

RECOVER Patient and Community Engagement Strategy

Background

The goal of the RECOVER Initiative is to improve our understanding of the long-term effects of COVID, enable treatments for people affected by COVID, and find ways to prevent these long-term effects.

We need to involve patients, caregivers, and community representatives as partners in the research process. This will help to frame research questions, promote participation in the RECOVER studies, and ensure that people from all communities and backgrounds are included.

RECOVER must ground patient engagement in best practices for meaningful and collaborative involvement. The National Institutes of Health (NIH) is strongly committed to continually evolving strategies for engaging patients to help guide RECOVER and to keep patients informed about progress.

This document provides a high-level overview of the RECOVER Initiative's engagement approach, strategy, and structure. The RECOVER Engagement Team will update the engagement strategy regularly to reflect evolving desires, challenges, priorities, and opportunities.

Engagement Approach

The [Principles of Community Engagement](#) (pdf), developed by federal agencies, defines community engagement as “the process of working collaboratively with groups of people who are affiliated by geographic proximity, special interests, or similar situations with respect to the issues affecting their well-being” (p.12).

Our approach is grounded in evidence-based, tested approaches to engaging patients, such as

- the [PCORI Engagement Rubric](#), which emphasizes patients as partners in planning, conducting, and disseminating research;
- the Meaningful Involvement of Patient Advocates approach (e.g., [Spieldenner et al, 2022](#) [pdf]), which emphasizes the voice of community members in decision-making and leadership; and
- the [Trauma-Informed Community Engagement](#) approach, which engages people with histories of trauma, recognizes the presence of trauma symptoms, and acknowledges the role that this has played in their lives.

Table 1. Patient and Community Member Engagement Rubric

Phase	How patients and community members may be involved in decisions
Planning the initiative and individual studies	<ul style="list-style-type: none"> • Co-designing and providing input on the overall initiative • Co-designing the structure of the initiative to maximize patient and community representation across each level of governance and activity • Co-defining the research questions and outcomes to be studied • Co-defining the characteristics of participants (inclusion/exclusion criteria) in individual studies • Co-designing individual study protocols (for example, to be feasible and cause minimal disruption to patients)
Conducting the initiative and individual studies	<ul style="list-style-type: none"> • Collaborating in selecting high-priority interventions to study • Ensuring accessible touchpoints for patients, caregivers, and community members who are not involved as Representatives • Refining and evaluating the patient and community engagement structure to ensure patients and community members are being heard • Co-creating recruitment processes and materials • Troubleshooting recruitment and retention challenges • Co-analyzing and helping interpret study findings
Disseminating the initiative, study activities, and study results	<ul style="list-style-type: none"> • Co-designing materials about the work of the initiative so they are easy to find, understand, and use • Weighing in on the pieces of information most critical for patients and communities to know about the initiative • Co-designing the initiative website • Co-designing materials to make study findings easy to find, understand, and use • Identifying pathways to reach patients and communities in an equitable way • Identifying the most relevant information and outcomes to disseminate • Participating as coauthors on RECOVER-related publications

Guiding Principles

As outlined in the PCORI Engagement Rubric and guiding principles, patient and community members will be involved in every phase of research, from planning to conducting to disseminating (as shown in **Table 1**). Major RECOVER Initiative decisions will be made in partnership with patient and community Representatives, and with broader input from patients and communities, as needed. Patient and community members who are not Representatives will be able to share ideas, concerns, hopes, and needs.

Consequently, RECOVER has adopted the following principles to underpin our continued engagement:

- **Inclusivity and diversity:** We will include a diverse group of people in the RECOVER study, including study staff, leaders, and participants. Our goal will be to include people of many races and ethnicities, ages, genders, jobs, education levels, incomes, U.S. locations, and those who have different health conditions. We will think carefully and often about who is not involved in RECOVER and how we can engage and involve them with respect.

- **Safety:** We will promote a culture of safety to ensure that Patient, Caregiver, and Community Representatives feel physically and emotionally secure, and that participants enrolling in the studies feel welcomed and engaged.
- **Transparency:** We will openly share information about the RECOVER study and its findings with participants and the public with the aim of fostering and maintaining trust.
- **Accessibility:** We will share information about the RECOVER study in a way that people can easily find and understand it. We will work to limit barriers to increase enrollment to studies.
- **Two-way communication:** Communication between RECOVER staff and the public, including participants, will be two-way so that both groups can send, receive, and share information. We will ask participants and the public for their input and questions about the RECOVER study and will use their feedback to improve the study. Participants and the public will be able to send us their questions, and we will listen carefully and answer them. These collaborative communications will inform and contribute to the decision-making processes of the initiative.
- **Accountability:** We will hold RECOVER staff and leaders responsible for making sure RECOVER follows research standards and ethics, including to do no harm and to avoid re-traumatizing individuals and communities.
- **Collaboration:** We will work and search for opportunities for collaboration to get input and feedback through forums and discussions.

Engagement Strategies

The strategies of the engagement plan are:

- Strategy 1: Designate a team dedicated to engagement across the entire RECOVER Initiative
- Strategy 2: Engage advisors with expertise in patient and community engagement
- Strategy 3: Establish formal engagement mechanisms and processes
- Strategy 4: Establish informal engagement mechanisms and processes
- Strategy 5: Refine and expand engagement approaches throughout the life of the initiative

Strategy 1: Designate a team dedicated to engagement across the entire RECOVER Initiative

As a large-scale initiative, RECOVER will plan and implement most activities through teams. RECOVER will form an Engagement Team with the internal processes and resources needed to support patient and community engagement over time. The team will include staff from the initiative's Administrative Coordinating Center and Clinical Science Core. The Engagement Team's work will be organized into four types of activities, shown in **Table 2**.

Table 2. RECOVER Engagement Team Activities

Focus	Activities
Identifying patient and community groups	Making sure that all relevant communities are included and that the initiative can identify the proper way to engage patient and community members
Planning for patient and community engagement	Developing an actionable plan to partner effectively with patients and community partners in planning, conducting, and disseminating information about the initiative and individual studies
Implementing patient and community engagement	<p>Providing training and learning opportunities on patient and community engagement to RECOVER Consortium members</p> <p>Forming, launching, and convening formal and informal mechanisms for patient and community engagement, such as facilitating review and input/evaluation at the individual study and initiative-wide levels</p>
Monitoring patient and community engagement	Refining the patient and community engagement structure to ensure equity in collaborating in the initiative, and ensure that patient and community members are being heard

Strategy 2: Engage advisors with expertise in patient and community engagement

RECOVER engagement activities are informed by two organizations that serve as external community and patient engagement advisors to the Engagement Team: Community-Campus Partnerships for Health (CCPH) (<https://ccphealth.org/>) and exPPect (<https://www.exppect.net/>). Both organizations support RECOVER's engagement efforts, including

- conducting broader community engagement listening circles,
- providing training across the initiative and serving as support to Task Forces and Committees,
- implementing local and community-focused awareness campaigns,
- developing community engagement materials and products, and
- creating and facilitating engagement methods for specific RECOVER activities.

Strategy 3: Establish formal engagement mechanisms and processes

Patient, Caregiver, and Community Representatives

Patient, Caregiver, and Community Representatives are involved across all levels of the RECOVER Initiative, including the Executive Committee, Steering Committee, Task Forces and Oversight Committees, and on Community Advisory Boards at RECOVER study sites (**Figure 1**).

Figure 1. Formal Engagement Mechanisms



RECOVER is committed to ensuring that Representatives are diverse in their education level, cultural identity, membership in Long COVID advocacy groups, level of experience with Long COVID research, level of engagement in local community advisory boards, and level of engagement with social media.

The first group of Representatives has been nominated by researchers from RECOVER study sites and through input from other researchers working on different initiatives across NIH, such as the Community Engagement Alliance Against COVID-19 Disparities. Every committee on RECOVER includes Representatives. These Representatives hold equal positions with every other committee member, are included in all meetings and correspondence, and are compensated for their time.

The nomination process for Representatives will occur regularly and, in the future, RECOVER will also consider individuals who nominate themselves to be Representatives.

Representatives will bring lived experience and wisdom to the work of the committees or task forces to which they are assigned. RECOVER will also tap Representatives for activities outside their committee functions and ask them to provide insights and guidance at the individual study and/or initiative-wide level. Representatives also will serve as liaisons to their communities, sharing the work of RECOVER.

National Community Engagement Group

RECOVER's National Community Engagement Group (NCEG) will serve as a central forum for Representatives to promote meaningful discussion through authentic partnership and shared decision-making. This group will help the initiative ensure that patients, caregivers, and families are at the center of the work, and that they are able to partner closely with researchers and scientists in the initiative.

The NCEG will place equity and the experience of patients, caregivers, and community members at the center of RECOVER. It will recognize their needs and desires for the research, the strengths their communities bring to building knowledge. And it will acknowledge and consider their lived experiences, which have often been challenged by historic and contemporary wrongs.

Members of the NCEG will also be part of the Executive Committee, Steering Committee, 12 RECOVER Task Force Committees, six RECOVER Oversight Committees, and the PASC Intervention Prioritization Panel. The NCEG will meet monthly.

NCEG members will provide meaningful input into RECOVER research, communication activities, and more, by:

- sharing thoughts from the patient and community points-of-view about the experience of patients with Long COVID
- providing advice and guidance on many study activities, including defining the most relevant research questions, developing appropriate study materials, and suggesting most effective ways to capture information from participants
- ensuring RECOVER study leaders follow the guiding principles mentioned earlier when engaging with the public and participants.

Strategy 4: Establish informal engagement mechanisms and processes

NIH Listening Sessions

RECOVER is hosting a series of Listening Sessions to ensure that we hear from key groups. These sessions are open to the public. During the sessions, a panel of NIH leaders presents information about the initiative and has a moderated Q&A discussion with representatives from different communities.

Community Listening Circles

To provide another critical source of two-way communication with patients and communities, CCPH will host an ongoing series of listening circles with representatives of regional and national minority-serving organizations. This will help us understand what community leaders know about Long COVID and help us establish research priorities and explore future collaborations. Patients and communities can give us information on what they are experiencing, what they need, and what they would hope to see through the RECOVER Initiative's efforts. The prioritized communities will include:

- Black and African American
- American Indian/Alaska Native

- Latinx and Hispanic
- Asian American, Pacific Islander, and Native Hawaiian
- People who live in rural areas
- People age 55+
- People ages 18–29
- Pregnant people and people with infants

Community Liaisons will be present during the listening circles and will help with interpreting findings and with follow-up. The Engagement Team will feed insights and recommendations to the broader initiative and to relevant committees or task forces so that we may act on the data and make revisions or updates as necessary.

Strategy 5: Refine and expand engagement approaches throughout the life of the initiative

We will plan to refine and expand our engagement strategies so that we hear from patients and communities unable to take part in the activities outlined above. Strategies 3 and 4 will inform Strategy 5 to ensure ongoing touchpoints and opportunities for input from the broader patient and community population.

Although these activities will ultimately depend on the input received from patients and community members, they may potentially include the following options:

- town halls
- a general “inbox” for queries, ideas, concerns, hopes, and needs; the inbox would be “staffed” so that those who submit emails will receive an immediate response, even if the specific answers or actions will take longer to provide
- email newsletters
- workshops or working sessions with patients and community members
- webinars
- local engagement events that bring together RECOVER Representatives, local study sites, and community partners to discuss how to reach communities most affected by COVID and Long COVID.

Process for Receiving and Responding to Inputs from Patients and Community Members

As with any effort to communicate about research work, it’s important for us to receive, respond to, and follow up on input from patients and community members. From Representatives in the governance structure, to participants in community Listening Sessions and Circles, to individuals and organizations at large, we will take all questions, concerns, ideas, and suggestions seriously. We will value and be respectful of the time and energy spent by individuals and groups to make their voices heard.

RECOVER will document the ways in which patient and community input shapes and informs the initiative. This will show transparency and provide opportunities for process improvement.