the EU level.

Research evidence on epidemiology, symptoms, treatment

Experts summarised the latest epidemiological evidence, current standards of care and promising pathways for new treatments for long COVID. More than 60 symptoms have been identified, with women carrying a higher risk of developing long COVID than men. The causes of long COVID remain elusive but research was advancing on identifying a range of factors implicated in the condition. Possible therapeutic strategies for patients with long COVID included preventing infection with vaccines and antiviral drugs and addressing immune system abnormalities and autoimmune responses. The average severity of long COVID was similar to that of complete hearing loss or the long-term consequences of moderate to severe traumatic brain injury. The challenges of accessing long COVID clinics and the need to transmit knowledge to primary frontline care providers was emphasised. Consensus guideline papers and educational activities could be utilised to share information with general practitioners.

Economic impact of long COVID

Speakers discussed the impact of long COVID on labour markets and the global economy. They noted that variations in the definition of long COVID made it difficult to accurately estimate the true economic impact, which included factors such as health spending, reduced quality of life, and loss of productivity. The loss of productivity due to long COVID was significant, with estimates ranging from 0.3% to 1.5% of gross domestic product (GDP). There also was a need for more research on the impact of long COVID on daily life, including work time and absence from work and the wider economic impact.

Health systems' response to long COVID

Experts highlighted efforts in the EU and US to improve data collection on long COVID, and advocated the exchange of best practices to support decision making and policy actions. There was widespread agreement on the need for more research on the wider impact of long COVID, including on the labour force and economic and social circumstances. The establishment of national support networks, and the integration of long COVID management into primary care and telemedicine to improve access to care should also be encouraged. The need to fully involve patients in the co-design and co-production of interventions, clinical trials and evidence-gathering was

emphasised. Health services needed to be organised to be more responsive to long COVID patient needs and to adopt models of care that put patients

at the centre.

Closing remarks and conclusions

Bringing the conference to a close, **Sandra Gallina**, Director-General for Health and Food Safety, European Commission, thanked the speakers and attendees for their contributions and for sharing their experiences with long COVID. She emphasised the need for swift action to address the challenges posed by long COVID, and called for international collaboration and the implementation of promising treatments and options in order to manage, treat, and potentially prevent the condition. She highlighted the significant economic and health system impacts of long COVID, and emphasised the importance of investing in research in order to better understand and address this complex issue.

