CEAL's CEACR Offers Community-Engaged Expertise to Long COVID Research

January 12, 2024

When you're pressed for time, it's tempting to go it alone, but that goes against the essence of community-engaged research.

The Researching COVID to Enhance Recovery (RECOVER) initiative was announced by NIH in February 2021. RECOVER seeks to increase understanding of and effective prevention and treatment strategies for the lingering health problems experienced by some people after COVID-19 infection. Called post-acute sequelae of SARS-CoV-2 or Long COVID, the constellation of symptoms was identified early in the pandemic, and patients with these symptoms galvanized the scientific community to research the condition.

Unprecedented in scope and size, RECOVER's goal is to build a national study population that represents the diversity of people affected by COVID and Long COVID. Through a cooperative effort that involves more than 200 researchers at close to 200 sites, RECOVER is studying 60 million health records, enrolling over 20,000 adults, pregnant people, and children, as well as the tissues and organs of deceased people with the permission of a loved one.

"We had to stand a lot of things up very quickly," says Janelle Linton, M.P.H., senior research project manager for community engagement for the RECOVER initiative.

Luckily, they didn't have to start from scratch when it came to community engagement. They turned to the Community Engagement Alliance Consultative Resource (CEACR).

CEACR brings together key expertise in community-engaged research developed by CEAL research teams during their own fast-paced, early days of the COVID-19 pandemic. CEACR was established in 2021 to elevate best practices for community-engaged research and provide customized expertise to optimize inclusive participation in research to CEAL sites, community-based organizations, and NIH-funded research teams working towards health equity.

"NIH's vision for CEAL and CEACR is to not lose the momentum for community-engaged research that was created out of the emergency during the pandemic," says Mylynda Massart, M.D., Ph.D., core director for engaging special populations at University of Pittsburgh's Clinical and Translational Science Institute and co-principal investigator for CEACR. "If we can apply

the same amount of teamwork and collaboration to other public health disparities, we can make significant impacts. We can extend our knowledge and resources and advance how we're doing this."

CEACR gave RECOVER the boost it needed to get this multi-layered and multi-partner initiative off the ground.

To ensure community participation in the multi-faceted research process, RECOVER called for the formation of a National Community Engagement Group (NCEG) of patient, caregiver, and community representatives who were involved in all aspects — from planning to framing research questions, promoting participation, and helping to ensure inclusion of diverse communities and backgrounds.

RECOVER developed documentation explaining the NCEG's goals and purpose and how it fits into RECOVER's overall research approach. However, the document was not a recruitment tool, nor was it customized for the diverse communities from which they wanted to recruit. RECOVER sought recommendations from CEACR to help identify representatives for the NCEG from a diversity of cultures and communities.

Pulling from their roster of over 50 experts in community-engaged research, CEACR assembled a panel to review the document with an eye toward recruiting representatives from American Indian and Alaska Native (AI/AN) tribal communities who have been hard hit by both COVID-19 and Long COVID.

"The expert panel really helped with the tone and design of the document," explains Linton. "They made over 22 recommendations that improved the content and appearance, including language, symbols, and photographs that many Tribal communities could relate to."

The result was a clearer and more relatable design that succeeded in recruiting both representatives to the NCEG and participants for the study. The NCEG now consists of 58 representatives, including six from AI/AN communities.

The collaboration was so successful that RECOVER has returned to CEACR to adapt materials to several different communities, including Spanish-speaking and Black populations. The RECOVER team has also used CEACR recommendations to strengthen outreach for study participants from diverse backgrounds.

"Communications is an iterative and collaborative sport," says Catherine Freeland, director of communications for RECOVER. "We tried to build on other people's shoulders because we could never have done this without the support of existing groups like CEAL and CEACR."

Topic(s): Health Disparities in Chronic Conditions, Community-Specific Health Disparities

Program: The Community Engagement Alliance Consultative Resource