

Addressing Long COVID: Key Themes and Recommendations from Community Listening Sessions

Executive Summary

This report summarizes discussions with 24 RECOVER Patient and Community Representatives. Most of the listening sessions highlighted persistent, interrelated gaps across healthcare, education, workplaces, and social support. Participants described Long COVID as a chronic condition that is both underdiagnosed and under resourced; children and other special populations are often overlooked and face unique barriers to care and accommodations. Seven themes and a set of priority recommendations for action were generated in partnership with NCEG Co-Chairs. While these findings do not represent all patient perspectives, they generate initial discussions on how to take action with opportunities to learn more from broader Long COVID communities.

Background and Introduction

The RECOVER National Community Engagement Group (NCEG) launched an initiative to gather information from Community Representatives about what is happening related to Long COVID in their communities. To meet this goal, the NCEG, assisted by the RECOVER Administrative Coordinating Center (ACC) Engagement team, implemented a series of 3 listening sessions where Community Representatives were invited to respond to the following questions:

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| <p>① What are you learning that Long COVID patients and families in your community are experiencing and need related to what it takes to get a diagnosis of Long COVID?</p> <hr/> | <p>① What are you learning that Long COVID patients and families in your community are experiencing and need related to their ability to continue to work?</p> <hr/> |
| <p>② What are you learning that Long COVID patients and families in your community are experiencing and need related to the need for financial support because of the inability to continue to work?</p> <hr/> | <p>② What are you learning that Long COVID patients and families in your community are experiencing related to getting help to meet their medical, mental health, social support, and financial needs, as well as to addressing concerns about social determinants of health?</p> <hr/> |
| <p>③ If you were setting priorities for our country to address Long COVID and improve the health and well-being of people and families living with Long COVID, what would be your top priorities?</p> | |

Key Findings

1 Healthcare Providers, Diagnosis, and Treatment

Providers often lack standardized guidance and training for diagnosing and managing Long COVID with competent care, producing fragmented care and delayed treatment. Patients called for standardized clinical pathways to diagnose and treat Long COVID, provider education, and multidisciplinary care models that can address symptoms across intersectional identities of senior, children, and Black, Indigenous, and People of Color (BIPOC) communities across urban and rural geographic areas.

2 Workplace and Financial Impact

Long COVID reduces work capacity and creates financial hardship. Many people struggle to access disability benefits, insurance coverage, workplace accommodations, or other protections for “invisible” disabilities. Participants emphasized the need for assistance navigating disability systems, advocacy support, and policies that recognize fluctuating limitations that make it harder to serve families. These challenges were also tied to the lack of clarity in diagnostic criteria.

3 Pediatrics and School Accommodations

Children with Long COVID are especially vulnerable to being dismissed or mischaracterized (e.g., labeled as lazy or difficult). Families report scarce pediatric-focused resources, limited school-based accommodations, truancy or disciplinary actions due to missed school, and difficulty accessing disability services for students. Participants called for pediatric care coordination and clear school policies to support attendance and learning adjustments, such as remote learning, as well as infection prevention protocols to make educational spaces safe.

4 Mental Health and Social Supports

Long COVID needs extend beyond clinical treatment to include mental healthcare and social support services. For instance, participants shared how lack of validation of their diagnosis has added to emotional distress, trauma, and perceived stigma. Fragmented service systems constrain access to integrated care that can address medical treatment with social determinants of recovery that focus on well-being.

5 Community Education, Stigma, and Engagement

There is a strong and consistent call for expanded community education about Long COVID. Stigma, misinformation, and low public awareness have impeded help-seeking and community support. Participants indicated a need for spaces where patients can share real-time insights about therapies and management strategies they have tried, particularly as formal clinical research continues to evolve. More intentional dissemination of Long COVID resources can strengthen community connection, awareness-building, and support clinical care improvements.

6 Systemic Disparities in Healthcare Access and Care

Structural inequity was cross-cutting across the other themes. As seen across other healthcare challenges, inequities related to race, ethnicity, age, income, language, geography (rural vs. urban), and disability status limit access to diagnosis, treatment, and other services. In the context of Long COVID, participants described a need to treat BIPOC patients with culturally competent care, anti-bias training for clinicians, and availability of providers who share patients’ cultural or linguistic backgrounds.

7 Advocacy and Accountability

Sustained advocacy is needed to secure research funding, build services, and hold systems accountable to communities affected by Long COVID. Participants urged concrete mechanisms for community oversight and provider advocacy on patients’ behalf (e.g., with employers, schools, or benefits systems).

Recommendations for Action



Research Findings and Treatment Advancements

Expand community-led and patient-led research and funding to advance prevention strategies, symptom management, treatment development, and pathways towards a cure.



Provider Education and Long COVID Crisis Response

Implement system-wide provider education and increase accountability to reduce minimizations of conditions and respond appropriately to the ongoing public health crisis of Long COVID.



Access to Care

Expand and simplify access to care by offering continued education for providers, training in culturally competent care, telehealth, virtual care visits, remote patient monitoring, and other options to improve access for rural and urban communities.



Awareness, Education, and Engagement

Launch and sustain large-scale public education campaigns to reduce stigma, improve understanding, prevent Long COVID, and involve key stakeholders.



Disability Rights, Protections, and Support Systems

Fortify disability rights and protections in workplaces, schools, and public spaces, and expand access to financial, mental health, emotional, and other supports.



Infection Prevention and Infrastructure

Implement and normalize effective infection prevention and control practices, improve air quality infrastructure, and add layered prevention strategies.

Conclusion

The listening sessions made clear that Long COVID is a systemic problem that requires coordinated clinical, social, educational, and policy responses and that children, BIPOC communities, rural communities, older adults, and people with limited resources are at greatest risk of being left behind. Rapid action on standardized guidance, multidisciplinary care, workplace and school protections, culturally competent outreach, and community accountability can reduce suffering and prevent long-term social and economic harms. Stakeholders should adopt the prioritized actions above and align funding and accountability measures to ensure equitable implementation.

Acronyms

ACC	Administrative Coordinating Center
BIPOC	Black, Indigenous, and People of Color
NCEG	National Community Engagement Group