

Response to Request for Information [NOT-OD-25-038](#): Inviting Feedback on the Framework for the NIH Strategic Plan for Disability Health Research FY26-FY30**Submitted by the
[Patient-Led Research Collaborative](#)**

Patient-Led Research Collaborative (PLRC) is pleased to address NOT-OD-25-038 seeking feedback on the framework for the NIH Strategic Plan for Disability Health Research FY26-FY30. PLRC's mission is to improve the breadth, depth, and speed of global research into Long COVID and associated conditions, and to advocate for policies and promote patient-centered care that improve the quality of life for Long COVID patients worldwide. PLRC members are people with Long COVID and infection-associated chronic conditions (IACC) who conduct and consult on research on these conditions, work towards advancing frameworks for patient-led and patient-centered research models, and advocate for better policies for the patient population. PLRC's work is grounded in the principles of disability justice and guided by knowledge that those who experience an illness are best able to identify research questions and solutions. We have been engaged with NIH institutes and centers, such as the National Center for Advancing Translational Sciences (NCATS) and the National Institute of Allergy and Infectious Diseases (NIAID). PLRC members serve as patient representatives in RECOVER, have provided expertise to the organization and participated in the RECOVER-TLC workshop¹ and now serve in several RECOVER-TLC working groups. The below summarizes some of our key recommendations for disability health research centered in patients with Long COVID and IACCs. If you have any questions on any of these, please reach out to us at team@patientledresearch.com.

Summary of Recommendations:*PLRC supports and emphasizes:*

- Long COVID as both a risk factor and an outcome of disability, meeting NIH criteria for a health disparity population.
- Severe underfunding of Long COVID disability health research and need for improved strategic planning for Long COVID research funding, requesting necessary congressional appropriations.

PLRC recommends implementing:

- Meaningful engagement with disabled communities, including advisory boards and patient-centered research.
- Accessibility in research: infection prevention (masking, ventilation, testing), meeting access needs, and ensuring ADA compliance.

- Recognition of dynamic disability—fluctuating symptoms, post-exertional malaise (PEM), and its impact on research and patient engagement.
- Research design development that prevents PEM and ensures it is measured as a key disability factor.
- Prioritization of patient-centered Long COVID clinical trials, particularly those on repurposed drugs for curative potential.
- Research on Long COVID in children and youth, with sustained funding for longitudinal studies.
- Disability health research on associations between social determinants of health (SDH)—e.g., housing instability linked to disease severity— and health outcomes for people with Long COVID.
- Ensure inclusion of diverse Long COVID phenotypes by accounting for symptom heterogeneity, severity, and SDH factors.
- Inclusion of homebound and bedbound patients through remote participation options.
- Assessment of disability accommodations needs, barriers to access, and their health consequences.
- Interventions to address ableism in healthcare, including medical education on PEM and Mast Cell Activation Syndrome.
- Development of wearable technologies for disability research and patient data validation.
- Research education funding to develop innovative pedagogical interventions that improve learning outcomes for students with energy limitations and cognitive impairment.
- Grant and fellowship programs to support disabled researchers throughout their careers, from graduate education to senior positions.
- Training and career support for disability health researchers with lived experience
- Inclusion of disabled researchers in grant review panels by adopting accessible panel review models.
- Training opportunities for the research workforce on disability justice, ableism, and accessibility ensuring research environments are inclusive and equitable.

Long COVID is a disabling illness that can develop after a SARS-CoV-2 infection, with disabled people at higher risk of developing it. Data from phase 4.2 of the Household Pulse Survey (HPS) on Long COVID² show that 26% of disabled Americans have ever experienced Long COVID, compared to 16.8% of their non-disabled counterparts. Long COVID impairs functional capacity — among US adults living with Long COVID, 80% experience activity limitations. The prevalence of Long COVID among people with pre-existing disabilities³ is 2.15 times higher than that of the general population. The disproportionately higher risk of Long COVID among disabled Americans likely stems from several factors including greater exposure to SARS-CoV-2 infections, increased vulnerability to COVID-19 disease, pre-existing conditions that increase the risk of Long COVID, and social determinants of health. COVID-19 prevalence is higher among people with learning disabilities than those without, the former also having worse

outcomes of COVID-19 disease than the latter⁴. Accumulating evidence shows that people with certain disabling pre-existing conditions are more likely to develop Long COVID, such as people with connective tissue disorders (OR 1.33, 1.10–1.60)⁵. Some disabling chronic illnesses like⁶ and fibromyalgia are both risk factors for and possible outcomes of Long COVID. Since disability is both a risk factor and an outcome of Long COVID, a significant portion of people with Long COVID may qualify as a health disparity population according to the NIH⁷. In order to implement this strategic plan, adequate funding is necessary and should be requested by NIH to Congress. Despite Long COVID-associated disability burden, in 2023 Long COVID had received only 10% of NIH research funding expected based on its impact measured in years lived with a disability⁸. Similarly, ME/CFS—a highly disabling IACC that is frequently diagnosed among people with Long COVID—received in 2023 less than 1% of the funding its impact would justify⁸. NIH must designate funding for disability health research commensurate with Long COVID's burden and long-term impacts in the American population.

With this in mind, we provide the following feedback on the draft framework for the strategic plan:

I. The appropriateness of the draft framework's cross-cutting themes and additional themes to consider.:

- 1) *Public Participation and Community Engagement*. PLRC strongly recommends meaningful engagement with people with pre-pandemic disabilities, people with Long COVID, and people disabled by COVID-19 through patient-centered research praxis. We encourage community based participatory research and engagement with the disability community (e.g. community advisory boards) to set immediate research priorities and long-term agendas. Accessibility of community advisory boards must take into account episodic illness and dynamic disability⁹. Early engagement is crucial, as well as sustained engagement throughout the research cycle and development of research agendas. We recommend applying the Patient-Led Research Scorecards¹⁰ (discussed below) as guidelines and measurable metrics of meaningful engagement. The documents “*Meaningful Involvement of Patient Advocates (MIPA) in RECOVER: Summary of Structural Proposal*”¹¹, submitted by Body Politic and the Patient-Led Research Collaborative in November 2021, and “*Engaging People With ME As Partners in the Collaborative Research Centers*”¹², developed by #MEAAction, should be used as a reference in the design of engagement strategies with people with Long COVID and IACCs.
- 2) *Accessibility*. It is essential that NIH institutes and centers ensure that patients with Long COVID and IACCs have their access needs met in all stages and modalities of research engagement. The following are high priority access recommendations:
 - a) SARS-CoV-2 infection prevention through masking and improved ventilation and air filtration is essential. Regular testing of personnel and patients should be implemented in research facilities. Patients should be informed beforehand about



masking policies and other infection prevention precautions at research sites and meetings (e.g. see FAQ from Cohen Center for Recovery from Complex Chronic Illnesses¹³). COVID-19 reinfections increase the odds of Long COVID and worsen disease outcomes for people with Long COVID^{14–16}. All measures of risk reduction should be taken to prevent reinfection and other airborne diseases. Meet the patient's access needs with preparedness, given the most frequent access needs¹⁷ of people with Long COVID, as well as with flexibility and adaptability, given the diversity of disabilities in the patient community. At minimum, ensure that research facilities and meeting venues follow ADA guidelines, especially those for Wheelchairs, Mobility Aids, and Other Power-Driven Mobility Devices¹⁸. Make a commitment to meet patient's access needs¹⁹ and to be transparent upfront about how patients can inquire about accessibility and accommodations.

- b) Account for limited energy and symptoms of cognitive dysfunction frequently experienced by many people with Long COVID. In the context of patient engagement and research communication, consider using plain-language summaries²⁰, and virtual (and virtually asynchronous) over in-person engagement.
 - c) Research efforts tend to exclude patients who are homebound or bedbound. Studies must be designed to accommodate moderate to severe patients, who may have limited mobility or no capacity to visit research sites. Possible accommodations include at home sampling/visits, virtual questionnaires, and several modalities of communication.
 - d) Work with patients to mitigate triggers of post-exertional malaise (PEM) and Mast Cell Activation Syndrome, including sensory sensitivities (e.g. light, noise, scent/chemical).
- 3) *Complexity and Heterogeneity*. Long COVID's multiple and potentially overlapping pathophysiology associates to its diverse phenotypic presentations, which vary in symptom number and type, severity, and disability impact. Symptom heterogeneity, functional impairment and disease severity may also be associated with social determinants of health (SDH). Disease phenotypes and subgroups should be accounted for in disability health research.
- 4) *Dynamic disability*. PLRC enthusiastically supports *dynamic disability* as a cross-cutting theme. Long COVID is a dynamic disability in which symptom presence and severity can fluctuate over time due to exogenous factors (e.g. weather, allergens) or factors that are endogenous (e.g. hormone fluctuations) or disease-associated (e.g. latent infections, post-exertional malaise–PEM). Thus, dynamic disability in Long COVID must be taken into account in research design and in patient engagement. PEM is a pathophysiological state where there is delayed worsening or appearance of symptoms in response to physical or cognitive exertion that was once tolerated prior to disease onset. At least 50% of people experience PEM, which is linked to fluctuations in symptoms and

functional capacity. More importantly, PEM must not only be prevented—avoiding iatrogenic harm—but also must be accounted for in disability health research. PEM must be measured as it is a highly disabling disease state.

II. The appropriateness of the draft framework’s strategic goals and potential opportunities, including potential benefits, drawbacks, or challenges, and additional goals or opportunities to consider.

Goal #1: Support high-quality, innovative, and impactful research to improve the health and well-being of people with disabilities of all ages.

We believe this goal is an appropriate strategic goal. Subgoals should include:

- Support for patient-centered Long COVID clinical trials must be a high priority to improve health outcomes of people with Long COVID. Patients have been advocating for clinical trials of pharmaceutical interventions with curative potential²¹, with trials targeting improvement of symptoms being second priority. Long COVID patients have emphasized the need for advancing clinical trials with repurposed drugs^{22,23}, which offer lower development costs and faster approval timelines. Currently, many patients are already using drugs off-label. From increased efficiency of intervention selection to improved study design, patient-centered clinical trials²³ with meaningful patient engagement have the greatest transformative potential to move the field forward toward the approval of curative interventions.
- Assess the current and projected need for disability accommodations and services among people with Long COVID, identifying barriers to access and emerging gaps in support. Simultaneously, determine the health impacts accrued by lack of access to disability accommodations, and design and test interventions to address barriers and improve health outcomes. People with Long COVID face multiple structural and institutional barriers obtaining accommodations and protections²⁴ under the ADA, Section 504, and Section 1557²⁵. Such challenges and their compound negative health outcomes must be measured and documented in order to design effective interventions that can address them.
- Study the impact of Long COVID on the health and quality of life of children and youth, and safeguard longitudinal disability health research programs across the lifespan. As of February 2024, up to 5.8 million of children in the US²⁶ were living with Long COVID, which has been documented to have a long-lasting disease burden in children²⁷, with pathophysiology similar to that documented in adults²⁸.
- Use strategic funding programs to advance understanding and solutions for the impact of social determinants of health on Long COVID health outcomes and quality of life. To date, there has been little incentive to research SDH associations with Long COVID phenotypic presentations, disease severity, and disability. The scarce data available demonstrate the profound associations between Long COVID and SDH factors. People with Long COVID are more likely to face housing insecurity²⁹ and instability³⁰, including lack of stable housing or concerns of losing it. Increased housing insecurity³¹ has been

associated with moderate or severe functional limitation in Long COVID. They are also more likely to experience inaccessible housing and issues like pests and mold, with worsening of housing conditions linked to symptom deterioration³⁰.

- We enthusiastically support interventional research to address ableism in the medical system, and encourage medical education on dynamic disability, and complex disease states such as post-exertional malaise and flare-ups of mast cell activation syndrome.
- We support development and leveraging of existing wearable technologies in disability health research. Patients often use data from wearable devices to manage their health, but often encounter barriers among health care practitioners in validating patient-data from wearable technology. Clinical validation of wearable data in the context of Long COVID could also assist patients in documenting limitations in functional capacity and accessing disability protections.

Goal #2: Build and sustain meaningful internal and external partnerships to promote disability health research.

We support this goal.

Goal #3: Promote engagement and inclusion of people with disabilities in the biomedical and behavioral research ecosystem.

We support this goal. We recommend that research projects apply the Patient-Led Research Scorecards¹⁰ developed by the Council of Medical Specialty Societies (CMSS) and PLRC to evaluate engagement of patients and stakeholders in research. The Patient-Led Research Scorecards¹⁰ provide a numeric rubric for evaluation according to four central themes of meaningful research engagement: 1) shared decision-making power and governance, 2) integration into the research process from design through analysis and reporting, 3) participation burden, accessibility, and trauma-informed engagement, and 4) research organization/institutional readiness to enable meaningful stakeholder engagement. Scorecards can be used as a requirement in grant applications (e.g. Rehabilitation Science Research Network for COVID, Catalyst Grant Funding Opportunity³²), to design research programs with meaningful patient engagement, and to conduct evaluation of patient engagement in ongoing research programs (e.g. REVERSE-LC Trial³³).

Goal #4: Develop a highly skilled scientific workforce that includes researchers with disabilities and researchers trained in disability health research.

We support this strategic goal. Strategic policies that warrant accessibility in the workplace and support the careers of disabled people will be essential to develop a workforce that is equitable and inclusive of disabled people. This starts with ensuring that people with Long COVID and

infection associated-chronic conditions (IACCs) are able to pursue higher education. To safeguard long-term development of a scientific workforce that meaningfully includes disabled researchers, we strongly recommend research education funding to support innovative pedagogical interventions that improve learning outcomes for the growing number of students with IACC-related energy limitation and impaired cognition³⁴. We also recommend grant and fellowship programs that support career pathways of current and future cohorts of disabled researchers, from graduate-level education to career seniority. We strongly recommend programs to train and support the careers of disability health researchers with lived experience. PLRC also recommends that the NIH adopts models of research grant evaluations that enable the meaningful participation of disabled researchers as panelists. Chronically ill and disabled people are rarely given decision-making power in biomedical research funding, leading to patient priorities being overlooked and under-researched. This hinders progress in understanding diseases and improving patient quality of life. PLRC has successfully implemented a model of patient-led panel through the Patient-Led Research Fund for Long COVID (PLRF) – which disbursed \$5 million to ten innovative biomedical research projects. Research projects were awarded by the PLRF through a rigorous and thorough review process developed by patient-panelists with Long COVID and other IACCs who also had relevant research backgrounds—a shift from the typical dynamic in biomedical funding, where researchers with lived experience seldom participate in panels because the process itself of panel review is largely inaccessible to disabled and chronically ill people. To warrant the success of these programs, it will be essential to foster training opportunities for the current research workforce in disability justice, ableism, and accessibility.

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