PROGRAM PROFILE

Confronting Uncertainty and Addressing Urgency for Action Through the Establishment of a VA Long COVID Practice-Based Research Network

Allison M. Gustavson, PT, DPT, PhD[a,b]; Alicia B. Woodward-Abel, MPH[a]; Tammy L. Eaton, PhD, MSc, FNP-BC[c,d]; Troy Layouni, MPH[e]; Sena Soleimannejad, MPH[f]; Carla Amundson, MA[a]; Emily Hudson, PhD[a]; Megan Miller, PhD[e,g]; Collin Calvert, PhD, MPH[a,b]; Marianne Goodman, MD[f,h,i]; Timothy J. Wilt, MD, MPH[a,b]; Norbert Bräu, MD, MBA[f,i]; Kristina Crothers, MD[e,g,j]; R. Adams Dudley, MD, MBA[a,b]; Aaron P. Turner, PhD[e,g]

Background: Learning health systems (LHS) show promise in making sense of uncertainty and emerging evidence in complex conditions. Long COVID challenges how care is delivered. The Veterans Health Administration has funded a Long COVID Practice-Based Research Network (LC-PBRN) to create an LHS-based infrastructure to promote interdisciplinary collaboration (eg, multidisciplinary clinicians, researchers, operational partners, policymakers, and intra-agency workgroups).

Observations: This article describes the LC-PBRN model, outlines associated lessons learned, and provides suggestions to assist with future PBRN implementations. Lessons learned include incorporating veterans' voices to ensure network efforts align with patient needs, developing an interdisciplinary leadership team to foster diverse viewpoints, setting clear expectations and goals with partners, and building engaging relationships to bridge gaps between internal and external partners.

Conclusions: The LC-PBRN experience can inform the evolving role of other PBRNs as an integral part of building and sustaining LHS infrastructure.

Learning health systems (LHS) promote a continuous process that can assist in making sense of uncertainty when confronting emerging complex conditions such as Long COVID. Long COVID is an infection-associated chronic condition that detrimentally impacts veterans, their families, and the communities in which they live. This complex condition is defined by ongoing, new, or returning symptoms following COVID-19 infection that negatively affect return to meaningful participation in social, recreational, and vocational activities.[1,2] The clinical uncertainty surrounding Long COVID is amplified by unclear etiology, prognosis, and expected course of symptoms.[3,4] Uncertainty surrounding best clinical practices, processes, and policies for Long COVID care has resulted in practice variation despite the emerging evidence base for Long COVID care.[4] Failure to address gaps in clinical evidence and care implementation threatens to perpetuate fragmented and unnecessary care.

The context surrounding Long COVID created an urgency to rapidly address clinically relevant questions and make sense of any uncertainty. Thus, the Veterans Health Administration (VHA) funded a Long COVID Practice-Based Research Network (LC-PBRN) to build an infrastructure that supports Long COVID research nationally and promotes interdisciplinary collaboration. The LC-PBRN vision is to centralize Long COVID clinical, research, and operational activities. The research infrastructure of the LC-PBRN is designed with an LHS lens to facilitate feedback loops and integrate knowledge learned while making progress towards this vision.[5] This article describes the phases of infrastructure development and network building, as well as associated lessons learned.

Author affiliations can be found at the end of this article.
Correspondence: Allison Gustavson (allison.gustavson@va.gov)

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DESIGNING THE LC-PBRN INFRASTRUCTURE

The LC-PBRN is a multisite operation with interdisciplinary representatives from 4 US Department of Veterans Affairs (VA) health care systems. Each site has ≥ 1 principal investigator (0.1-0.4 full-time equivalent [FTE]) and ≥ 1 project staff member (0.5-0.8 FTE). The lead site also employs data and statistical support staff (1.5 FTE). To build this infrastructure, VHA Health Services Research awarded $1 million in November 2023 to the 4 sites. The funding was distributed over 2 years. Additional funding will be required for sustainability. The components and key infrastructure elements of the LC-PBRN are outlined in the Table. The 2-year LC-PBRN implementation activities is outlined in the Appendix.

Vision

The LC-PBRN's vision is to create an infrastructure that integrates an LHS framework

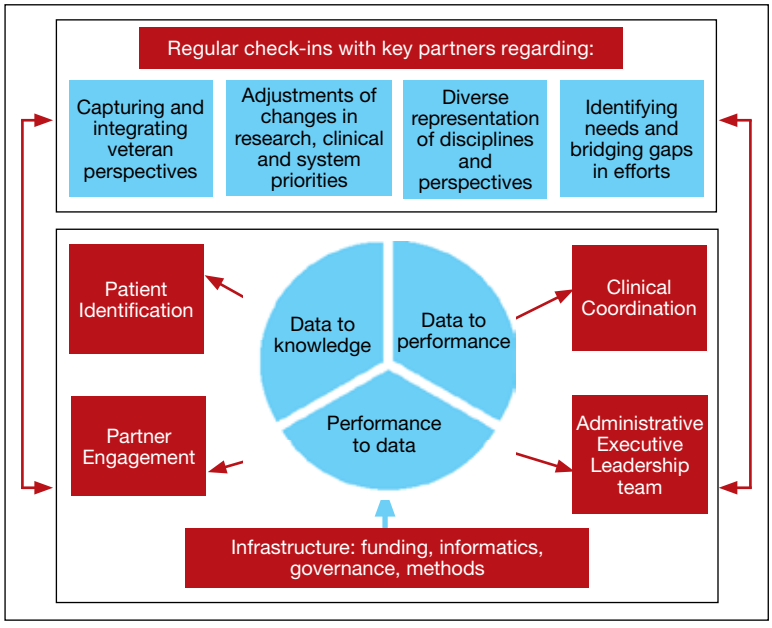

FIGURE 1. Long COVID Practice-Based Research Network activities within the learning health system cycle.

by unifying the VA research approach to Long COVID to ensure veteran, clinician, operational, and researcher involvement (Figure 1). A critical aspect of this is a unifying definition of Long COVID, for which the LC-PBRN has adopted the National Academies of Science, Engineering, and Medicine (NASEM) definition: "Long COVID is an infection-associated chronic condition that occurs after SARS-CoV-2 infection and is present for at least 3 months as a continuous, relapsing and remitting, or progressive disease state that affects one or more organ systems."[6] This is a working definition to be refined over time, as necessary, based on new data. The LC-PBRN aligns with existing VA initiatives by serving as a centralized hub for internal and external networking. This approach ensures shareholder needs are identified, resources are allocated appropriately, and redundancy in efforts is avoided. In this spirit, the LC-PBRN maintains a long-term vision of collaborating with other systems to support national efforts to address Long COVID.

Mission and Governance

The LC-PBRN operates with an executive leadership team and 5 cores. The executive leadership team is responsible for overall LC-PBRN operations, management, and direction setting of the LC-PBRN. The executive leadership team meets weekly to provide oversight of each core, which specializes in different aspects. The cores include: Administrative, Partner Engagement and Needs Assessment, Patient Identification and Analysis, Clinical Coordination and Implementation, and Dissemination (Figure 2).

The Administrative core focuses on interagency collaboration to identify and network with key operational and agency leaders to allow for ongoing exploration of funding strategies for Long COVID research. The Administrative core manages 3 teams: an advisory board, Long COVID council, and the strategic planning team. The advisory board meets biannually to oversee achievement of LC-PBRN goals, deliverables, and tactics for meeting these goals. The advisory board includes the LC-PBRN executive leadership team and 13 interagency members from various shareholders (eg, Centers for Disease Control and Prevention, National Institutes of Health, and specialty departments within the VA).

The Long COVID council convenes quarterly to provide scientific input on important overarching issues in Long COVID research, practice, and policy. The council consists of 22 scientific representatives in VA and non-VA contexts, university affiliates, and veteran representatives. The strategic planning team convenes annually to identify how the LC-PBRN and its partners can meet the needs of the broader Long COVID ecosystem and conduct a strengths, opportunities, weaknesses, and threats analysis to identify strategic objectives and expected outcomes. The strategic planning team includes the executive leadership team and key Long COVID shareholders within VHA and affiliated partners.

The Partner Engagement and Needs Assessment core aims to solicit feedback from veterans, clinicians, researchers, and operational leadership. Input is gathered through a Veteran Engagement Panel and a modified Delphi consensus process. The panel was formed using a Community Engagement Studio model to engage veterans as consultants on research.[7] Currently, 10 members represent a range of ages, genders, racial and ethnic backgrounds, and military experience. All veterans have a history of Long COVID and are paid as consultants. Video

TABLE. Design of LC-PBRN Core Infrastructure

Component	Key Infrastructure Elements
Vision	To centralize Long COVID clinical, research, and operational activities across the VA to ensure shareholder needs are identified, resources are allocated appropriately, and redundancy in efforts is avoided.
Mission and governance	Executive leadership team meets weekly and consists of 5 principal investigators, 4 coinvestigators, and 11 LC-PBRN staff. The team is located at 4 geographically diverse VA facilities. Each core is led by 1 of 5 principal investigators with ≥ 1 coinvestigator and 1 study coordinator. All cores meet at least biweekly. Cores: Administrative, Partner Engagement and Needs Assessment, Patient Identification and Analysis, Clinical Coordination and Implementation, and Dissemination.
Key partners	LC-PBRN Specific: Long COVID council, LC-PBRN advisory board, LC-PBRN sites/clinicians, LC-PBRN pilot sites, LC-PBRN Veteran Engagement Panel. VA Clinical Operations: VA Long COVID Field Advisory Board, VA Long COVID Community of Practice, Office of Specialty Care, Office of Primary Care. VA Research & Interagency Collaborations: VA Office of Research & Development, US Department of Health & Human Services Office of Long COVID Research and Practice, National Institutes of Health.
LHS feedback loops	Maintain channels for communication with key partners. Conduct a modified Delphi process to identify VA research priorities across clinicians, researchers, and veterans. Utilize the Veteran Engagement Panel for research/clinical practice feedback from veterans with Long COVID. Integrate reflection into weekly executive leadership meetings.

Abbreviations: LC-PBRN, Long COVID Practice-Based Research Network; LHS, learning health systems; VA, US Department of Veterans Affairs.

conference panel meetings occur quarterly for 1 to 2 hours; the meeting length is shorter than typical engagement studios to accommodate for fatigue-related symptoms that may limit attention and ability to participate in longer meetings. Before each panel, the Partner Engagement and Needs Assessment core helps identify key questions and creates a structured agenda. Each panel begins with a presentation of a research study followed by a group discussion led by a trained facilitator. The modified Delphi consensus process focuses on identifying research priority areas for Long COVID within the VA. Veterans living with Long COVID, as well as clinicians and researchers who work closely with patients who have Long COVID, complete a series of progressive surveys to provide input on research priorities.

The Partner Engagement and Needs Assessment core also actively provides outreach to important partners in research, clinical care, and operational leadership to facilitate introductory meetings to (1) ask partners to describe their 5 largest pain points, (2) find pain points within the scope of LC-PBRN resources, and (3) discuss the strengths and capacity of the PBRN. During introductory meetings, communications preferences and a cadence for subsequent meetings are established. Subsequent engagement meetings aim to provide updates and codevelop solutions to emerging issues. This core maintains a living document to track engagement efforts, points of contact for identified and emerging partners, and ensure all communication is timely.

The Patient Identification and Analysis core develops a database of veterans with confirmed or suspected Long COVID. The goal is for researchers to use the database to identify potential participants for clinical trials and monitor clinical care outcomes. When possible, this core works with existing VA data to facilitate research that aligns with the LC-PBRN mission. The core can also use natural language processing and machine learning to work with researchers conducting clinical trials to help identify patients who may meet eligibility criteria.

The Clinical Coordination and Implementation core gathers information on the best practices for identifying and recruiting veterans for Long COVID research as well as compiles strategies for standardized clinical assessments that can both facilitate ongoing research and the successful implementation of evidence-based care. The Clinical Coordination and Implementation core provides support to pilot and multisite trials in 3 ways. First, it develops toolkits such as best practice strategies for recruiting participants for research, template examples of recruitment materials, and a library of patient-reported outcome measures, standardized clinical note titles and templates in use for Long COVID in the national electronic health record. Second, it partners with the Patient

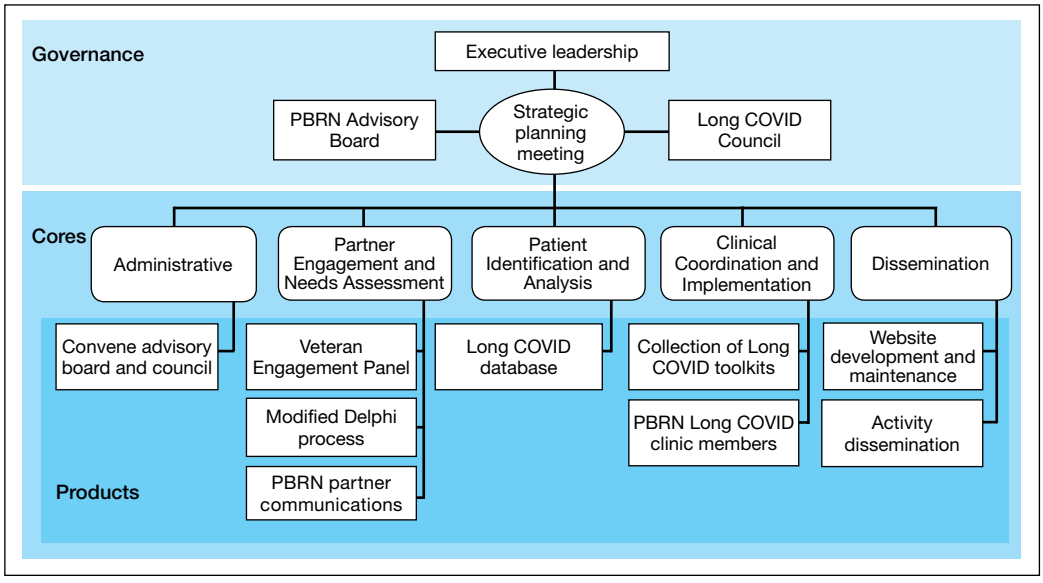

FIGURE 2. Long COVID Practice-Based Research Network (PBRN) Organizational Structure and Products

Identification and Analysis core to facilitate access to and use of algorithms that identify Long COVID cases based on electronic health records for recruitment. Finally, it compiles a detailed list of potential collaborating sites. The steps to facilitate patient identification and recruitment inform feasibility assessments and improve efficiency of launching pilot studies and multisite trials. The library of outcome measures, standardized clinical notes, and templates can aid and expedite data collection.

The Dissemination core focuses on developing a website, creating a dissemination plan, and actively disseminating products of the LC-PBRN and its partners. This core's foundational framework is based on the *Agency for Healthcare Research and Quality Quick-Start Guide to Dissemination for PBRNs*.[8,9] The core built an internal- and external-facing website to connect users with LC-PBRN products, potential outreach contacts, and promote timely updates on LC-PBRN activities. A manual of operating procedures will be drafted to include the development of training for practitioners involved in research projects to learn the processes involved in presenting clinical results for education and training initiatives, presentations, and manuscript preparation. A toolkit will also be developed to support dissemination activities designed to reach a variety of end-users, such as education materials, policy briefings, educational briefs, newsletters, and presentations at local, regional, and national levels.

Key Partners

Key partners exist specific to the LC-PBRN and within the broader VA ecosystem, including VA clinical operations, VA research, and intra-agency collaborations.

LC-PBRN Specific. In addition to the LC-PBRN council, advisory board, and Veteran Engagement Panel discussed earlier, the LC-PBRN has 8 VA Long COVID clinical sites that have joined the network. As part of the network, these sites gain greater insight into the Long COVID ecosystem within the VA through priority access to the Long COVID Veteran Engagement Panel and recognition as members of the network. The LC-PBRN also meets monthly with pilot projects conducted at other VA facilities to learn more about how Long COVID research is being implemented and identify how the LC-PBRN can assist in troubleshooting barriers.

VA Clinical Operations. To support clinical operations, a Long COVID Field Advisory Board was formed through the VA Office of Specialty Care as an operational effort to develop clinical best practice. The LC-PBRN consults with this group on veteran

engagement strategies for input on clinical guides and dissemination of practice guide materials. The LC-PBRN also partners with an existing Long COVID Community of Practice and the Office of Primary Care. The Community of Practice provides a learning space for VA staff interested in advancing Long COVID care and assists with disseminating LC-PBRN to the broader Long COVID clinical community. A member of the Office of Primary Care sits on the PBRN advisory board to provide input on engaging primary care practitioners and ensure their unique needs are considered in LC-PBRN initiatives.

VA Research & Interagency Collaborations. The LC-PBRN engages monthly with an interagency workgroup led by the US Department of Health and Human Services Office of Long COVID Research and Practice. These engagements support identification of research gaps that the VA may help address, monitor emerging funding opportunities, and foster collaborations. LC-PBRN representatives also meet with staff at the National Institutes of Health Researching COVID to Enhance Recovery initiative to identify pathways for veteran recruitment.

LHS Feedback Loops

The LC-PBRN was designed with an LHS approach in mind.[10] Throughout development of the LC-PBRN, consideration was given to (1) capture data on new efforts within the Long COVID ecosystem (performance to data), (2) examine performance gaps and identify approaches for best practice (data to knowledge), and (3) implement best practices, develop toolkits, disseminate findings, and measure impacts (knowledge to performance). With this approach, the LC-PBRN is constantly evolving based on new information coming from the internal and external Long COVID ecosystem. Each element was deliberatively considered in relation to how data can be transformed into knowledge, knowledge into performance, and performance into data.

First, an important mechanism for feedback involves establishing clear channels of communication. Regular check-ins with key partners occur through virtual meetings to provide updates, assess needs and challenges, and codevelop action plans. For example, during a check-in with the Long COVID Field Advisory Board, members expressed a desire to incorporate veteran feedback into VA clinical practice recommendations. We provided expertise on different engagement modalities (eg, focus groups vs individual interviews), and collaboration occurred to identify key interview questions for veterans. This process resulted in a published clinician-facing Long COVID Nervous System Clinical Guide (available at longcovid@hhs.gov) that integrated critical feedback from veterans related to neurological symptoms.

Second, weekly executive leadership meetings include dedicated time for reflection on partner feedback, the current state of Long COVID, and contextual changes that impact deliverable priorities and timelines. Outcomes from these discussions are communicated with VHA Health Services Research and, when appropriate, to key partners to ensure alignment. For example, the Patient Identification and Analysis core was originally tasked with identifying a definition of Long COVID. However, as the broader community moved away from a singular definition, efforts were redirected toward higher-priority issues within the VA Long COVID ecosystem, including veteran enrollment in clinical trials.

Third, the Veteran Engagement Panel captures feedback from those with lived experience to inform Long COVID research and clinical efforts. The panel meetings are strategically designed to ask veterans living with Long COVID specific questions related to a given research or clinical topic of interest. For example, panel sessions with the Field Advisory Board focused on concerns articulated by veterans related to the mental health and gastroenterological symptoms associated with Long COVID. Insights from these discussions will inform development of Long COVID mental health and gastroenterological clinical care guides, with several PBRN investigators serving as subject matter experts. This collaborative approach ensures that veteran perspectives are represented in developing Long COVID clinical care processes.

Fourth, research priorities identified through the Delphi consensus process will inform development of VA Request for Funding Proposals related to Long COVID. The initial survey was developed in collaboration with

veterans, clinicians, and researchers across the Veteran Engagement Panel, the Field Advisory Board, and the National Research Action Plan on Long COVID.[11] The process was launched in October 2024 and concluded in June 2025. The team conducted 3 consensus rounds with veterans and VA clinicians and researchers. Top priority areas included the testing assessments for diagnosing Long COVID, studying subtypes of Long COVID and treatments for each, and finding biomarkers for Long COVID. A formal publication of the results and analysis is the focus of a future publication.

Fifth, ongoing engagement with the Field Advisory Board has supported adoption of a preliminary set of clinical outcome measures. If universally adopted, these instruments may contribute to the development of a standardized data collection process and serve as common data elements collected for epidemiologic, health services, or clinical trial research.

LESSONS LEARNED AND PRACTICE IMPLICATIONS

Throughout the development of the LC-PBRN, several decisions were identified that have impacted infrastructure development and implementation.

Include veterans' voices to ensure network efforts align with patient needs. Given the novelty of Long COVID, practitioners and researchers are learning as they go. It is important to listen to individuals who live with Long COVID. Throughout the development of the LC-PBRN, veteran perspective has proven how vital it is for them to be heard when it comes to their health care. Clinicians similarly highlighted the value of incorporating patient perspectives into the development of tools and treatment strategies.

Develop an interdisciplinary leadership team to foster the diverse viewpoints needed to tackle multifaceted problems. It is important to consider as many clinical and research perspectives as possible because Long COVID is a complex condition with symptoms impacting major organ systems.[12-15] Therefore, the team spans across a multitude of specialties and locations.

Set clear expectations and goals with partners to uphold timely deliverables and stay within the PBRN's capacity. When including a multitude of partners, teams should consider each of those partners' experiences and opinions in decision-making conversations. Expectation setting is important to ensure all partners are on the same page and understand the capacity of the LC-PBRN. This allows the team to focus its efforts, avoid being overwhelmed with requests, and provide quality deliverables.

Build engaging relationships to bridge gaps between internal and external partners. A substantial number of resources focus on building relationships with partners so they can trust the LC-PBRN has their best interests in mind. These relationships are important to ensure the VA avoids duplicate efforts. This includes prioritizing connecting partners who are working on similar efforts to promote collaboration across facilities.

Clinical practice implications. The LC-PBRN is working towards clinical practice initiatives derived from this process in partnership with the Long COVID Community of Practice and the participating clinical sites. This may include efforts to increase the uptake of standardized instruments endorsed by clinical partners that facilitate assessment of outcomes. PBRN partners can then use outcomes data to ask and answer clinically relevant research questions and assess care quality to inform the learning process that is integral to an LHS. Future dissemination efforts will be centered around individual initiatives and deliverables from the LC-PBRN.

CONCLUSIONS

PBRNs provide an important mechanism to use LHS approaches to successfully convene research around complex issues. PBRNs can support integration across the LHS cycle, allowing for multiple feedback loops, and coordinate activities that work to achieve a larger vision. PBRNs offer centralized mechanisms to collaboratively understand and address complex problems, such as Long COVID, where the uncertainty regarding how to treat occurs in tandem with the urgency to treat. The LC-PBRN model described in this article has the potential to transcend Long COVID by building infrastructure necessary to proactively address current or future clinical conditions or populations with a LHS lens. The infrastructure can require cross-system and sector

collaborations, expediency, inclusivity, and patient- and family-centeredness. Future efforts will focus on building out a larger network of VHA sites, facilitating recruitment at site and veteran levels into Long COVID trials through case identification, and systematically support the standardization of clinical data for clinical utility and evaluation of quality and/or outcomes across the VHA.

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Author affiliations
[a]Minneapolis Veterans Affairs Health Care System, Minnesota
[b]University of Minnesota, Minneapolis
[c]University of Michigan, Ann Arbor
[d]Veterans Affairs Ann Arbor Healthcare System, Michigan
[e]Veterans Affairs Puget Sound Health Care System, Seattle, Washington
[f]James J. Peters Veterans Affairs Medical Center, Bronx, New York
[g]University of Washington, Seattle
[h]Veterans Integrated Service Network (VISN) 2 Mental Illness Research, Education, Clinical Center
[i]Icahn School of Medicine at Mount Sinai, New York
[j]Seattle-Denver Center of Innovation (COIN) for Veteran-Centered and Value-Driven Care

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APPENDIX. Implementation Timeline

Topic	Project mo
Strategic planning	
Year 1	1-2
Year 2	12-13
Advisory board	
Established	4-6
Meetings	7, 11
Expert council	
Established	5-7
Meetings	8, 12, 16
Veteran Engagement Panel	
Recruitment	8-10
Meetings	12, 16, 19, 22
Delphi	
Recruitment	11-14
Modified process	12-21
Long COVID case identification	19-24
Clinical tool collection	9-21
Clinical site	
Recruitment	14-16
Meetings	17, 20, 23
Website development	1-3
Activity dissemination	19-24