HHS Gave Million-Dollar Grants to Nine Long COVID Clinics; Here's How They Plan to Use the Funding

December 22, 2023 By Betsy Ladyzhets and The Sick Times

This fall, the federal government announced a new grant program to support long COVID care: the Agency for Healthcare Research and Quality (AHRQ) awarded million-dollar grants to nine clinics across the country, designed to help these centers extend their reach and develop best practices for addressing this complex chronic disease. Each clinic can receive up to $5 million over five years, with $45 million set aside for the overall program.

This grant program builds upon the successes of existing clinics that have been caring for people with long COVID over the last four years. AHRQ specifically sought to support multidisciplinary clinics, or centers that bring together different medical specialists to examine and treat patients' complex symptoms across multiple organ systems. Past reporting by both me and my co-editor Miles Griffis has found that multidisciplinary clinics can be helpful for some people with long COVID, but even the most comprehensive clinics may provide poor guidance if they are not informed by the latest research.

AHRQ also focused on funding clinics poised to improve care for underserved populations, such as communities of color and those living in rural areas. The agency calls this "a first of its kind grant program," said Dr. Abby Cheng, a physical medicine and rehabilitation doctor at Washington University in St. Louis who is a lead clinician on the university's AHRQ grant. The goal isn't to fund scientific research, but rather "to rapidly invest resources in communities and then hopefully use those as models to improve care nationwide," she added.

Cheng and her colleagues at the other eight awarded clinics plan to use this funding to expand their own services — hiring more staff and increasing their capacity to help patients — while working with primary care centers, community groups, and other partners in their areas to provide outreach and education about long COVID. Leaders from each clinic will meet regularly to share lessons from their work, both with each other and with government officials at the Department of Health and Human Services (HHS) as it builds the Office of long COVID Research and Practice.

"The hope will be that what we're learning from these grants can actually translate into policy at the HHS level or inform that [long COVID] office to make more sustainable change," said Dr. Sarah Jolley, medical director of the University of Colorado's long COVID clinic, another AHRQ grant

recipient. To inform policy, the clinics will collect data and produce reports about their efforts; each clinic must submit annual progress reports to receive renewed funding, according to AHRQ.

Long COVID advocates have expressed excitement about the AHRQ program, but say that much more funding is needed to truly address the needs of millions of Americans with this condition. "I think it's totally a step in the right direction, and we also need to be doing more," said Alison Sbrana, an advocate who previously helped lead the support group Body Politic and advises the University of Colorado's clinic. As people with long COVID and related conditions are not well-served by the existing healthcare system, the AHRQ program could support better models of care, she said.

Sbrana noted that AHRQ has funded some centers that are informed by the history of infection-associated diseases, a significant improvement from the National Institutes of Health's RECOVER program, which has garnered criticism for its failure to learn from these conditions. Still, she would like to see AHRQ and other federal agencies more actively solicit input from people with lived experience and provide funding directly to patient-led groups.

The government should also "fund support groups" and "patient advocacy organizations run by sick people that can't even sustain themselves," Sbrana said, referring to Body Politic's wind-down earlier this year. "We were doing the work, too."

People with long COVID should be directly involved in developing healthcare models for this disease, agreed Karyn Bishof, founder of the Covid-19 Longhauler Advocacy Project, which worked with Rep. Ayanna Pressley on the Treat Long COVID Act. Currently, "most, if not all, models of care typically do not involve patients in their development and planning," she said, adding that including such expertise is crucial to improving patients' health outcomes.

In response to questions from The Sick Times, a spokesperson from AHRQ said the grant program was informed by patient perspectives via a January event about best practices for treating long COVID, held by the agency and Sen. Tim Kaine's office. The spokesperson also noted a need for "continued investment at the federal and community level" to support people with long COVID, along with continued investment in research.

"AHRQ will have the opportunity to oversee, evaluate, and monitor the effectiveness of specific long COVID clinic services and models of care," said Dr. Laura Sessums, AHRQ's chief medical officer, in a statement to The Sick Times. "The oversight will enable us to find and share best practices, educational tools, and resources with the broader medical community."

The Sick Times spoke to principal investigators at seven out of the nine clinics that received these awards, to learn about their approaches for managing long COVID and plans for the funding. We've included key points from each interview below.

University of Texas Health Science Center at San Antonio

Location: San Antonio, Texas

Principal investigator who spoke to The Sick Times: Dr. Monica Verduzco-Gutierrez, physiatrist and rehabilitation medicine specialist

Approach for managing long COVID: Patients are “seen in a very holistic way,” Verduzco-Gutierrez said, thanks to collaboration between doctors with different specialties. During the intake process, doctors ask about patients’ medical histories (including how many times they’ve had COVID-19, vaccinations, and prior medications), and go through their symptoms to determine which are patients’ biggest concerns. The clinic also often screens patients for common symptoms like orthostatic intolerance and post-exertional malaise. The doctors can provide management strategies for some symptoms, while others might require additional testing and visits to specialists.

Plans for expanding the clinic: The clinic is expanding and rearranging its space for doctor visits to facilitate better collaboration between physicians, Verduzco-Gutierrez said. Patients will be able to easily see multiple doctors in one visit or even have multiple doctors in the same appointment to discuss a multi-systemic issue. They also plan to hire staff to support coordination between doctors.

Plans for outreach and education: Building upon an existing program called Project ECHO, the San Antonio clinic will work with both primary care clinics in the University of Texas system and other nearby clinics that provide care to underserved populations, to educate primary care doctors about long COVID. The clinic also plans to partner with community health organizations — particularly with promotores, and community health workers in Latino communities — to spread the word about this disease.

Other comments: “It’s an amazing grant because we get funding to support our clinics and our efforts… but we still need separate dollars to do clinical trials,” Verduzco-Gutierrez said.

Intake information: Patients may be able to self-refer to the clinic or may need a referral from a primary care doctor, depending on their insurance provider. A positive test is not required; in fact, the clinic will see patients dealing with long-term symptoms after non-COVID infections, Verduzco-Gutierrez said.

Stanford University

Location: Stanford, California

Principal investigator who spoke to The Sick Times: Dr. Linda Geng, primary care and population health physician

Approach for managing long COVID: Stanford’s clinic takes a “whole person approach to care,” informed by strategies for caring for other people with complex, chronic conditions, Geng said. Her specialty prior to Covid-19 was helping people with “puzzling conditions” find diagnoses, while her co-principal investigator, Dr. Hector Bonilla, has past experience with myalgic encephalomyelitis (ME). Patients at Stanford’s clinic receive individualized care based on their symptoms and have

opportunities to participate in research, Geng said.

Plans for expanding the clinic: The AHRQ grant will allow Stanford's clinic to "increase capacity" through hiring staff and developing resources for patients from different backgrounds, Geng said. She listed social workers, nurse navigators (who help patients navigate the healthcare system), and health workers who speak multiple languages as hiring priorities.

Plans for outreach and education: The Stanford clinic will work closely with two community health providers, the San Mateo Medical Center and the Community Health Center Network, which collectively serve about 400,000 low-income people across Northern California, according to a Stanford press release. Specialists from the clinic will mentor and "serve as a resource" for primary care doctors in these networks, Geng said. The clinic also plans to develop educational materials for both potential Long Covid patients and doctors, which it will promote with the help of community partners.

Other comments: Post-infectious diseases are "an area of medicine that has been long neglected in terms of resources and research," Geng said. In addition to addressing long COVID, she hopes the AHRQ program can be extended to other related diseases and help the healthcare system "be ready for the next pandemic."

Intake information: Stanford's clinic requires physician referrals; learn more about the process and their offerings here. Geng noted there is currently a "long waitlist."

Washington University in St. Louis

Location: St. Louis, Missouri

Principal investigator who spoke to The Sick Times: Dr. Abby Cheng, physical medicine and rehabilitation physician

Approach for managing long COVID: Patients who seek care at the Washington University clinic first meet with a long COVID-focused doctor and a social worker, who evaluate their symptoms and medical records, Cheng said. Then, patients may be directed to specialists within the clinic's multidisciplinary network as well as community resources. Patients with long COVID and similar infection-associated diseases can also attend group sessions at the university's Living Well Center, which focus on symptom management strategies like pacing and sleep optimization, Cheng said.

Plans for expanding the clinic: Like other clinics, Washington University plans to hire additional staff to support patients. The clinic aims to hire case managers (who will help patients navigate the healthcare system along with managing financial needs, such as transportation to appointments) and behavioral health counselors. Some staff will be based at the St. Louis Integrated Health Network, one of the university's partners on this grant.

Plans for outreach and education: The Washington University clinic will work with several community partners, including health centers that provide care to underserved patients in St. Louis, to teach both doctors and their patients about long COVID. The clinic is also working with the University of Missouri, which has its own iteration of the Project ECHO program, to support doctors in rural parts of the state. "Our big goals are to improve the care experience and serve even more patients across St. Louis and surrounding rural region," Cheng said.

Other comments: Before Covid-19, Cheng specialized in musculoskeletal conditions like Ehlers-Danlos Syndrome (EDS) and hypermobility, which may overlap with long COVID. She sees the AHRQ program as “an opportunity to really treat patients with all of these symptoms better, regardless of if it’s related to long COVID or not.”

Intake information: The Washington University clinic requires physician referrals and positive COVID-19 tests.

University of Colorado Denver

Location: Denver, Colorado

Principal investigator who spoke to The Sick Times: Dr. Sarah Jolley, pulmonary and critical care medicine specialist

Approach for managing long COVID: The University of Colorado’s clinic started in the spring of 2020 and has “evolved over time,” Jolley said. It now has a multidisciplinary approach, with doctors across different specialties seeing patients; one day each week, patients can see multiple doctors at a time. Common strategies for care include teaching patients about pacing and using therapeutics that have been helpful for ME/CFS, such as low-dose naltrexone. The clinic also refers patients to peer-to-peer support groups.

Plans for expanding the clinic: The University of Colorado team is working closely with doctors at Colorado’s two other multidisciplinary Long Covid clinics: one at National Jewish Health, also in Denver, and the second at Family Health West, a critical access hospital in the rural Western Slope. The AHRQ grant will support hiring health navigators (similar to the case managers or nurse navigators at other grantees) for all three clinics. These staff will help patients apply for workplace accommodations and public resources along with navigating their healthcare, Jolley said.

Plans for outreach and education: The University of Colorado clinic and its partners will develop training for primary care practices across the state, aiming to “support provider knowledge and awareness of Long Covid,” Jolley said. In addition, the clinics will use Colorado’s version of the Project ECHO program to support telehealth appointments: patients who live far from Denver will receive remote appointments in collaboration with their primary care doctors. Plus, the AHRQ grant will fund outreach to different Colorado communities on long COVID, building on existing engagement programs around chronic disease at the university’s Colorado Clinical and Translational Sciences Institute.

Other comments: “We know long COVID is going to be here for a while, so I think there will definitely be a need for longer-term funding models to create a sustainable model of care delivery,” Jolley said. To not extend funding beyond the current five-year grants “would be a loss,” she added.

Intake information: The University of Colorado clinic takes new patients through physician referrals.

Icahn School of Medicine at Mount Sinai

Location: New York City, New York

Principal investigator who spoke to The Sick Times: Dr. Juan Wisnivesky, clinical epidemiologist and Chief of the Division of General Internal Medicine

Approach for managing long COVID: Mount Sinai has two existing Long Covid clinics: one is a multidisciplinary clinic and the second, led by Dr. David Putrino, focuses on rehabilitation and recently announced an expansion into other post-infectious diseases. The AHRQ grant is not supporting either of these clinics directly, Wisnivesky said; rather, it will fund a new program offering long COVID care to underserved New Yorkers.

Plans for expanding the clinic: The new Mount Sinai program involves adding long COVID services to two primary care clinics in the hospital's network, which serve about 20,000 patients in Harlem and the South Bronx (NYC neighborhoods that include many low-income and minority residents). Clinicians with long COVID experience will train healthcare workers at these clinics to recognize the disease, conduct medical testing, and help direct patients to specialists, with a foundation "in the setting where these patients already receive care," Wisnivesky said. He is particularly interested in developing tools for cognitive testing, as he also works on the RECOVER clinical trial focused on cognitive symptoms.

Plans for outreach and education: Wisnivesky and his colleagues are starting to work with local community organizations on outreach, he said.

Other comments: As the nine clinics that received AHRQ grants begin to meet, Wisnivesky looks forward to learning from the other sites' successes and developing shared resources, including educational materials for healthcare workers and outreach materials for potential patients, he said. "Hopefully, there will be materials that come out of this effort that can be disseminated across primary care," he said.

Intake information: The new Mount Sinai program will open in early 2024. Its first patients will be people in the primary care clinics who already have long COVID diagnoses, then providers will be able to refer additional patients to the centers.

University of Pittsburgh

Location: Pittsburgh, Pennsylvania

Principal investigator who spoke to The Sick Times: Dr. Alison Morris, immunologist

Approach for managing long COVID: While the University of Pittsburgh's Long Covid clinic is run out of the School of Medicine's pulmonary department, it is "very multidisciplinary," Morris said. The clinic helps patients meet with doctors of different specialties, offers referrals, looks for potential diagnoses of other conditions that may be related to or exacerbated by long COVID, and provides opportunities to participate in research. Patients are often referred to physical therapy, Morris said; she did not provide specific details when asked about how the clinic screens for post-exertional malaise.

Plans for expanding the clinic: The Pittsburgh specialty clinic plans to work closely with family

medicine clinics based at the same university to improve their capacity for caring for people with long COVID, Morris said. The specialty clinic itself is also adding more capacity to "bring people from outside communities" in for appointments if their needs can't be addressed by primary care doctors.

Plans for outreach and education: In collaboration with the University of Pittsburgh's family medicine clinics, the long COVID specialty clinic will develop educational materials for doctors, such as online lectures and guidance about recognizing common symptoms. Many of those family medicine clinics are located in underserved parts of Pittsburgh or nearby western Pennsylvania, Morris said. The specialty clinic is also working with the university's Black Equity Coalition, a group of Black physicians and experts, which will provide input on serving people with long COVID among communities of color in the Pittsburgh area.

Other comments: "One clinic can't really serve the needs of the entire surrounding community," Morris said. Outreach and education is crucial, particularly for helping doctors recognize long COVID among their patients, she said.

Intake information: Patients can make appointments with the University of Pittsburgh clinic online; referrals are not required.

Kennedy Krieger Institute

Location: Baltimore, Maryland

Principal investigator who spoke to The Sick Times: Dr. Laura Malone, pediatric neurologist and director of the institute's pediatric post-Covid clinic

Approach for managing long COVID: Kennedy Krieger Institute's clinic is the one pediatric long COVID clinic among AHRQ's grantees. Similarly to the adult clinics funded by this grant, this center takes a multidisciplinary approach: multiple providers will evaluate patients together, then "provide cohesive and individualized recommendations," Malone said. The clinic's team includes a behavioral psychologist and a social worker, who helps patients and their families identify resources that may be helpful for the whole family. The team also refers patients to other specialists at the Kennedy Krieger Institute and Johns Hopkins University.

Plans for expanding the clinic: One of the clinic's major focuses is helping pediatric patients with school accommodations, such as extra time for assignments or breaks during the school day, Malone said. The AHRQ grant will support the clinic in researching "what barriers there may be for children with long COVID within the school, how to mitigate those barriers, and how to improve functioning overall."

Plans for outreach and education: Malone and her colleagues will develop educational resources for pediatricians who may be seeing children with long COVID. The Kennedy Krieger Institute is setting up an ECHO program, similar to those at other institutions, to focus specifically on pediatric long COVID; through the program, pediatricians will be able to receive education and mentorship on treating this condition. The clinic will also develop resources specifically related to school accommodations for children with long COVID.

Other comments: "I think long COVID is still under-recognized in pediatrics," Malone said. Her

clinic has seen around 150 to 200 patients, she estimated, which is likely a significant undercount of the number of children who may need this care. “Increased recognition” from pediatricians is crucial to support these patients, she said.

Intake information: More information about the Kennedy Krieger Institute clinic is available here; families can make appointments directly or get a referral. Demand may be high as the clinic provides “extensive evaluations,” Malone said.

Other clinics

We also reached out to principal investigators from the University of Washington and Emory University for details about their AHRQ grant plans but didn’t hear back before the time of their publication.

More details about the University of Washington’s clinic are available here, and the university’s press release about their award is here. Their website states that, due to a high volume of patients, the clinic is “currently only accepting new referrals for established UW Medicine patients, patients living within King County, and UW Medicine employees.”

Emory University published a press release about their award here. The grant will support a group called the “Atlanta Long COVID Collaborative,” which doesn’t appear to have a website or public information about patient intake, though it is currently hiring a postdoctoral fellow.

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