



Washington DC

Cite this as: *BMJ* 2022;378:o2266<http://dx.doi.org/10.1136/bmj.o2266>

Published: 20 September 2022

Long covid: protesters outside the White House demand better care

Bob Roehr

Protesters took to the pavement outside the White House on 19 September to demand a better deal for people affected by long covid, complaining that the Biden administration's plans fell short on action and funding.

"The pandemic is over," President Joe Biden declared the night before in a pre-recorded interview which aired on the news magazine *60 Minutes*. "We still have a problem with covid," he said. "We're still doing a lot of work on it but the pandemic is over. If you notice, no one's wearing masks. Everybody seems to be in pretty good shape. And, so, I think it's changing."

But the scene outside the presidential mansion the next day belied that message. Wearing black masks and red shirts, protesters called for research, medical treatment, and social services for those with long covid. Around half would qualify for a diagnosis of myalgic encephalomyelitis/chronic fatigue syndrome. The protest was organised by #MEAction, an international network of patient advocates.

"I went undiagnosed for 15 years, because doctors are not educated about the condition," Jennifer Nish told *The BMJ*. Nish, from Lubbock, Texas, said that she was inspired to help organise the protest to raise awareness. "I don't want anyone to go through what I had to go through," she said and called on "the White House to treat this like the emergency that it is."

JD Davids, an HIV activist of many decades, said that two reports on long covid that the Biden administration has released were "a major disappointment because they don't make anything new happen. The action plan for research could be promising, but it's not funded."

At the Centers for Disease Control and Prevention "responsibility is constantly shifting, because there is no one currently permanently assigned" to long covid, Davids said. Two long covid positions are being advertised at the Department of Health and Human Services, "but there is not an institution to put the structures in place. We are seeing sporadic support but not political will."

Davids would like to see the kind of comprehensive research agenda that led to effective treatments for HIV, as well as "financial support for people who have lost everything. People are being rejected when they apply for disability benefits."

Medical providers need to be trained, insurance coverage needs to be assured, and social services programmes need to be adapted to long covid, according to the protesters. The problems are exacerbated by fragmented healthcare delivery in the US, where responsibilities are divided between private organisations and government ones operating at the national, state, and local levels.

Estimates of the number of Americans with long covid begin at around 20 million and could be more than twice that number. Davids noted, "The pandemic is just beginning, in many ways."

Clarification: On 20 September we added the word "permanently" in the sentence concerning responsibility at CDC.