TuSalud

Kennedy's HHS Commits to Long COVID, but Without Clear Funding

Following two roundtable discussions, HHS announced a public awareness campaign and medical resource platform.

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Health secretary Robert F. Kennedy Jr. asserted at a roundtable event on long COVID today [September 18] that the gathering marked "the start of a sustained national effort" on the overlooked disease. The event featured two panel discussions of government officials, researchers, clinicians, and patient advocates, as they discussed long COVID's underlying biology as well as development for potential treatments and biomarkers.

Speakers in both panels asserted that long COVID was a serious public health problem that demanded urgency. They also stressed the importance of listening to people with the disease — but some patient advocates watching were skeptical that the new HHS initiatives will meet their needs.

In a press release following the event, Health and Human Services (HHS) announced a new long COVID public education and awareness campaign as well as an "open source" medical resource platform. During the roundtables, leaders from the Food and Drug Administration (FDA), Advanced Research Projects Agency for Health (ARPA-H), and the National Institutes of Health (NIH) committed to prioritizing long COVID.

Still, there were not any announcements of significant new government funding for research into the disease or support for people experiencing it, a major demand from advocates over the past few years.

Secretary Kennedy opened the meeting with the news that the HHS was launching a "Long COVID consortium," which he had first shared during a recent Senate Finance Committee hearing earlier this month. He stated the department is commencing the new group in response to requests from Senators Roger Marshall (R-KS) and Todd Young (R-IN). Kennedy said he receives daily calls about long COVID and repeated that the disease impacts his own family.

It is unclear who is part of the consortium, how other long COVID community members might participate, or what research roadmap the consortium will follow. In response to detailed questions from The Sick Times, an HHS spokesperson referred back to Thursday's press release with no

further information.

“Long COVID patients demanded urgency — and today Sec. Kennedy and Congressional champions delivered, with new commitments from NIH, ARPA-H, FDA, and to engage drug companies to cut delays and speed research breakthroughs,” wrote Meighan Stone, executive director of the Long COVID Campaign, in a statement.

The new consortium appears to be separate from the National Institutes of Health’s RECOVER program, which held a workshop last week to announce new clinical trials. Republican lawmakers have previously criticized that program — a trend that continued during the roundtables, as both Secretary Kennedy and FDA director Marty Makary said that it has spent over $1 billion with “nothing to show for it.”

Speaking at the event, NIH director Jay Bhattacharya referenced last week’s workshop and the newly announced trials, saying that the RECOVER-Treating Long COVID initiative is focused on “practical trials.” Bhattacharya also stressed an urgent need for research, saying he did not want people to wait years for trial results before accessing treatments. “Next year I want there to be 20 million people with answers,” he said. (While Bhattacharya and other speakers cited an estimate of 20 million Americans with long COVID, some research suggests the true prevalence may be higher.)

Jason Roos, acting director of ARPA-H, also committed to quick action. “In short order, after this forum, we can come up with a plan” for the agency to address long COVID with high-risk, high-reward research, he said. He added that this plan will occur on the order of weeks, not months or years.

Some long COVID advocates watching the livestream event were critical of the new initiatives and skeptical that the HHS is equipped to appropriately tackle this crisis under Kennedy.

“I felt there were some positive aspects — I particularly appreciated Akiko Iwasaki, Michael Peluso and Ziyad Al-Aly’s involvement,” wrote advocate C.H. Romatowski, referring to leading long COVID researchers who spoke at the roundtables. “But the long COVID community will not get the care we urgently need without robust infrastructure in science and public health.”

Under Secretary Kennedy, the HHS has significantly cut staff and funding across federal health agencies, including long COVID initiatives and grants. Earlier this year, the Trump administration canceled programs and threatened research funding for the disease. In February, the administration terminated the HHS’s long COVID advisory committee and closed the agency’s Office of Long COVID Research and Practice. It also cut grants for Long COVID pathobiology research; those grants were later restored thanks to community advocacy.

Romatowski also noted that today’s event was “counterprogramming to an ACIP [Advisory Committee on Immunization Practices] meeting expected to continue RFK Jr.’s attacks on both” science and public health. ACIP’s members voted to change recommendations for childhood vaccines.

In addition, people watching the livestream flagged that both panels included predominantly white and male speakers, even though long COVID disproportionately impacts women, transgender people, and people of color. "The Roundtable discussions were dangerous for women, queer, Black, Latin, and disabled communities. There was no representation of these communities, which means those who need the most education and support will have an even less stake in clinical trials and research," wrote Chimére L. Sweeney, founder of the Black Long COVID Experience, in an email. Future HHS consortium efforts must feature more diverse representation of people with long COVID and physicians treating the disease, Sweeney added.

"The makeup of the panels was not representative of the affected population to such a degree that the homogeneity appeared pointed and purposeful," said #MEAction scientific director Jaime Seltzer. With many of the long COVID advocacy groups she said patients rely on absent at the roundtables, Seltzer is concerned about what the proposed public awareness campaign might convey.

The proposed webpage also received criticism, as some advocates said there are many existing websites on long COVID; another website is not a top priority for people with the disease.

Other discussion during the roundtables centered on barriers to long COVID research and healthcare. The speakers discussed a need for biomarkers to inform clinical trials and treatment options, identifying subtypes within long COVID's many symptoms and underlying biological issues, challenges with FDA review of trial plans, insufficient knowledge of long COVID among primary care providers, and more.

Long COVID is considered a "risky investment" by pharmaceutical companies, said Michael Peluso, speaking from his experience working on clinical trials at the University of California, San Francisco. He supported an idea, first proposed by Sen. Young earlier in the discussion, that HHS convene a roundtable of pharmaceutical representatives next to better understand their concerns.

Secretary Kennedy also asked questions about adverse outcomes from COVID-19 vaccines, in line with his history of anti-vaccine views. Researchers and clinicians on both panels acknowledged that some people do have chronic symptoms following vaccination in a condition often called post-COVID vaccine syndrome. Internist Jordan Vaughn and former Centers for Disease Control and Prevention director Robert Redfield in particular spoke about their experiences treating patients who have symptoms following vaccination; both have also previously advocated for further research into the COVID-19 vaccines.

Other speakers emphasized the research connecting long COVID symptoms and underlying biology to SARS-CoV-2 infection. Millions developed the disease before COVID-19 vaccines even existed.

Another speaker with a checkered history in the long COVID community was Bruce Patterson, a physician and scientist who leads the company IncellDX, previously investigated by Mother Jones. During the event, he claimed that he's treated people with Long COVID with a high success rate with a combination of maraviroc and atorvastatin. Patterson and his colleagues plan to soon start a clinical trial testing this

combination, he said.
Some advocates also criticized the event for its last-minute nature. It was announced in a press release on Wednesday afternoon, less than 24 hours before the start time.

The lack of advanced notice for the event “harmed health and prevented meaningful engagement, leaving many patients crashed and extremely sick,” said Karyn Bishof, founder of the COVID-19 Longhauler Advocacy Project (C19LAP), in a statement. “Going forward, events must be accessible to the long COVID community so we can meaningfully attend and contribute. ‘Nothing about us, without us’ must apply across every stage — brainstorming, planning, recruiting, advertising, facilitation, analysis, dissemination, and long-term follow-through.”

However, Bishof also noted some positive aspects of the event, including renewed national attention, work going beyond the NIH RECOVER program, potential public education initiatives — which have long been a focus for C19LAP — and the promise of bipartisan support from Sen. Young. “We are thrilled to hear that HHS is planning for a public awareness campaign, and this can be very meaningful and change the tide — if they’re science-driven, adequately funded, and co-built with credible patient-led groups,” she said.

Despite the high rates of COVID-19 rates currently circulating in a late summer/early fall surge, only one person wore a mask: patient advocate Devin Russell of the Long COVID Foundation. As only one of two patient advocates on both panels, he brought up the importance of people with long COVID avoiding reinfection. Several speakers also referred to the pandemic in the past tense, implicitly dismissing the in fact ongoing crisis even as they claimed to support people with long COVID.

“Long COVID is a unique kind of hell,” Russell said during the event, and many people with the disease are “hanging on by a thread” as they await evidence-based treatments.

Miles Griffis and Betsy Ladyzhets contributed jointly to this story. For more details about discussion during the roundtable event, see Betsy’s live blog thread on Bluesky.

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