Response to the National Library of Medicine (NLM) RFI NOT-LM-24-001
Inviting Input to Maximize the Effectiveness and Efficiency of the Network of National Libraries
of Medicine (NNLM)

Submitted by the
Patient-Led Research Collaborative
August 30, 2024

Important priorities that NNLM should address, including those related to the NLM Strategic Plan 2017-2027, the USCD Long Range Plan, the NIH-wide Strategic Plan, changes and advancements in technology, changes and advancements in health and healthcare, topics of importance to you and your communities, and other related skill and knowledge needs.

NNLM can help accelerate Long COVID research. NNLM can support centralized digital repository of Long COVID research by creating a National Long COVID Research Database, following the NNLM's first strategic pillar to accelerate data-driven discovery and human health and leveraging the infrastructure from the NLM National Center of Biotechnology Information and the NNLM National Center for Data Services. A National Long COVID Research Database would facilitate the coordination of interdisciplinary research while maximizing use of data and catalyze data-driven discovery[1]. Integration platforms that can support storage of de-identified individual-level data from innovative imaging technologies, next-generation sequencing, and clinical studies can accelerate research into pathophysiology, treatments and cures of Long COVID.

NNLM can help improve public health education on Long COVID. Public awareness on Long COVID is lacking, causing delays in care and support. A survey of 2,828 U.S. adults showed that 37.5% had never heard of Long COVID, despite its wide impact. Long COVID awareness was less likely among Black and Hispanic participants, and those of lower educational attainment and income. Contrasting these data, Household PulseSurvey Phase 4.1 data show that Long COVID prevalence is the highest among Hispanics or Latinos (35.1%, 95%CI=32.2–38.0) compared to any other race or ethnicities surveyed, and that Long COVID prevalence is lowest among those with a bachelor's degree or higher (24.3%, 95%CI=23.5–25.2) compared with those with a high school diploma or GED (32.7%, 95%CI=30.7–34.7), or those with less than a high school education (43.6%, 95%CI=38.0–49.3).

NNLM can help improve healthcare education on Long COVID and infection associated chronic conditions. Most healthcare providers are not confident about diagnosing or treating Long COVID. In a survey of 806 U.S. physicians, only 7% and 4% reported being "very

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[1] Ziyad Al-Aly et al., "Long COVID Science, Research and Policy," *Nature Medicine*, August 9, 2024, https://doi.org/10.1038/s41591-024-03173-6.

confident" in diagnosing and treating Long COVID, respectively[2]. Long COVID care is often fragmented, with poor care coordination, and clinicians who struggle to manage the multiple symptoms and comorbidities presented by people with Long COVID[3]. Negative interactions with healthcare providers are frequently reported among people with Long COVID. In a survey of 5,638 people with Long COVID, 52.9% participants reported having at least one negative interaction with a healthcare provider[4]. In the same study, having a positive interaction with a healthcare provider was associated with odds of depression symptoms, highlighting the importance of provider interactions in the health of people with Long COVID. Long COVID care is hindered by healthcare professional's lack of recognition and education about Long COVID and infection-associated chronic conditions, with many Long COVID cases being undiagnosed or misdiagnosed[1].

Strategies that NNLM could employ to collaborate with new and existing participants including libraries, health organizations, and community organizations to reach health professionals and public health practitioners, researchers, information professionals, and the public more effectively.

Supporting NNLM's strategic pillar to use person-centric and community-conscious design to deliver actionable health information, NNLM can collaborate with Long COVID patient-led organizations to create a toolkit of library resources with public health information about Long COVID. Long COVID public health education needs include its definition, main symptoms, prevention, how and where to get a diagnosis, healthcare centers that provide Long COVID care, and how to search for clinical trials for Long COVID. Public health education for Long COVID in children and adolescents is especially lacking. The general public can be engaged more effectively with resources that inform and direct them to services that can assist them in getting care tailored to people with Long COVID. Additionally, partnering with patient organizations to publish a living systematic review of Long COVID research could help keep providers, patients, and the broader public up-to-date on research in an accessible and digestible way.

NNLM can also play a pivotal role in outreach efforts to increase patient engagement opportunities both in research studies and in development of public health policies for people with Long COVID. NNLM should encourage dissemination of Long COVID research results to include plain language summaries, preferably reviewed by community members, and where research questions and results are clearly stated and applicable to populations. Additional

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[2] de Beaumont, "Poll: Physicians Agree Long COVID Is a Problem but Are Unprepared to Treat It: More Research Funding and Medical Training Needed," 2023, https://debeaumont.org/news/2023/long-covid-poll/.

[3] Ann M. O'Hare et al., "Complexity and Challenges of the Clinical Diagnosis and Management of Long COVID," *JAMA Network Open* 5, no. 11 (November 3, 2022): e2240332, https://doi.org/10.1001/jamanetworkopen.2022.40332.

[4] Yochai Re'em et al., "Factors Associated with Psychiatric Outcomes and Coping in Long COVID," *Nature Mental Health* 1, no. 5 (May 2023): 361–72, https://doi.org/10.1038/s44220-023-00064-6.

resources like links, visuals, and infographics should address common community questions and provide guidance on understanding and using research findings.

Through the NNLM, Long COVID research results can be proactively disseminated through grant programs and community health workers, with findings aggregated on easily searchable platforms such as ME-pedia.org. Educational programs and awareness could be raised about the libraries' role in research access, and UX/UI protocols should be established to facilitate navigation of important article sections. Documents must meet WCAG accessibility standards, include glossaries, and offer audio versions. Additionally, articles referenced in research papers should be freely accessible or accompanied by plain language summaries. Finally, we recommend that participants should have access to their data, and preprints should be encouraged.

Strategies that could be used to collaborate with and address the needs of minority and underserved populations.

Through All of Us, NNLM can improve the reach of public health information about Long COVID to minority and underserved populations. In collaboration with Long COVID patients and community organizations, NNLM can develop culturally sensitive resources geared to marginalized populations. These materials can be distributed in public libraries within the NNLM. Another relevant strategy is training of library personnel (i.e. librarians, social workers) to improve the delivery of health information and healthcare resources about Long COVID. Participating libraries can also hold public Long COVID information meetings and support Long COVID patient-led support groups.

Components of a 21st century medical library, including services and resources that could be offered to a variety of audiences.

Supporting the NLM legislative mandate to disseminate biomedical information, NNLM can collaborate with Long COVID patient-led organizations to add a packet of publications to every public library, covering Long COVID, infection-associated chronic conditions, and disability justice.

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Thank you again for the opportunity to provide feedback. We look forward to working alongside NNLM to solve Long COVID and other IACCs.

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