

My name is Steven Deeks. I am a Professor of Medicine at the University of California, San Francisco. Like many people working on COVID, I was prior to last year engaged full time in the study of HIV. I directed a cohort devoted in part to determine how HIV affects long-term health. Our extended team has also been studying how other infections, including Ebola, caused long-term complications.

We realized early in the pandemic that people who survived acute COVID might develop long-term complications. We repurposed our HIV cohort to study COVID and began enrolling study participants in April. We are now doing intensive investigations on “Long COVID”, or PASC. Given our expertise, we are primarily focused on identifying possible mechanisms and treatments for this disease.

With regard to today’s meeting, I wanted to describe in general terms what is known and what is not known about Long COVID.

There are only a few things we know with some certainty.

First, the syndrome is real. There is almost universal consensus that undefined proportion of individuals who survive the acute infection will have some residual symptoms that persist for weeks to months. Achieving consensus within the medical establishment that syndrome is real is very important, as prior post-infectious complications not received much attention by the biomedical community. It is my hope that by simply acknowledging that the syndrome is real will reduce much of the stigma around these issues.

Second, there are several different types of long-COVID. Some have predominantly cardiovascular symptoms, such as cough, palpitations and reduced exercise reserve. Other have primary more neuropsychiatric symptoms. Still others have chronic malaise and other factors that have high effect on quality of life. We assume the biology and treatment for these syndromes will be different.

Third, although symptomatic long-COVID is common, only a proportion – maybe a few percent – have profound and disabling symptoms. Still given that there may be over 50 million people in this country alone who have had COVID, the number of people who will be profoundly affected

by long COVID will likely be in the millions. This has huge implication for our health care system and Social Security.

This is all that we can say for sure. We have many important unknowns.

First, there is no consensus on how to define, diagnose or measure this syndrome. In fact, there is no universally accepted name. Everyone is using different definitions and the state-of-the-art is a mess.

Second, we do not really the prevalence and natural history of the syndrome. Most studies suggest that about 20% of adults develop long-term problems. The problem is more common in those who had very symptomatic acute disease but importantly can occur in those who were relatively asymptomatic. Women are more likely to suffer long-term issues than men, which I think provides important insights into the mechanism. Anecdotally, most clinicians feel the symptoms slowly improve for most but not everyone.

Third, we do not know how much of what people are experiencing is solely due to the infection. The pandemic has had a massive effect on the health of everyone. Social isolation can affect one's health in complicated ways, as can the loss of one's livelihood. Untangling all of these issues will be challenging.

Fourth, we do not know the mechanism for long-COVID. This may now be the most critical question for the field to address. It is also what the NIH does best. In the 1980s, massive investments from the NIH led to the discovery of how HIV replicates. Once this happened, industry was able to rapidly develop effective therapies. Fortunately, the NIH is now investing heavily in such work.

Fifth, we need to engage industry and the regulatory agencies. Developing therapies will not happen unless we somehow find a way to incentivize our partners in the pharmaceutical industry.

Finally, we need to engage all of the affected communities more fully. This will require dedicated resources and the input of experts on health disparities and related issues.