Patient-led partnership models for rebuilding public health trust:

Lessons from Long COVID patient-driven advocacy and the COVID-19 pandemic

Meaningful Long COVID patient engagement must be integrated into every stage of solution-building—from brainstorming and planning to recruitment, outreach, analysis, dissemination, and long-term follow-through. The lived experiences of patient are not just perspectives but essential data points that ground research, policy, and clinical practice in real-world impact. By collaborating with patients as equal partners, stakeholders can design efforts that are better informed, more efficient, and responsive to actual needs. This approach reduces wasted resources, accelerates effective solutions, and ensures gaps in care and research are closed. Most importantly, it helps prevent the progression of disease, disability, and death, turning collective knowledge into collective progress.

C19 LAP — Long COVID Collaborative Associations

LONGHAULER ADVOCACY PROJECT — COVID-19

www.longhauler-advocacy.org

Long COVID Data

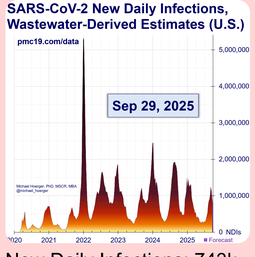
- Develop Long COVID, reinfections increases risk (CDC)
- Rise in U.S. disability rate since 2020 (FRED)

- Children reporting ADL limitations (NIH)

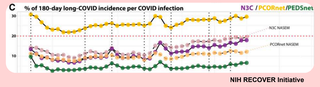
- Number of clinicians that felt equipped to identify Long COVID (AHRQ)

- Estimated 2024 Cost of LC $230B

COVID-19 remains a major threat. Long COVID continues to rise.

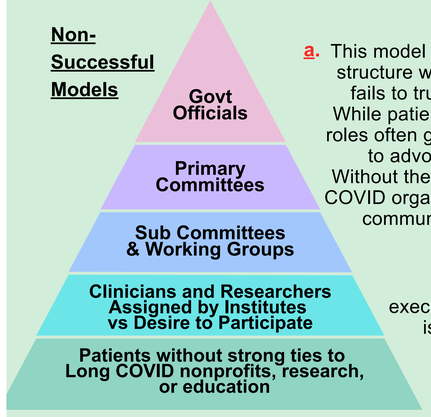


- New Daily Infections: 743k
- Weekly Infections: ^ 5.5M
- New Daily LC Cases: 149k
- New Weekly LC Cases: 1.1M
- Daily Excess Deaths: 350
- Weekly Excess Deaths: 2,600

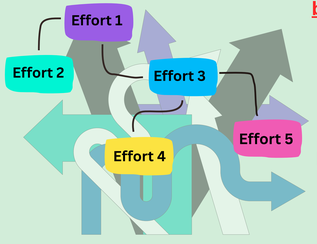


Non-Successful Long COVID Response Models

Non-Successful Models

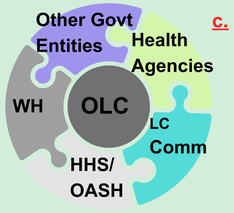


a. This model relies on a steep, multi-tiered structure with numerous committees but fails to truly center patient partnership. While patients are formally included, key roles often go to those without strong ties to advocacy, research, or education. Without the expertise of patient-led Long COVID organizations, decisions drift from community priorities, delaying action. Opaque and unaccountable decision-making leads to tokenism, bias, and stalled execution, where lived experience is absent, priorities distort and progress falters



b. Across the country, efforts like state Long COVID offices, university programs, and CIL initiatives fill local gaps but remain disconnected, uncoordinated, and unsustainable. Lacking collaboration with patient organizations that understand the full Long COVID landscape, they duplicate work, miss systemic needs, and fail to scale. Real progress requires linking these isolated efforts under a unified, patient-led framework.

Previous Semi-Successful Model



c. The most effective model to date was the Office for Long COVID (OLC), which coordinated a whole-of-government, patient-centered approach before being cut in 2025. While promising, the OLC fell short as coordination often stopped at discussion, communications remained siloed, and patients had limited direct access to agencies, with the OLC serving mainly as an intermediary.

Desired Long COVID Response Model & How This Model Restores Public Health Trust

Nothing About Us, Without Us

Trust in public health eroded because systems acted on communities, not with them. This model restores it by making public health responsive, participatory, and transparent, transforming it from an institution people endure into a partnership they believe in. It replaces top-down control with shared governance between patients and cross-sector leaders, rebuilding credibility through collaboration and measurable impact.

- **Lived experience leads:** Patients and caregivers co-design programs, policies, and research priorities. Their lived knowledge shapes every stage, from planning to evaluation , ensuring that public health reflects real-world needs.
- **Long-term partnership, not consultation:** Patient and community representatives hold standing, compensated roles within agencies, advisory boards, and oversight structures. They remain engaged beyond crises, providing continuity, accountability, and perspective that evolve with time.
- **Information everyone can see:** Transparent dashboards, open data, and plain-language updates make progress visible and measurable. Communities can track results and hold institutions accountable
- **Action, not promises:** Clean-air standards, telehealth expansion, and equitable care pathways demonstrate protection in practice, not rhetoric. When people see change in their settings, confidence follows.
- **Every sector shows up:** Government, healthcare, education, employers, and community organizations coordinate under a shared strategy. This consistency turns fragmented systems into a network people can rely on.
- **Trust through honesty:** Public health acknowledges uncertainty, learns from mistakes, and adjusts visibly proving that integrity is rooted in transparency, not perfection.

We Need You!

Learn How Your Sector Can Help Resources Here!

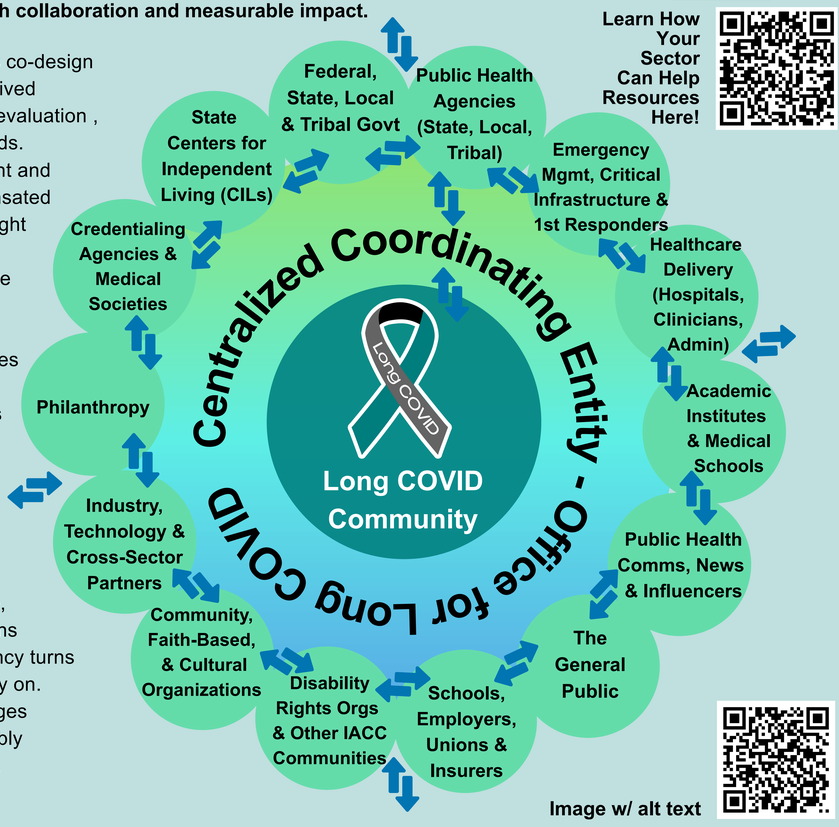


Image w/ alt text

Alt Text (Comprehensive Description):

Title and Authors:

Poster titled “Patient-led partnership models for rebuilding public health trust: Lessons from Long COVID patient-driven advocacy and the COVID-19 pandemic,” created by the COVID-19 Longhauler Advocacy Project (C19LAP). The poster prominently features C19LAP’s logo and website (www.longhauler-advocacy.org) in the top-right corner, alongside the tagline emphasizing patient-driven systems change.

Overall Layout and Background

The poster is designed with a three-column structure flowing from left to right, using a teal and turquoise color scheme with red and purple accents. It visually contrasts non-successful models of Long COVID response with a desired, patient-led partnership model that rebuilds public health trust.

The background includes shaded boxes, arrows, icons, and data graphics illustrating the evolution from disconnected, top-down systems toward a coordinated, patient-centered framework.

Left Column: Long COVID Data and Failed Response Models

1. “Long COVID Data” (Top Left Blue Box):

Lists key national statistics:

- 20%: Developed Long COVID after infection (CDC).
- 80%: Children reporting ADL (Activities of Daily Living) limitations (NIH).
- 15%: Clinicians felt equipped to identify Long COVID (AHRQ).
- Estimated 2024 cost of Long COVID: $230B (FRED).
- Notes that COVID-19 remains a major threat and Long COVID continues to rise.
- A small chart shows U.S. SARS-CoV-2 daily infections and wastewater-derived case estimates with the latest date labeled September 29, 2025.
- Below it, weekly and daily national metrics are shown (e.g., 743K new daily infections, 2,600 daily deaths).

2. “Non-Successful Long COVID Response Models” (Center Left, Purple Gradient Box):

Diagram of a hierarchical pyramid structure labeled “Non-Successful Models.”

Top tier: Govt Officials.

Second tier: Primary Committees.

Third: Subcommittees & Working Groups.

Fourth: Clinicians and Researchers Assigned by Institutes.

Base: Patients without strong ties to Long COVID nonprofits, research, or education.

This pyramid symbolizes a disconnected, bureaucratic structure that sidelines patient leadership.

3. Corresponding Narrative (a, b, c subsections):

- (a) Describes the multi-tiered model as steep and opaque, failing to center patient partnership, leading to tokenism, bias, and slow or stalled progress.
- (b) Explains how scattered efforts—like state Long COVID offices, university groups, and Centers for Independent Living—fill local gaps but are disconnected, uncoordinated, and unsustainable. Without collaboration with patient organizations holding comprehensive landscape data, they cannot scale or sustain impact.
- (c) Highlights that the most effective prior model, the Office for Long COVID (OLC) within HHS/OASH, coordinated a whole-of-government response but was cut in 2025. It notes that communication often stalled, patients lost access, and coordination stopped short of direct action.

A small cluster of five colored bubbles labeled “Effort 1–5” visually represents disconnected, one-off initiatives.

Middle Column: Desired Long COVID Response Model

Header: “Desired Long COVID Response Model & How This Model Restores Public Health Trust” (Teal banner).

Main Statement:

A large block of text explains that trust in public health eroded because systems acted on communities, not with them. This model rebuilds trust by making public health responsive, participatory, and transparent — replacing top-down control with shared governance between patients and cross-sector partners.

Bullet List of Core Principles (accompanied by icons for each):

- Lived experience leads: Patients and caregivers co-design programs, policies, and research priorities.
- Long-term partnership, not consultation: Patients hold standing, compensated roles within agencies, boards, and oversight structures.
- Information everyone can see: Transparent dashboards, open data, and plain-language updates make progress visible.
- Action, not promises: Examples include clean-air standards, telehealth expansion, and equitable care pathways.
- Every sector shows up: Government, healthcare, education, and community orgs coordinate under one strategy.
- Trust through honesty: Institutions own mistakes and evolve with transparency rather than perfection.

To the left, a vertical illustrated checklist runs through stages of brainstorming, planning, recruiting, advertising, facilitation, analysis, dissemination, and longitudinal follow-through, emphasizing the slogan “Nothing About Us, Without Us.”

Right Column: Coordinated Model Diagram

Circular Diagram (Teal Gradient):

At the center is a dark teal circle labeled “Centralized Coordinating Entity – Office for Long COVID” surrounded by another labeled “Long COVID Community.”

These are encircled by sixteen sectors, each connected with arrows symbolizing coordination and shared governance:

1. Federal, State, Local & Tribal Government
2. Public Health Agencies (State, Local, Tribal)
3. Emergency Management, Critical Infrastructure & First Responders
4. Healthcare Delivery (Hospitals, Clinicians, Administrators)
5. Academic Institutes & Medical Schools
6. Public Health Communications, News & Influencers
7. The General Public
8. Schools, Employers, Unions & Insurers
9. Disability Rights Orgs & Other IACC Communities
10. Community, Faith-Based, & Cultural Organizations
11. Industry, Technology & Cross-Sector Partners
12. Philanthropy
13. Credentialing Agencies & Medical Societies
14. State Centers for Independent Living (CILs)

Blue bidirectional arrows between each sector illustrate mutual communication and collaboration with the Long COVID community at the center.

QR Code Section (Top Right Corner):
Labeled “We Need You!” with text inviting viewers to “Learn How Your Sector Can Help Resources Here!” followed by a QR code linking to C19LAP resources.

Overall Message
The poster visually contrasts fragmented, bureaucratic models (left) with a collaborative, transparent, patient-led model (right). It argues that patient leadership restores trust in public health by grounding systems in lived experience, transparency, and long-term partnership across all sectors. The final emphasis: “Investing in patient leadership is not charity—it is strategy.”

Alt Text Summary:
A three-column research poster by C19LAP comparing failed, fragmented Long COVID response systems with a proposed patient-led, cross-sector coordination model. It includes data visuals, flowcharts, and a circular systems diagram centered on a “Centralized Coordinating Entity” that connects patients, government, academia, healthcare, and community partners to rebuild public health trust through transparency, shared governance, and measurable impact.