



## A MESSAGE FROM THE RADx-UP CDCC

The CDCC has been asked to develop a set of common data elements (CDEs) focused on symptoms associated with long COVID (also known as post-acute sequelae of SARS-CoV-2). These CDEs will give us tools to measure the prevalence, protective factors, and risk in the many different populations and communities that are part of RADx-UP. These new CDEs will be added to the NIH RADx-UP CDEs as **optional** tier two questions.

We would like to take this opportunity to work with projects and community partners to develop and refine these CDEs in order to ensure that these questions are appropriate for the communities RADx-UP projects serve.

Please consider joining a focus group to support the development of these long COVID CDEs. This focus group will represent community, academic, and patient perspectives. We are especially interested in community partners and others who have first-hand experience with long COVID.

If interested in joining, [please complete this short survey](#) by **Monday, September 19**. Contact [Allyn Damman](#) with your questions.

### The Details



The RADx-UP Long COVID CDE Focus Group will include around 20 individuals including project investigators, community partners, operational staff from the CDCC, and people with long-COVID symptoms or concerns.

**Please see below for additional details:**

- Focus Group members will be asked to attend an orientation session, review the starter pack of long COVID CDEs, complete a feedback survey, and join at least one post-review feedback session. All combined, these activities will take approximately five hours to complete.
- Community members and non-academic community partners who join the Focus Group will be reimbursed at an hourly rate, up to \$500, for their time.
- Once the long COVID CDEs have been incorporated into the full set of NIH RADx-UP CDEs, Focus Group members may have the opportunity to join a smaller task force that will craft best practices for rapid development of CDEs, and then prepare a report and publish a manuscript.
- CDCC leaders, CDCC Data Core personnel, and NIH leaders will provide guidance, review, and approval for these additional CDEs.
- In the fall, we plan to finalize and make available the first iteration of the long-COVID CDEs for tier two data collection.

### Learn more



#### What is Long COVID?

Many people recover fully within a few days or weeks after being infected with SARS-CoV-2, the virus that causes COVID-19. But others have symptoms that linger for weeks, months, or even years after their initial diagnosis.

Some people seem to recover from COVID-19 but then see their symptoms return, or they develop new symptoms within a few months. Even people who had no symptoms when they were infected can develop symptoms later. Either mild or severe COVID-19 can lead to long-lasting symptoms. Long COVID, long-haul COVID, post-COVID-19 condition, chronic COVID, and post-acute sequelae of SARS-CoV-2 (PASC) are all names for the health problems that some people experience within a few months of a COVID-19 diagnosis. Symptoms of long COVID may be the same or different than symptoms of COVID-19. Long COVID can also trigger other health conditions, such as diabetes or kidney disease.



#### What are Common Data Elements?

The RADx-UP consortium is a network of more than 125 community-engaged research project teams and mini-grant recipients across all 50 states, and U.S. territories and Tribal Nations.

All of these project teams and recipients use the NIH RADx-UP Common Data Elements (CDEs), which provide a standard set of study questions for their COVID-19 testing studies. The CDEs allow the RADx-UP consortium to aggregate data from across all the populations and communities that projects study and engage.