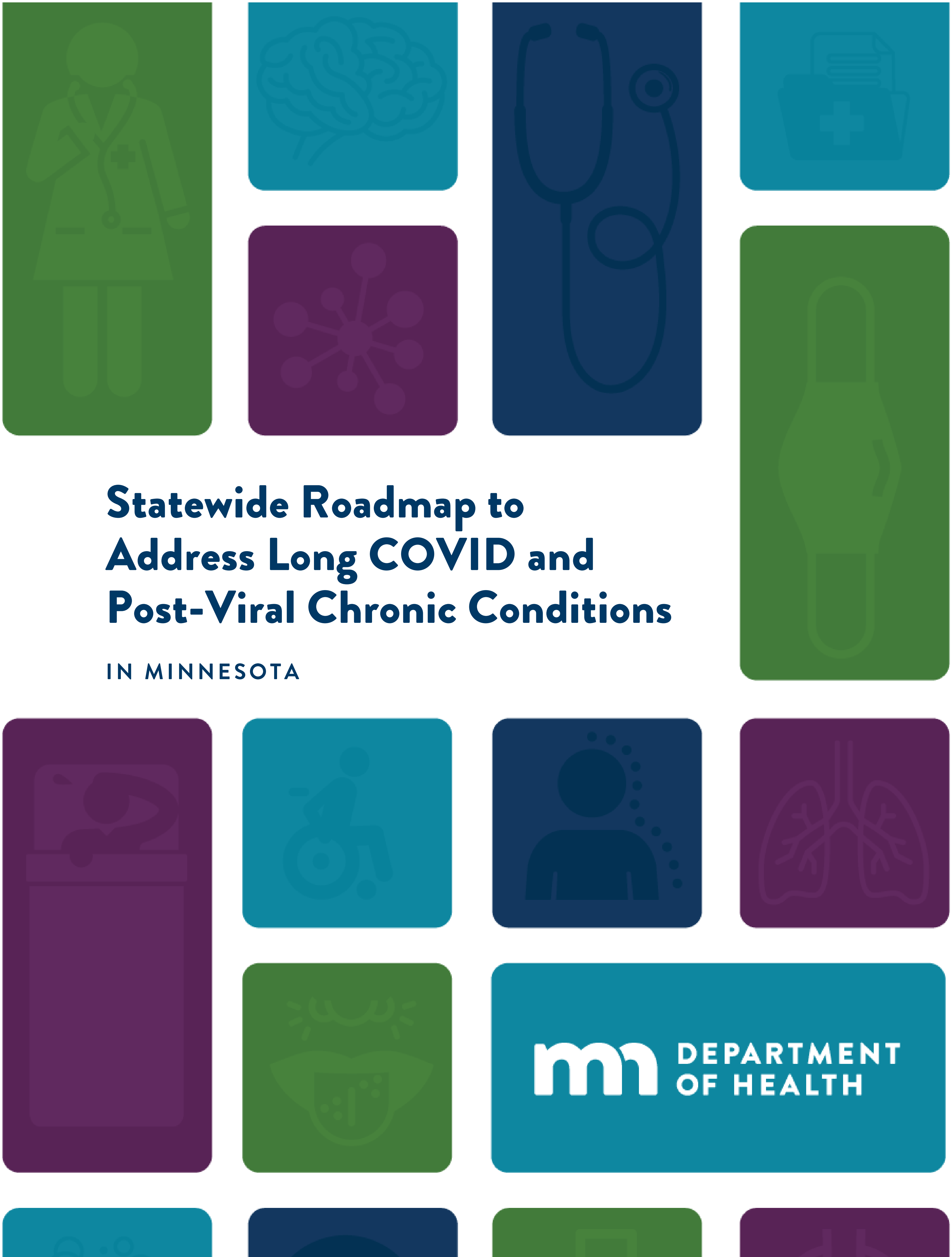

Statewide Roadmap to Address Long COVID and Post-Viral Chronic Conditions

IN MINNESOTA

DEPARTMENT OF HEALTH

Statewide Roadmap to Address Long COVID and Post-Viral Chronic Conditions

May 2026

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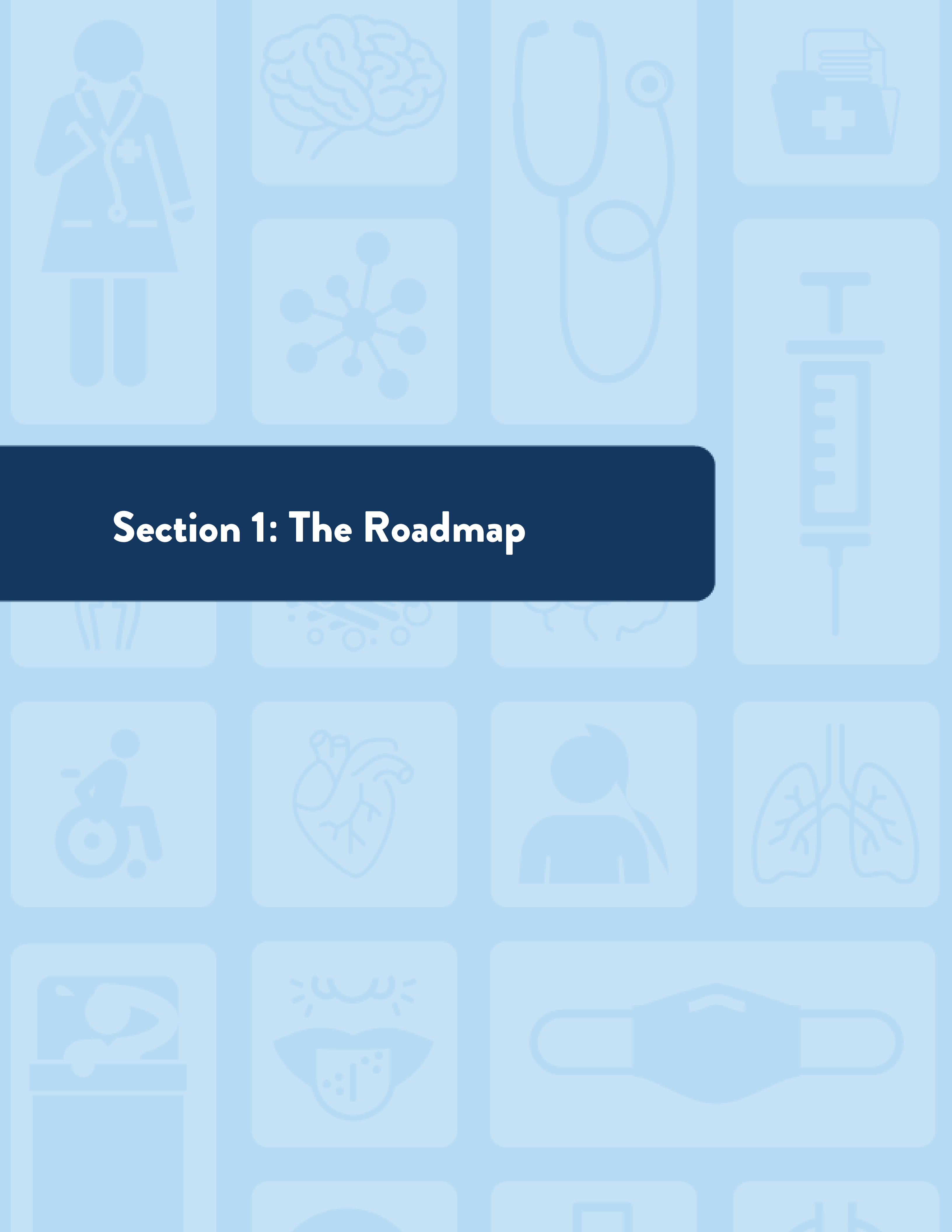


Section 1: The Roadmap

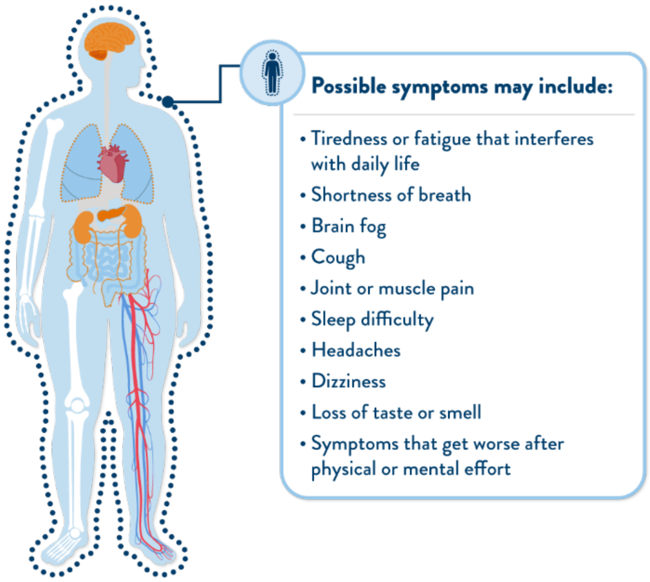
Introduction

In a matter of months, the COVID-19 pandemic brought long COVID, a **post-viral infection-associated chronic condition (IACC)**, to the spotlight. People from all backgrounds and communities who acquired the SARS-CoV-2 virus began experiencing symptoms that lasted for weeks, months, or years after their acute infection.

Millions of people in the United States, including children, have reported life-altering fatigue, **post-exertional malaise (PEM)**, shortness of breath, chronic pain, cognitive impairment (“brain fog”), neurologic dysfunction, heart palpitations, an altered sense of taste and smell, and more. For some, COVID-19 has worsened or lead to the onset of other chronic conditions such diabetes, stroke or blood clots, **myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS**), pulmonary fibrosis, mast cell activation syndrome, **postural orthostatic tachycardia syndrome (POTS)**, and heart disease.

These lasting symptoms can prevent people from working, attending school, and taking care of themselves or their families, leading to profound emotional, physical, and financial impacts on people with post-viral IACCs and those close to them.

Whether symptoms are intermittent or persistent, moderate or disabling, many people with post-viral IACCs face significant challenges obtaining recognition, diagnosis, and appropriate care. Symptoms are often complex, fluctuating, and difficult to measure through conventional clinical approaches. As a result, people frequently encounter delays in diagnosis, fragmented care, uncertainty around treatment and management options, and difficulty accessing the supports needed to maintain daily functioning and quality of life.



Possible symptoms may include:

- Tiredness or fatigue that interferes with daily life
- Shortness of breath
- Brain fog
- Cough
- Joint or muscle pain
- Sleep difficulty
- Headaches
- Dizziness
- Loss of taste or smell
- Symptoms that get worse after physical or mental effort

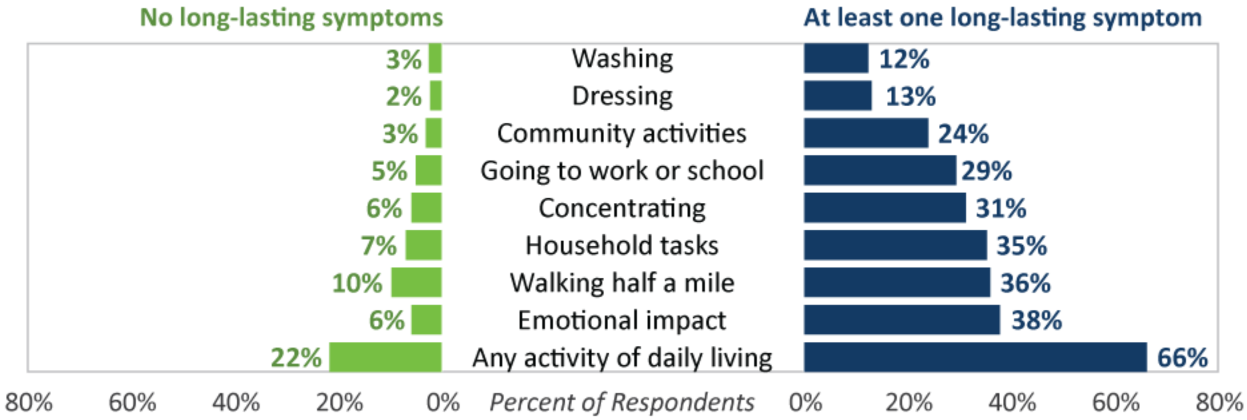
NOTE: This is not a complete list. People may have one or many symptoms. Health conditions other than long COVID can also cause these symptoms.

Did you know?

Post-viral IACCs have been around for centuries. Similar experiences occurred after the 1918 influenza pandemic: scores of accounts describe people suffering from “debilitating lethargy” and “nervous disorders” for years after their infection, children who couldn’t recover lost ground at school, and many who were “never quite the same since [their acute illness].” Other viral outbreaks throughout the last century have continued to add to these chronically afflicted populations, with many suffering from conditions like ME/CFS. As of 2021-2022, an estimated 57,000 Minnesotans have ME/CFS and, as of 2024, an estimated 395,000 Minnesotans may have experienced long COVID, including 17,000 children and youth.

Viral infections like COVID-19 are still with us. The number of people experiencing long COVID and similar conditions continues to grow every year. The impact on a person's daily activities can be substantial. In a survey from the Minnesota Department of Health (MDH), two-thirds of Minnesotans with long-lasting symptoms after COVID-19 had difficulty performing daily activities, such as bathing themselves, performing household tasks, or going to work or school.

People with long-lasting symptoms reported more difficulty with activities of daily living.



Over the last century, diagnosis of post-viral IACCs has been more common in women and often labeled as psychosomatic, perpetuating gender-based stigma and trauma. The COVID-19 pandemic highlighted these and other social and structural inequities, biases, and barriers. Many people had less access to preventive measures, healthcare resources, and social supports due to their age, gender, sexual orientation, race, ethnicity, income, geographic location, disability status, cultural identity, and more. People experiencing these inequities may also be more often dismissed when seeking medical care and services for post-viral IACCs. These challenges are compounded for people who belong to more than one disadvantaged group. When their symptoms are downplayed or are attributed to psychological factors, it can reinforce years of stigma and trauma already experienced by marginalized groups. This discourages patients from seeking further care, and, ultimately, prevents timely diagnosis, alleviation of symptoms, and potential recovery. Such biases can also increase the risk of misinformation and social isolation. It is critical that this work be done through a lens of health equity.

A comprehensive response to post-viral IACCs must also incorporate Principles of **Disability Justice**, including leadership of those most impacted, recognizing wholeness, and applying an intersectional lens that recognizes how an individual's lived experiences and intersecting identities shape their ability to navigate complex medical and social support systems. Beyond healthcare, people with post-viral IACCs often face barriers in education, employment, social relationships, housing, and other basic needs systems. Minnesota must take action to address these challenges because these conditions are affecting the health, community participation, economic stability, and quality of life of Minnesotans. Proactive, coordinated action can reduce long-term societal and economic impacts, improve outcomes for individuals with post-viral IACCs, and ensure people with post-viral IACCs have interdependent pathways to live a full community life.

Recognizing the need for coordinated, cross-sector action, MDH, Management Analysis and Development (MAD), and a steering committee made up of people with post-viral IACCs, health professionals, community representatives, and public health, conducted listening sessions and workgroups to identify gaps, barriers, and opportunities to improve the quality of life for

Minnesotans experiencing post-viral IACCs. Guiding this work is a shared recognition that post-viral IACCs significantly affect Minnesotans and are shaped by socioeconomic and structural inequities. These inequities contribute to stigma, bias, and poor outcomes, and require practical recommendations grounded in social and disability justice.

The result of these efforts is the "Statewide Roadmap to Address Long COVID and Post-Viral Chronic Conditions." This is the first edition of ***'the roadmap'****, and MDH will continue to revisit and update it in future years as funding allows, and implementation progresses.*

PURPOSE & VISION

The ***purpose*** of this roadmap is to identify opportunities to ensure people experiencing post-viral IACCs are seen, believed, diagnosed, receive the medical care they deserve, get the support they need, and are recognized as a whole person who actively participates in their community, regardless of their background.

The ***vision*** for this roadmap is that as diagnostic markers, treatments, cures, and services are pursued for people living with post-viral IACCs, Minnesota can lead as a state where people experiencing these conditions are able to live, learn, and work in communities that understand and respond to their needs. Meanwhile, their health concerns are urgently and comprehensively addressed through an integrated, equitable, and responsive system of providers, insurers, employers, community services, public health, and person-centered care. The vision promotes:

- Minnesotans living with post-viral IACCs engage in and contribute to their communities to their personal fullest, free from stigma.
- Minnesotans living with post-viral IACCs can easily navigate formal, non-clinical, and governmental systems to access the support required for their distinct needs in respectful ways.
- Minnesotans living with post-viral IACCs are served by caring health systems that are resourced and structured to meet their distinct needs in respectful ways, while making tangible progress toward cures and effective treatments.

This vision is centered on people living with post-viral IACCs, yet it also explicitly recognizes opportunities for those dedicated to improving the lives of people with post-viral IACCs and all those who create thriving communities in Minnesota.

Our approach at-a-glance (full details in Appendix A)

The roadmap was developed between May 2025 and May 2026 through a structured, multiphase process led by MDH in partnership with MAD.

The project included people with post-viral IACCs not only as interviewees, but as members of the workgroups and steering committee. The project team was intentional in the selection process to ensure a variety of voices would inform and provide input to this work, including people of color, people with a variety of disabilities, immigrants, people in rural communities, and LGBTQIA+ people. Their unique lived experiences and input helped shape the vision, recommendations, and final revisions of the roadmap.

The project support team adjusted how people could participate, offering flexible timelines, different formats for input, and opportunities to give input over time, to better support access and reduce cognitive burden for contributors.

How workgroups developed the recommendations

Summaries from the initial listening sessions informed each workgroup's discussions, and the workgroups—along with the steering committee—used this input to shape and refine the recommendations presented in this report. The recommendations reflect the impact of these conditions on the whole person across health, daily life, and community systems, not just medical care.

A survey was provided to the listening session participants and other key contributors near the end of the project to gather final feedback on vision statements and priority recommendations. Where possible, this feedback was incorporated into the final report, and all feedback received is summarized in Appendix F.

While final decision-making stayed within the project's formal structure, this work moves toward more inclusive, cross-sector approaches that recognize lived experience, shared responsibility, and the need for more connected systems.

Progress and future

This is not meant to be a roadmap for MDH, nor is it designed as an implementation plan. Rather, it is a starting point that highlights opportunities for action among the public, patient advocacy groups, healthcare providers and health systems, social service providers, insurers, government agencies, decision-makers, teachers, employers, and public health. Others will also need to own and lead these activities. There is a need to increase awareness of post-viral IACCs throughout Minnesota. There is increasing recognition that better identification and diagnosis of post-viral IACCs in primary care is a priority, along with more seamless referrals and integration with well-informed specialty care providers in physical medicine and rehabilitation, neurology, cardiology, pulmonology, psychology, and others. Accurate and valid systems to monitor the health, economic, and social impacts of post-viral IACCs in Minnesota are needed.

The roadmap highlights the need to grow and support a knowledgeable healthcare workforce and to redesign health systems to support a whole-person approach of care for people living with post-viral IACCs. It highlights the need for improved coordination and navigation of medical care with support services and programs required for daily living beyond the clinical encounter. The roadmap highlights the need to streamline processes to attain disability recognition for people affected by post-viral IACCs. The roadmap identifies numerous collaborative opportunities to leverage resources and actions across domains. The roadmap provides recommendations for more efficient, effective, and equitable person-centered approaches to achieve the vision where people living with post-viral IACCS can respectfully live, learn, and work in their communities, free from stigma.

This roadmap will only succeed through coordinated action across sectors and communities. We invite healthcare professionals, policymakers, service organizations, business leaders, community members, people living with post-viral IACCs, and others committed to prevention and management to help champion and implement these recommendations.

How to use this roadmap

This roadmap is designed to support a wide range of audiences working to improve the lives of people living with post-viral IACCs in Minnesota. It outlines a shared vision for the future, identifies system-level recommendations, and provides actionable guidance to inform decision-making, policy development, and implementation.

Because post-viral IACCs affect many aspects of daily life, this report supports multiple sectors and a range of individual perspectives and actions. It centers people living with post-viral IACCs and recognizes the broader systems involved in navigating and supporting them, including caregivers, employers, educators, healthcare providers, community organizations, and policymakers. Each group will find different entry points into the roadmap depending on their role and goals.

Gain context and understanding

Everyone can begin by grounding themselves in the lived experiences of people with post-viral IACCs. The summary of listening sessions **(Appendix D)** shares insights and experiences of people with post-viral IACCs and their caregivers. The introduction at the beginning of this report also provides critical context for understanding why change is needed and where systems are currently falling short. Appendix E provides a glossary of key terms and concepts used throughout this report. **Appendix F** includes additional feedback received by key contributors as the draft was being finalized.

Implement recommendations and support action

Section 2, the Supplemental Guide to Recommendation Implementation is designed to support cross-sector partners to implement these recommendations and guide coordinated action. The workgroups identified a broad set of recommendations. Given project scope and timing, only a portion were explored in depth. Additional recommendations are included in **Appendix C**. **Appendix F** includes additional action steps and considerations for recommendation implementation that were offered by key contributors during the final feedback survey.

Guide to policy and decision-making

The **Policy Considerations** section provides decision-makers, advocates, and policy makers guidance on policy changes that would improve the lives of people with post-viral IACCs, remove barriers, and accelerate progress. Those who want to learn more about how this roadmap was developed with input from people with lived experience can review **Appendix A** and **Appendix D** (People with lived experience listening summary).

Navigating the roadmap by audience

Individuals living with post-viral IACCs and their caregivers

- Use the **Introduction** to better understand post-viral IACCs and their impacts across Minnesota, and to support conversations with caregivers, providers, and others in your network.
- Review **Charting a path forward** to see how lived experience informs the vision and recommendations — and where your voice can continue to shape change.

- Review **Section 2 (Supplemental Guide)** for details on various recommendations, barriers that necessitate change, suggested actions, and indicators of success.
- Refer to **Appendix B** for educational resources on navigation of post-viral IACCS.
- Explore **Appendix D** **(listening session insights)** to see how your experiences align with others.

Implementers, advocacy organizations, policymakers, and legislators

- Use this roadmap to convene stakeholders, build alignment, and move from recommendations to action.
- Review the **Introduction** to understand the need for system change.
- Use **Charting a path forward** to identify priority recommendations for public life, formal assistance, and health outcomes and align around a shared vision.
- Refer to **Section 2 (Supplemental Guide)** for implementation guidance, including rationale, action steps, and indicators of success.
- Review **Policy considerations** to identify where legislative action can enable or accelerate progress.
- Explore **Appendix F** for additional considerations for implementation that were offered by key contributors during the final feedback survey.

Healthcare providers, specialists, and allied health professionals

- Review the **Introduction** to understand the broader context and impact of post-viral IACCs.
- Review the **vision for systems change** and **Recommendations for health outcomes** in to guide clinical practice improvements and system alignment.
- Refer to **Section 2 (Supplemental Guide)** **-** **Health outcomes** to review details on recommendations and other implementation guidance, including rationale, action steps, and indicators of success.
- Explore **Appendix B** for additional clinical and research resources.
- Refer to **Appendix D** to better understand patient experiences navigating care.

Care coordinators, benefits navigators, and community-based organizations

- Review the **Introduction** to understand system-level challenges.
- Review the **vision for systems change** and **Recommendations for formal assistance** to identify opportunities to strengthen navigation and support systems.
- Refer to **Section 2 (Supplemental Guide)** **-** **Formal assistance** to review details on recommendations and other implementation guidance, including rationale, action steps, and indicators of success.
- Refer to **Appendix B** for additional tools and resources.
- Use **Appendix D** to understand where individuals encounter barriers across services.

Employers and schools

- Review the **Introduction** to understand the broader context and impact of post-viral IACCs.
- Review the **vision for systems change** and **Recommendations for formal assistance** for actions that could support accommodation, flexibility, and inclusion.
- Review **Section 2 (Supplemental Guide)** **-** **Formal assistance** for detailed recommendations related to schools and employers.
- Use **Appendix D** to understand real-world challenges individuals face in navigating school and workplace systems.

Contributors

This roadmap was shaped by the time, expertise, and lived experience of many individuals who participated in the steering committee, workgroups, interviews, or a listening session. Individuals across the project support team, steering committee, and broader contributor group were deeply engaged in challenging assumptions, refining ideas, and strengthening the recommendations. We are grateful for their sustained commitment, thoughtful involvement, and the time they invested to inform this work. For more information on the process involved, visit **Appendix A**.

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Charting a path forward

Post-viral IACCs affect many aspects of daily life and require navigating systems that are often fragmented and not designed to meet the needs of people with complex chronic conditions. Impacts extend beyond physical and mental health symptoms to include challenges in maintaining employment, accessing services, sustaining relationships, and participating fully in community life.

In response, this roadmap organizes recommendations across three interconnected areas of focus — public life, formal assistance, and health outcomes — to reflect the range of systems that shape these experiences. These focus areas were informed by the opportunities framework outlined in the U.S. Department of Health and Human Services Health+ Long COVID Human-Centered Design Report (2022). Together, they represent the conditions needed for individuals living with post-viral IACCs to access care, maintain stability, and participate fully in society.

The vision statements that follow reflect themes and priorities identified through listening sessions, workgroup input, and steering committee review.

The recommendations in the tables that follow are organized by focus area. Given the breadth of these areas, each recommendation includes an associated theme to ensure a comprehensive approach. The tables include the name of the recommendation, a theme, a brief description, and an abbreviated summary of suggestion actions. **The full details of each recommendation are included in Section 2: Supplemental Guide to Recommendation Implementation.** This section includes ample context around each recommendation, including the suggested action steps, barriers that necessitate change, indicators for success, and existing efforts or partners who could support implementation.

A vision for systems change

As diagnostic markers, treatments, cures, and services are pursued for post-viral infection-associated chronic conditions, Minnesota can lead as a state where people with these conditions are able to live, learn, and work in communities that understand and respond to their needs. Meanwhile, their health concerns are urgently and comprehensively addressed through an integrated, equitable, and responsive system of providers, insurers, employers, community services, public health, and person-centered care.

Public life

Living and contributing without barriers

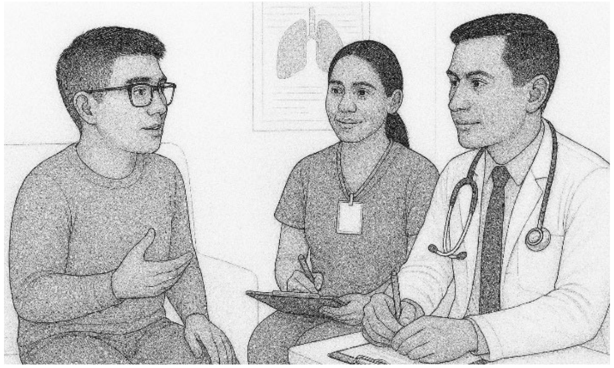
Vision: All Minnesotans living with post-viral chronic conditions engage in and contribute to their communities to their personal fullest, free from stigma.

Formal assistance

Supports that are accessible and responsive

Vision: All Minnesotans living with post-viral chronic conditions can easily navigate formal, non-clinical, and governmental systems to access supports for their distinct needs in respectful ways.

Health outcomes



Care that meets complex needs

Vision: All Minnesotans living with post-viral chronic conditions are served by a care system that is resourced and structured to meet their distinct needs in respectful ways, while making tangible progress toward cures and effective treatments.

Recommendations for public life

All Minnesotans living with post-viral chronic conditions engage in and contribute to their communities to their personal fullest, free from stigma.

Recommendation	Description	Suggested actions for implementation
1: Public awareness campaigns **Theme**: Public awareness	Develop public awareness campaigns to increase understanding of post-viral IACCs. Tailor messaging for: general public/social circles of people with post-viral IACCs; frontline health workers and healthcare providers; people with post-viral IACCs and their caregivers.	• Bring together communications leaders from different sectors who understand the condition to create clear, accessible public awareness messages and materials. • Use existing meetings and networks to align organizations around shared messaging and help spread consistent information to broader audiences.
2: Define, assess, and enhance system navigator roles **Theme**: Support systems	Conduct a comprehensive statewide assessment of various “navigator” roles that assist people with post-viral IACCs to understand gaps and ultimately increase capacity and funding stability.	• Use existing data to understand where navigation support is working and where gaps exist. • Clearly define navigator roles (formal and informal) with input from people with lived experience and those working within systems. • Show the impact of navigation (outcomes, costs, burnout) to secure funding and make these roles sustainable.
3: Support group expansion and coordination **Theme:** Support systems	Foster the growth and coordination of support group opportunities for people with post-viral IACCs and their caregivers.	• Gather information on current support groups and work with providers to assess opportunities to expand or adjust services for Minnesotans.

Recommendations for formal assistance

All Minnesotans living with post-viral chronic conditions can easily navigate formal, non-clinical, and governmental systems to access supports for their distinct needs in respectful ways.

Recommendation	Description	Suggested actions for implementation
1: Enhance disability recognition across formal assistance assessments and systems **Theme:** System navigation	Recognize post-viral IACCs as conditions with related disabilities and design navigation systems that are inclusive of the spectrum of disabling conditions that are experienced. Ensure assessment processes are not solely dependent on diagnosis, but grounded in listening, individualized assessment, and structured screening to gauge severity, frequency, and functional impact.	• Convene experts to audit and revise assessment tools to better capture functional impact, variability, and cognitive burden beyond diagnosis-based models. • Pilot improved approaches, train staff statewide, and strengthen oversight and policy flexibility to ensure consistent, accurate eligibility decisions based on real-world disability.
2: Buddy program/peer support **Theme:** System navigation	Explore a buddy or peer support program to strengthen navigation and well-being.	• Assess and define peer support models, roles, and safeguards. • Build a flexible, tiered structure with compensation for participation. • Pilot matched buddy and low-intensity options (e.g., phone calls, virtual visits) with strong oversight. • Measure outcomes like reduced isolation, service connection, and satisfaction to refine the model.
3: Invest in community health worker (CHW) infrastructure	This recommendation would call for investment and expansion of the CHW workforce:	• Align stakeholders to define CHW roles and system fit; develop post-viral IACC training, workflows, and access points.

Recommendation	Description	Suggested actions for implementation
CHWs improve health outcomes by providing education, coaching, and advocacy. Specific tasks include assisting with care management, improving medication awareness, offering social support, and helping residents navigate complex social and health systems. **Themes:** System navigation, access to assistance, policy formation	• Develop post-viral IACC-specific training for CHWs. • Leverage and expand reimbursable care pathways to support CHW services, including framing CHW work as reimbursable homecare or navigation visits through insurance and related programs. • Embed navigation support through reimbursable CHW models. • Support policies and investments that sustain and scale CHW infrastructure beyond authorization, including funding and long-term viability.	• Pilot and test delivery models. • Identify and remove barriers to reimbursement (policy change likely needed). • Build return on investment and sustainability strategy, including workforce and funding (legislative support may be required).
4: Online resource centers: Materials expansion targeting social service professionals **Theme:** Support systems	Enhance existing online resource centers to support social services professionals (e.g., medical social workers, community health, case managers, support group facilitators, etc.) interacting with this population to provide more curated information on post-viral IACCs.	• Establish a workgroup to assess current resources and referrals used by social service professionals and identify gaps and improvements.
5: Strengthen infrastructure between community, health, and formal assistance systems of care **Theme:** Access to assistance, policy formation	Strengthen the connective infrastructure between nonprofits, health systems, insurers, and the state to improve access to formal assistance.	• Work together across healthcare, community organizations, and support services — with input from people with lived experience — to fix referral gaps and create shared guidelines, simple data practices, and a trusted list of resources. • Pilot closed-loop referrals. • Fund administrative coordination (may require policy/funding changes) to ensure sustainable, accountable integration.
6. Telehealth and remote assessments **Theme:** Access to assistance, policy formation	Expand low-barrier access to assistance by recognizing telehealth and remote assessments for healthcare and formal assistance as essential modes of care for people with post-viral IACCs.	• Assess gaps in telehealth use and access. • Make it easier to pay for telehealth and fix rules that limit access; ensure providers routinely offer telehealth when appropriate

Recommendation	Description	Suggested actions for implementation
		and have clear guidance on when to use phone, video, messaging, or in-person care. • Pilot remote services. • Expand broadband/device access; educate patients on availability (policy changes are likely needed).
7. Support accommodation guidance and promote disability inclusion in schools and workplaces **Theme:** School and workplace accommodations	• Restore and localize guidance for school and workplace accommodations related to post-viral IACCs. • Increase awareness of disability rights and enforce rights in Minnesota. • Develop and disseminate employer-facing education modules focused on Americans with Disabilities Act (Americans with Disabilities Act (ADA)) accommodations.	• Assess needs and gaps across employers, schools, and lived experience. • Curate and translate existing accommodation guidance into tools and training tailored to post-viral IACCs. • Deliver at scale through trusted channels, and pilot, refine, and sustain through ongoing ownership, feedback, and continuous improvement.

Recommendations for health outcomes

All Minnesotans living with post-viral chronic conditions are served by a care system that is resourced and structured to meet their distinct needs in respectful ways, while making tangible progress toward cures and effective treatments.

Recommendation	Description	Suggested actions for implementation
1: Disseminate formal CMSS (Council of Medical Specialty Societies) resources to primary care providers and specialists **Theme:** Preparation for healthcare professionals	Expand formal educational opportunities by disseminating existing CMSS resources, focusing on both primary care providers and specialists who receive referrals. These evidence-based resources were produced via a federally-funded collaborative effort that included a multidisciplinary panel of primary care, specialists, advanced practice providers, and patients.	• Inventory post-viral IACC CMSS resources to identify gaps, and supplement with authoritative sources. • Integrate into widely used platforms (e.g., UpToDate), and disseminate via health systems, professional societies, electronic health records, and health plans. • Develop concise, point-of-care summaries for easy access (may require system/policy alignment).
2: Unified clinical pathways and point-of-care clinical tools **Theme:** Structural improvement	Develop and disseminate practical point-of-care tools, cross-specialty clinical pathways embedded into electronic health records (EHR) systems to help clinicians and nurses identify post-viral IACCs, support patients, and develop care plans.	• Develop a point-of-care clinical-tools roadmap with pathway placement, users, inputs, and gaps. • Leverage and assess existing tools for integration into care pathways. • Pilot cross-specialty care processes, share findings. • Explore telementoring models to support providers.
3: Education modules for allied health professionals and support staff **Theme**: Preparation for healthcare professionals	Develop education modules for allied healthcare professionals and students to improve understanding and support of post-viral IACCs.	• Identify priority allied health professions. • Codevelop new modules with experts and those with lived experience where gaps exist. • Disseminate through professional networks and education systems and expand over time to broader healthcare roles (may require policy or accreditation alignment).

Recommendation	Description	Suggested actions for implementation
4: Annual Minnesota post-viral IACC clinical symposium **Theme**: Preparation for healthcare professionals	Host an annual Minnesota post-viral IACC clinical symposium to share emerging evidence, case studies, and treatment approaches.	• Define a distinct vision for a MN PV-IACC event. • Prioritize an initial audience and outcomes with room to expand. • Recruit partners to support white-paper development.
5. Person-centered clinical care **Theme:** Structural improvement	Promote person-centered clinical protocols that validate lived experiences, integrate trauma-informed care, prevent harm, and reduce stigma and harm for post-viral chronic conditions.	• Codevelop post-viral IACC care standards with input from diverse lived experience, prioritizing marginalized groups. • Engage healthcare leaders in implementation and convene clinical and patient communities to refine trauma-informed, patient-centered practices. • Develop communication strategies that help strengthen trust, therapeutic relationships, and patient self-efficacy.

Policy considerations

The following policy considerations are grouped into four potential areas of focus. Each includes a limited set of illustrative examples intended to generate ideas and support the development of a more comprehensive policy agenda. The examples provided are not exhaustive and do not reflect the full range of existing or ongoing efforts related to disability policy, healthcare reform, social welfare policy, and other related system issues.

Comprehensive policy and system reform should be person-centered and consider a multi-payer framework. This approach would best address the numerous barriers encountered by those seeking care and support across various systems, including healthcare, disability determination, and social services.

Policies that expand healthcare access and affordability

Enabling access to quality healthcare and insurance coverage is crucial for people with post-viral IACCs, who may need the help of primary care, specialists, medications, therapies, home healthcare, long-term care, and more to manage their conditions and fully participate in society. Reducing costs to the healthcare system overall is also imperative. As with other chronic conditions, management of symptoms in collaboration with a multidisciplinary care team can reduce expensive hospitalization and visits to the emergency department. The considerations below could ultimately increase access to care and decrease costs.

- Increase interoperability and coordination within and across systems to increase efficiency, reduce the burden for the patient, and expedite care.
- Reimbursement and insurance coverage:
    - Pay for Community Health Worker (CHW) services, including home healthcare visits, wraparound service support, and system navigation assistance.
    - Coverage for a “buddy” program/peer extenders (reimbursable as a home healthcare visit, based on a created plan of care).
    - Include coverage for complementary healing services and modalities and integrative medicine.
    - Rethink activities categorized as “health promotion” (such as checking in on the person) that could be reimbursable and prevent disease/disability progression.
    - Cover symptom management and capacity-enhancing treatments. They are often considered “maintenance,” which disqualifies them from certain coverage.
- Reduce Medicaid coverage losses via exemptions for work requirements.
    - Expand list of diagnoses included in the CMS definition for “medical frailty” to include comorbidities common to post-viral IACCs, such as codes for ME/CFS (G93.32), POTS (G90.A), and long COVID (U09.9).

  - See A Guide to Reducing Coverage Losses Through Effective Implementation of Medicaid's New Work Requirement from the Center on Budget and Policy Priorities for other considerations.
- Make telehealth a standard of care that is reimbursable.
- License naturopathic doctors in Minnesota so that they are billable and have prescriptive rights.
- Pilot idea for person-centered care model that serves those with post-viral IACCs.

Policies that prioritize quality of life

Many drivers of health, well-being, and stability exist outside of the healthcare system. Policy must extend beyond the treatment of a chronic condition and address the broader destabilizing effects these illnesses can have on individuals, families, communities, and society. For many people with disabling post-viral IACCs, access to healthcare, disability benefits, income support, housing assistance, caregiving, workplace accommodations, and other services can serve as critical stabilizing forces that help maintain safety, functioning, and quality of life. At the same time, navigating these systems can itself become a source of further instability when access is delayed, fragmented, or difficult to obtain.

People with post-viral IACCs may struggle with activities of daily living, employment, food security, housing stability, and other essential needs. It is critical that they can access benefits, services, and programs intended to support people with disabilities (see Guidance on "Long COVID" as a Disability Under the Americans with Disabilities Act (ADA), Section 504, and Section 1557 | HHS.gov).

However, many systems designed to provide support are under strain, including workforce shortages, service backlogs, administrative complexity, and limited system capacity. Disability determination and related processes already present significant barriers. People with post-viral IACCs may face additional challenges due to difficulty obtaining a formal diagnosis, fluctuating symptoms, energy limitations, cognitive impacts, and other severe symptoms of their condition.

A guiding objective should be to ensure that people can access the support they need as quickly, consistently, and equitably as possible to help stabilize their lives and reduce the cascading impacts of illness. The following considerations highlight opportunities to improve access to systems and services and increase the quality of life for those disabled by post-viral IACCs.

- Prioritize keeping people at home over institutionalization. One pathway is access to home- and community-based services via waivers.
- Reform of disability assessments and determination processes might include:
  - Recognition of the potential relapsing/remitting nature of these conditions. Point-in-time assessments may not represent a person's symptoms or abilities during a flair-up.
  - Allow remote assessments via telehealth visits to qualify for benefits/programs/services.
  - Reconsider who qualifies to conduct the assessment and expand the list of providers/staff who can do so.

    - Accept different validated scales/scores that demonstrate loss of function and impact on Activities of Daily Living (ADLs), cognitive impairment, etc. for qualification, given there is not a laboratory diagnostic test.
    - Address outdated income/asset limits, which haven't been updated since 1983 despite annual inflation.
    - Amend the assessments that are required to receive coordinated care benefits. Current process is too long and intense for people with severe post-viral IACCs. Streamline or break into multiple visits.
    - Broaden the resources available that serve to stabilize people with disabilities to include people with post-viral IACCs.
    - Expedite State Medical Review Team (SMRT) process for homebound individuals.
    - Recognize fatiguing illnesses as disabling.
- Broaden Americans with Disabilities Act (Americans with Disabilities Act (ADA)) applicability and strengthen enforcement of Americans with Disabilities Act (ADA) requirements.
- Bolster civil rights protections for people with disabilities to ensure they are treated equally and shielded from discrimination in order to promote fairness across various aspects of public life.

Policies for support and sustain systems

Those working within systems — and the systems themselves — also need support to provide the care and services that aid in the stabilization of people with post-viral IACCs. Without an eye toward sustainability, care and services can drop off. Below are some ideas that were shared by key contributors for building and bolstering system capacity.

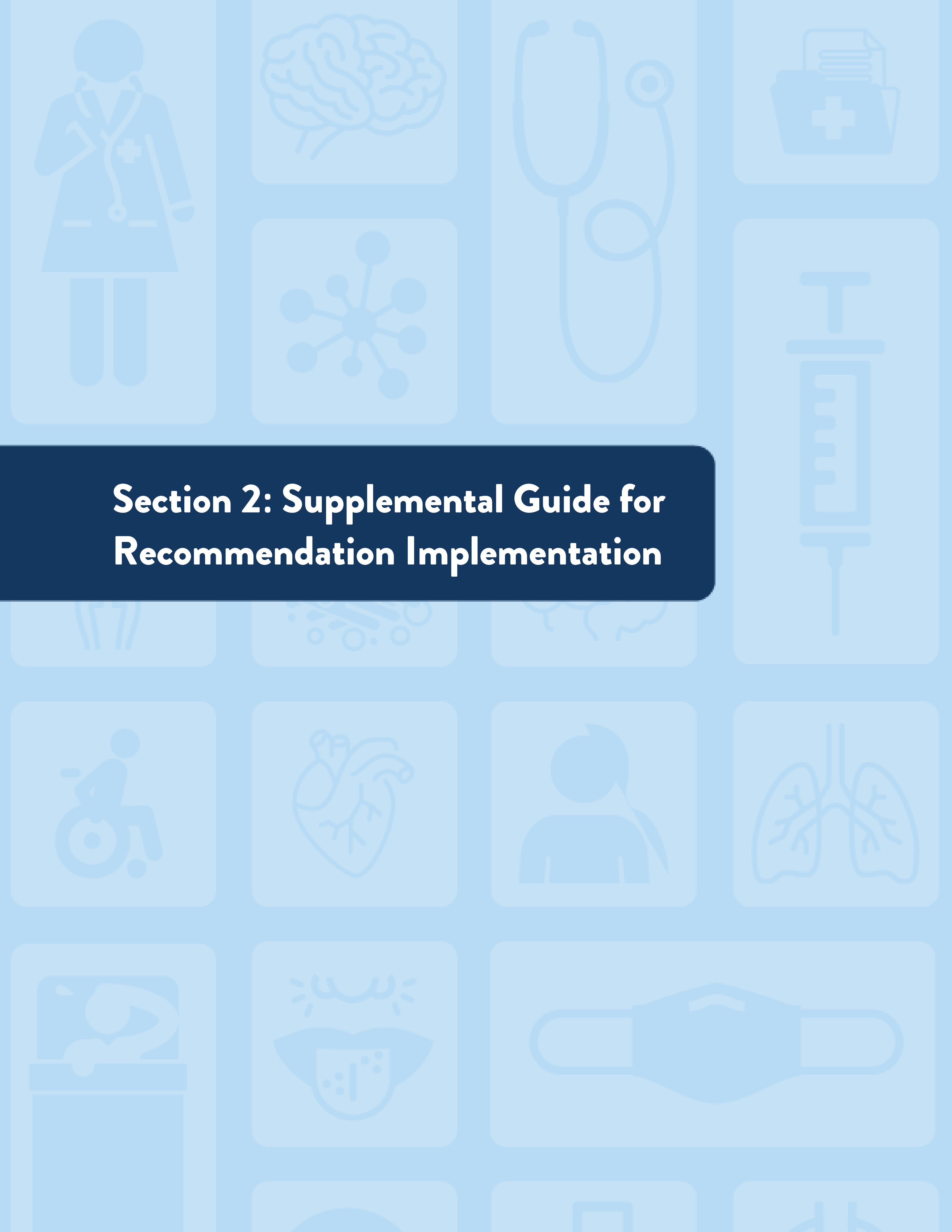
- Support funding and infrastructure to grow, incorporate, and reimburse the community health worker workforce.
- Address barriers to telehealth.
    - Continue the higher reimbursement rates that were accepted during the COVID-19 emergency. Cover telephone/non-video calls.
    - Fund smaller clinics to secure the infrastructure, space, technology, and equipment to hold HIPAA-compliant virtual conversations.
    - Expand the broadband services needed to enable telehealth visits. Facilities in remote areas and the communities they serve may lack the requisite broadband access, which is a wide-reaching equity issue.
- Increase interoperability and coordination within and across systems to increase efficiency for healthcare, saving money.
- State policymakers should consider investments in workforce training (similar to dedicated funds for HIV/AIDS provider education), patient access to multidisciplinary care, integrated supportive counseling/mental health services, public education, and reimbursement reforms. Codifying these recommendations into state-level guidance or funding priorities

would align health systems with the evidence-informed care model (see Understanding Long COVID: Implications for Family Physicians' from the American Academy of Family Physicians).

Policies that bolster public health

- Vaccinations for acute viral infections such as COVID-19, RSV, and influenza should continue to be made available, affordable, and accessible. Vaccination should also be encouraged and promoted by reputable healthcare providers and public health agencies. Accessibility should include in-home vaccination options, such as those allowed during the COVID-19 public health emergency. Similarly, access to free COVID testing kits and masks, available via mail, help protect people from infection/reinfection and reduce community spread.
- Harmonize and standardize definitions and disease coding (see detailed recommendations in Section 2). This can increase access to insurance coverage, disability benefits, accommodations, and services, while also bolstering data for better disease monitoring and research (see Health Outcomes Recommendations for more on disease monitoring and definitions).
- State and local public health and community sectors should expand the conceptual framework for stabilizing families, children, and individuals with post-viral IACCs to advance public health outcomes. This can also enhance awareness of the scope of public health and help prepare communities for future public health crises.

Section 2: Supplemental Guide for Recommendation Implementation



Supplemental guide for recommendations

This section provides important context for those who are implementing the recommendations put forth in this roadmap. Decision-makers, policy makers, advocates, and others who will be leading these efforts should consider the following details for each of the recommendations that were previewed in the previous section. Each recommendation includes a description, theme, gaps and barriers that make this change necessary, suggested action steps for implementation, what success looks like, and existing efforts or partners that implementors can look to as they get started.

Overview of Recommendations

Focus area: Public health

1. Public awareness campaigns
2. Define, assess, and enhance navigator role
3. Support group expansion and coordination

Focus area: Formal assistance

1. Enhance disability recognition across formal assistance assessments and systems
2. Buddy program/peer support
3. Invest in community health worker (CHW) infrastructure
4. Online resource centers: Materials expansion targeting social service professionals
5. Strengthening infrastructure between community, health, and formal assistance systems of care
6. Telehealth and remote assessments
7. Support accommodation guidance and promote disability inclusion in schools and workplaces

Focus Area: Health Outcomes

1. Disseminate formal CMSS (Council of Medical Specialty Societies) resources to primary care providers and specialists
2. Unified clinical pathways and point-of-care clinical tools
3. Annual Minnesota post-viral IACC clinical symposium
4. Education modules for allied health professionals and support staff
5. Person-centered clinical care

System improvements and system transformation

Members of the work groups and steering committee emphasized that recommendations must address both incremental system improvements and more fundamental, transformational change up to and including policy and funding shifts at the state and federal levels.

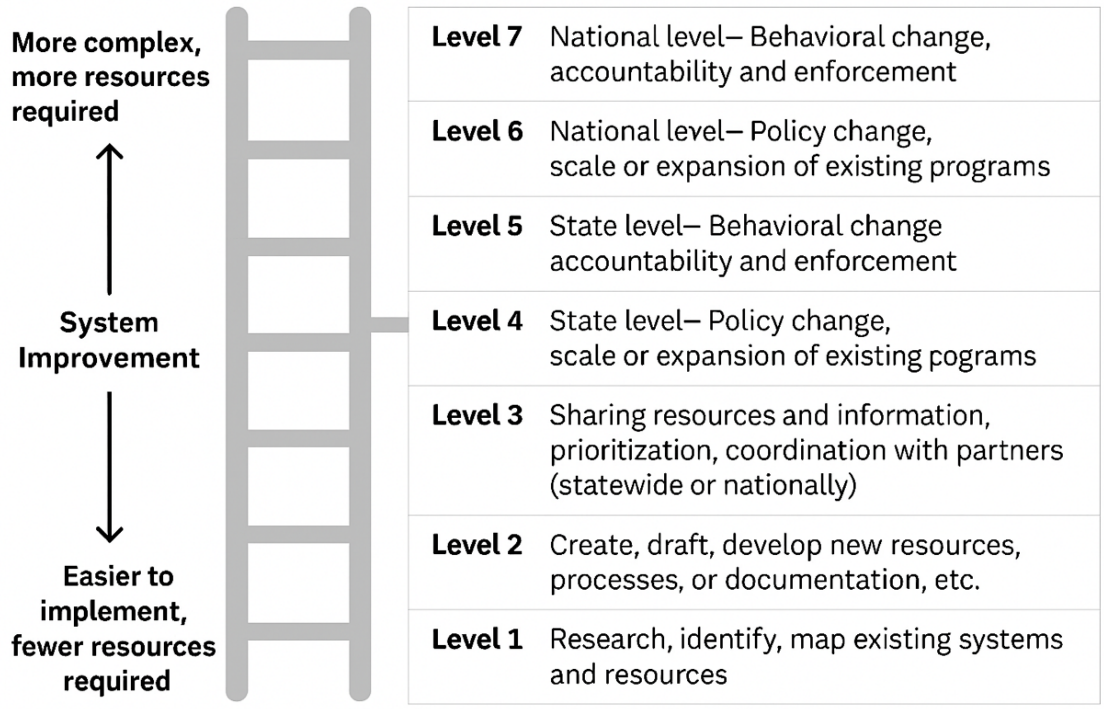
To support this, MAD adapted a systems transformation ladder from the Brookings Institution (Winthrop, R., Ziegler, L., & Ershadi, M. (2021). *Conversation Start Tools,* Brookings Institution). The ladder is used in this report as an organizing framework to sort recommendations by the type and depth of the system change required.

The structure helps distinguish between:

- Near-term, lower-resource "early wins"
- Moderately complex changes requiring coordination across partners
- Longer-term structural policy changes that require significant alignment and investment

The diagram below illustrates how recommendations are mapped across these levels to support prioritization and implementation planning.

Systems transformation ladder



Level 7	National level– Behavioral change, accountability and enforcement
Level 6	National level– Policy change, scale or expansion of existing programs
Level 5	State level– Behavioral change accountability and enforcement
Level 4	State level– Policy change, scale or expansion of existing pograms
Level 3	Sharing resources and information, prioritization, coordination with partners (statewide or nationally)
Level 2	Create, draft, develop new resources, processes, or documentation, etc.
Level 1	Research, identify, map existing systems and resources

The project support team assessed each recommendation against the system change framework. The recommendations include the suggested level placement and an explanation of why it was placed at that level. Some recommendations, especially those that span systems, fall across multiple levels of system change. Those levels are all indicated for each recommendation.

Focus Area: Public life

Recommendation 1: Public awareness campaigns

"We need more media coverage of long COVID and the related conditions…and we need media coverage to not be all White men or all White women with the illness, but we need examples that will relate to every community."

Recommendation description

Develop targeted public awareness campaigns for key audiences, including general public, healthcare providers, healthcare educators, and individuals with post-viral IACCs and their caregivers. Campaigns should increase understanding, reduce stigma, support early symptom recognition, and connect people to trusted information, support, and care pathways. They should also be culturally tailored and linguistically appropriate depending on the audience.

Theme: Public Awareness
Proposed System Level(s): 2 and 3 (Creating new tools and resources, Working together better)

Why it's placed here: Campaign development and dissemination are feasible, but effectiveness and impact depend on clear next steps for message recipients and available resources.

ACTION STEPS

- Convene knowledgeable communications leads from various supporting organizations to identify and craft key messages and easily replicated educational materials for reaching target audiences, including the public.
- Leverage existing supporting organizations to build organic agreements around promoting key messages to their networks and contacts. Highlight awareness days/annual observances.
- **Campaign 1 | Audience:** General public/social circles of people with post-viral IACCs. Choose appropriate strategies and channels depending on the target demographics. When possible, tailor the framing and language to fit the cultural and linguistic needs of the audience. **Goal:** Through the voices of people with lived experience and those in their social circles, introduce common language around post-viral IACCs and model supportive conversations with people who may be impacted.
- **Campaign 2 | Audience:** Frontline health workers and healthcare providers. Reaching this audience may require engagement with health system leadership, educational institutions, and/or professional societies. **Goal:** Through the voices of people with lived experience and healthcare professionals, clarify manifestations and impacts of post-viral IACCs and model productive, supportive conversations with people who may be impacted. Point to resources for healthcare providers.
- **Campaign 3 | Audience:** People with post-viral IACCs and their caregivers. Choose appropriate strategies and channels depending on the target demographics. When possible, tailor the framing and language to fit the cultural and linguistic needs of the audience. **Goal:** Through the voices of people with lived experience and caregivers, introduce common language around post-viral IACCs and tools to enhance self-advocacy and productive conversations in different settings. Point to resources for tracking symptoms, seeking care and assistance, and connecting with others with common lived experience.

Gaps and barriers making this change necessary

- **Isolation.** Those with post-viral IACCs often experience isolation due to debilitating symptoms and a lack of public understanding. They may even begin to second-guess themselves and what they are feeling. A campaign helps people better understand what they or a loved one is experiencing and can point them to resources to counter their sense of isolation and lack of useful information.
- **Lack of credible and trustworthy information.** Limited, inconsistent information and widespread misinformation about post-viral IACCs undermines trust in healthcare, delays recognition, and prevents people from accessing available care, support, and services.
- **Skepticism and shaming.** There is a lack of public understanding about these conditions which often results in skepticism that serves to shame those who are suffering. A campaign helps people understand that post-viral IACCs (and not just long COVID) are uniquely debilitating, real, vary in symptoms and duration and impact every aspect of someone's life.
- **Reframing long COVID as a post-viral IACC.** Many people don't want to be reminded of the COVID pandemic and turn away from any reminder of the virus or the possibility of long COVID. This is dangerous to community health and harms those experiencing this condition. This avoidance mentality also reduces the effectiveness of those within formal and informal community support systems who have useful information to share with possible patients and those caring for them. A thoughtfully executed awareness campaign would reframe long COVID from "pandemic baggage" to one of numerous post-viral IACCs that merit attention and resources.
- **Cost.** Even campaigns that "piggyback" on existing communications require money and staff time to implement.
- **Lack of actionable next steps.** An important consideration is that even if people are made aware of these conditions, there is not a clear answer as to what they can do about it in the absence of reliable pathways for care and support. Most campaigns advise people to contact a healthcare provider if they recognize the symptoms in themselves or a loved one. The current reality is that they may face dismissal or even harm from providers who are not educated on identifying and managing these conditions. This creates something of an ethical quandary for the messenger that must be considered before campaigns are launched.

What success looks like (from multiple perspectives)

People with post-viral IACCs and their caregivers

- Decrease in the negative stigma attached to these conditions and greater sense of support and acceptance from family, coworkers, peers, and the broader community.
- Greater sense of belonging to a larger community, including around sharing common experiences in the healthcare system and their public lives.
- People with post-viral IACCs feel reassured that community organizations and the healthcare system haven't abandoned them.
- Increased confidence in how to tell their story to family, schools/employers, and medical community.

Community organizations

- Get more familiar with post-viral IACCs and have increased interest in understanding their organization's role in supporting those impacted.
- Those developing services and programs understand the benefits of including voices from people with lived experience in the process and embrace the following principles:
  - People with post-viral IACC are the experts in their unique experiences.
  - We are all learning together while we equip systems to better support these unique experiences.
  - Groundwork has been laid by many patient communities across many different conditions. We can learn from that work.
  - Supporting community and connection is a non-negotiable part of wellness.
  - System design must conserve personal/caregiver resources by being people-centered.
  - No one is left behind.
  - We all have a part to play — diversified resources ensure ownership across practitioners, organizations, systems, and communities.

Healthcare employees (including schedulers, lab workers, clinic welcome staff, etc.)

- More sensitive to the support necessary for post-viral IACC patients.
- Smoother referral pathways/procedures within clinic settings that provide patients with tangible steps they can take post-visit.
- Patients feel comfortable bringing up their struggles with post-viral IACCs to their primary care providers, nurses, etc. Patients leave their appointments feeling heard.

Existing efforts and partners (state, local, others)

- Still Here: Communicating about Long COVID | Public Health Communications Collaborative
- Voices of Long COVID playlist
- Long COVID | Pima County, Arizona
- Long COVID Justice
- IACC Resource Guide | Infection Associated Chronic Conditions Initiative (IACCI)
- Healthcare Appointment Checklist for Long COVID | CDC
- Getting Ready to Talk about Long COVID with Your Child's Doctor | RECOVER
- Good day/Bad day questionnaire | Bateman Horne Center
- Minnesota Dystonia Support Group | Dystonia Medical Research Foundation
- How to Get On - Blog focused on how to have a great disabled life
- #MEAction Network
- Comprehensive Guide to LC | C19LAP | COVID-19 Longhauler Advocacy Project

Focus Area: Public life

Recommendation 2: Define, assess, and enhance navigator role

Recommendation description

Conduct a comprehensive statewide assessment of various “navigator” roles that assist people with post-viral IACCs to understand gaps and ultimately increase capacity and funding stability.

Theme: Support Systems
Proposed System Level(s): 3 and 4 (Working together better, State level policy change or expansion).

Why it’s placed here: Recommendation implementation requires resources and partner collaboration or buy-in. We need to get a clearer picture of what navigator roles do, why and when navigators are necessary, and how their roles fit within different organizations. We also need to understand how they function within healthcare and insurance systems.

ACTION STEPS

- Conduct cross-sector landscape analysis using existing assessments to define navigator roles, gaps, and community-specific needs.
- Develop standardized role definition, competencies, and training informed by lived experience and provider input.
- Build evidence case (return on investment, burnout drivers, outcomes) to secure sustainable funding and integrate navigation into health and social systems.

Gaps and barriers making this change necessary

- **Lack of a clear definition for navigator role.** There isn’t a clear or shared definition of what a navigator is (formal, informal, etc.), which may impact potential for reimbursement or other funding opportunities. There may not be public clarity regarding a difference between a volunteer peer health extender and a community health worker whose ability to assist is dependent on reimbursement codes.
- **Need for funding and staffing for navigator positions.** Funding may be needed for these roles, especially when considering how wide the scope of the navigator’s role would be. Consideration would have to be made for how many navigators per state, per county, per city, etc.
- **No central system to evaluate the navigator network.** There is no coherent public health effort to synthesize and evaluate the system — we mostly know what we know from word of mouth or from subject matter experts, but we don’t have a place to go and really look at gaps and opportunities. The existing system is imperfect (e.g., Center for Community Health).
- **No single group leading or coordinating the effort.** Time and resources spent responding to federal actions have deprioritized collaboration and coordination efforts.

What success looks like (from multiple perspectives)

People with post-viral IACCs and their caregivers

- People with post-viral IACCs and caregivers have informed, proactive helpers who can point them to trusted, local (when possible) resources and support related to their condition and/or disabling symptoms and needs beyond the clinical encounter. This includes knowing the programs this person might qualify for and helping them apply. The "ultimate vision" is for health and social service systems to be connected such that these roles and duties are embedded, and a navigational "middleman" isn't necessary.

Providers and community organizations

- Have clearer understanding of existing community needs/barriers across various regions.
- A clear estimate for the funding necessary to meet needs and remove barriers to care as well as adequate evidence to strategically advocate for sustained funding and resources for navigational roles.
- Clearer understanding of why navigators are getting burned out and what is needed for sustainability.
- A white paper that summarizes these findings and serves as another tool for advocacy.

Existing efforts and partners (state, local, others)

- Review findings from existing Community Health Needs Assessments, OSHII/SHIP assessments, community health worker-related research, other local and state public health assessments.
- Existing assessments and research around healthcare extenders (such as "buddy" programs) that could potentially be leveraged here. Also, there is likely literature around why these navigators are needed in general, as well as ample qualitative data around why people with post-viral IACCs in particular need navigators.

Focus Area: Public life

Recommendation 3: Support group expansion and coordination

"I know my dad's relationship with his wife has been very strained. Our parents are divorced. My mom and dad are divorced. All of our relationships are basically at their breaking point."

Recommendation description

Foster the growth and coordination of support group opportunities for people with post-viral IACCs and caregivers.

Theme: Support Systems
Proposed System Level(s): 2 and 3 (Creating new tools or resources, Working together better)

Why it's placed here: Focuses on capacity-building, coordination, and guidance rather than large-scale system change.

ACTION STEPS

- Leverage existing convenings and supportive organizations to poll participants on existing support groups in Minnesota or available to Minnesotans from external entities.
- Develop and promote a public survey that supportive organizations can promote to those on the mailing list that are experiencing these diseases or caring for them. Data collected could be compiled and shared with organizations currently providing support group services.
- Convene support group providers to assess and discuss their capacity to expand and/or adjust their services.

Gaps and barriers making this change necessary

- **Unclear about the state of existing support groups.** We don't know who is currently providing/supporting these group efforts let alone how consistently these groups meet, or how many are live (such as via Zoom) versus asynchronous (such as via Facebook). Many support groups are completely volunteer driven making visibility, longevity, and focus difficult to assess.
- **Lack of skilled facilitators.** Ensuring that the facilitation of these groups is structured to allow for everyone to have a voice, but also not too rigid to feel too clinical or "sterile." There are numerous gaps and barriers related to successful support group expansion including overcoming language and cultural barriers, concerns about privacy, and the potential to spread misinformation. There must also be a plan for successful facilitation and meeting/participation guidelines as well as a need for facilitators to be skilled at crisis management/psychological first aid.
- **Qualifications for advice.** Existing legal constraints around what information can be shared (e.g., liability, not giving medical advice).

- **Awareness-building.** Organizations face challenges in communicating the purpose and relevance of support groups to individuals with post-viral IACCs and in supporting participation across groups that include people with different diagnoses but overlapping symptoms.
- **Practicalities that foster good participation.** The coordination of individuals with post-viral IACCs/long COVID to find times that work and a location or meeting method (i.e., Zoom) that can work for most of the support group participants is a difficult logistical barrier.
- People with lived experience don't have a known place to find each other and learn from each other.
- These conditions are particularly impactful in terms of isolating people, particularly when inconsistent (but usually low or limited) energy levels limit opportunities for people with lived experience to chase down these opportunities.
- There is an apparent lack of support groups for younger people.
- Many support groups lack diverse representation, leading to microaggressions and compounded stressors/trauma/isolation.
- A local group creates more confidence in participating openly, and suggestions for care/support are also more localized.

What success looks like (from multiple perspectives)

People with post-viral IACCs and their caregivers

- Support groups provide an improved sense of connection and less sense of isolation. Symptoms show some visible or felt improvement by the individual.
- People with post-viral IACCs and caregivers have a place to contribute/give, not just receive, where their lived experience becomes valuable to others and to the system. People feel they have a network of support outside the system and in each other.
- People with post-viral IACCs can and do connect with each other and have collective access to others with information. They can participate in ways that work for them (camera off, chat-only, asynchronous).

Organizations offering support groups

- Within different communities (perhaps measured by tracking "pilot" communities) regular support group meetings are established that are not volunteer dependent. "Regular" is determined ahead of time (perhaps monthly, or at least on a schedule that is followed).
- Community organizations, others with information are able to speak to a large and diverse group of people with lived experiences at once, streamlining their communication efforts.
- Organizations have capacity and feel equipped to host and facilitate support groups, have ready access to resources to share, and do not fear potential legal or other consequences.

Existing efforts and partners (state, local, others)

- Fibromyalgia, ME/CFS, and Related Conditions Facebook Support Group
- Post-COVID recovery & COVID-19 patient forum | Mayo
- Research, Clinical Care, and Education | Bateman Horne Center
- Brigham and Women's Hospital in Boston runs a program (for their patients only**)**, that includes a monthly patient-led conversation, a caregiver support group, and a patient support group, all via Zoom. They also have a Discord server as a private space to connect, a Google drive of resources, and Signal groups. And they send out a weekly newsletter with other workshops, resources, and opportunities for engagement.
- Previously there were Slack channels from patient-led organization Body Politic that were effective, but they lost funding. Seek to evaluate and replicate.

Focus Area: Formal Assistance

Recommendation 1: Enhance disability recognition across formal assistance assessments and systems

“Home and community-based services assessments need to be revised to [include] questions that acknowledge that some of us have fluctuating chronic conditions that are disabilities. The way they ask the questions, it's binary A or B, on or off, yes or no. They have me get up and say, “let me see you walk” …what [they] don't understand is, I can walk right now across the room. See me on a day when I can't even get up off the couch. See me on a day when I'm counting and saving energy so that I can either get to the bathroom the appropriate number of times or maybe make some food and eat. And then I don't even have enough energy to eat the food after I make it. They don't understand these conditions and the questions exclude us by the nature of the way they ask the questions. So we don't get assessed for enough hours.”

Recommendation description

Recognize post-viral IACCs as conditions with related disabilities and design navigation systems that are inclusive of the spectrum of disabling conditions that are experienced. Ensure assessment processes are not solely dependent on diagnosis, but grounded in listening and individualized assessment, in addition to structured screening to gauge severity, frequency, and functional impact.

Theme: Policy Formation, System Navigation
Proposed System Change Level: 1, 2, 3, 4, and 5 (Understanding what already exists, Creating new tools, Working together better, State level policy change or expansion, State level behavioral change or accountability).

Why it’s placed here: This recommendation spans multiple levels — from research and tool development to provider behavior change — and may not be strictly a policy issue.

ACTION STEPS

- Convene cross-sector experts (assessors, clinicians, the State Medical Review Team (SMRT), and people with lived experience) to audit Minnesota assessment tools and revise them to capture functional impact, variability, cognitive burden, post-exertional malaise (PEM), and recovery time. Relax diagnosis-driven eligibility rules and rigid scoring models.
- Pilot and refine improved approaches. Test enhanced methods (e.g., narrative inputs, “good day/bad day” framing, functional prompts) in high-volume entry points; iterate based on lived-experience feedback.
- Train and equip staff statewide. Develop and deliver training and plain language tools to ensure assessors and frontline support staff can recognize fluctuating disability, evaluate functional needs, and apply updated tools consistently.
- Strengthen oversight and enable policy flexibility. Implement quality review of decisions (e.g., denials, under-authorization), establish feedback loops for frontline supportive staff, and pursue policy or regulatory changes to allow eligibility determinations based on functional limitations.

Gaps and barriers making this change necessary

- **Limited recognition and understanding of post-viral IACCs.** Formal assistance providers and assessors lack familiarity of post-viral IACCs (particularly fluctuating, invisible, and cognitive symptoms) leading to under-recognition, reliance on self-education and missed opportunities to connect individuals to appropriate resources.
- Individuals conducting assessments may fail to accurately interpret or elicit information when individuals struggle to articulate symptoms or when energy limitations and fluctuation are not well understood.
- **Assessment design may not adequately assess disability.** Eligibility and assessment tools (e.g., MNChoices, home- and community-based services, waivers, etc.) rely on rigid rubrics, diagnosis, and/or binary or score-based models that can miss the fluctuation of illness, variability of conditions, and cognitive impairments.
- **Overreliance on standardized scoring over lived experience.** Rubrics, scales, and constrained data fields prioritize computed "levels of need" over qualitative input and exclude conditions that do not fit pre-defined categories.
- **System-induced navigation burden and workaround behavior.** When systems do not reliably recognize need, individuals must self-navigate, rely on informal networks, or learn how to "work around" assessments to qualify for services, shifting the burden of system failure onto the individual.

What success looks like (from multiple perspectives)

People with post-viral IACCs and their caregivers

- People experiencing post-viral IACCs feel seen during assessment as their symptoms and conditions are included, identified, and assessed for benefits and supportive services.
- Individuals receive timely, appropriate, and sufficient supports (including adequate service hours and access to case workers) that improve well-being and stability.
- Interactions with systems are safe and sustainable for people with post-viral IACCs. Seeking services doesn't worsen health or create additional burdens.
- Individuals report positive experiences with assessments and services, including opportunities to provide feedback on unmet needs and program quality or system performance.

Formal assistance systems and providers:

- Staff are trained, confident, and equipped to recognize and assess the full spectrum of post-viral IACCs, especially fluctuating, cognitive, and energy-limited conditions, with training grounded in lived experience and practical application.
- Assessment tools and processes accurately capture functional impact and variability, reflecting lived experience through more nuanced, flexible, and person-centered approaches.

- Assessments and interactions are high quality. Staff have time to listen, communicate in paced and personalized ways, and rely on direct input rather than assumptions or rigid interpretation.
- Systems consistently connect individuals to appropriate supports; case workers understand available services, calibrate support levels appropriately, and coordinate effectively across resources.
- Workforce practices reinforce quality and consistency through training, incentives, collaboration, and promotion of relevant resources and symptom management supports.
- Continuous improvement is embedded: tools, technologies, and follow-up processes identify unmet needs, refine support, and strengthen service delivery over time.

Existing efforts and partners (state, local, others)

- Look to resources and lessons learned from initiatives supporting other, non-physically apparent chronic conditions (fibromyalgia, autoimmune diseases, ME/CFS, etc.).
- Consider more detailed assessments (e.g., Bateman-Horn example) or other scales, like the COMPASS 31 (Composite Autonomic Symptom Score-31).
- Vocational Rehabilitation Services (VRS): Look for conference trainings and collaborate with counselors and staff. Potential building connection or opportunities to collaborate between the Minnesota Department of Employment and Economic Development and MDH.
- MnCHOICES | Minnesota Department of Human Services (DHS)
- The State Medical Review Team (SMRT) | Minnesota DHS
- Home care services | Minnesota DHS: program focused on eligibility based on symptoms (not diagnosis). Assistance with the paperwork burden may be available.
- Disability Hub MN: initial entry way; already an established platform.
- Local advocacy organizations: have trainings out there and ready to support.
- Long COVID Guide for Social Security Disability Claims (PDF) | SSA
- ME/CFS Guide for Social Security Disability Claims (PDF) | SSA

Focus Area: Formal Assistance

Recommendation 2: Buddy program/peer support

"As a trans person, I have another barrier to getting just some random person from an agency to come work with me in very intimate ways. The idea of a buddy program is an ideal solution. I think about the queer community, I think there's a lot of people that want to volunteer to do stuff, there are able-bodied people in the community, and there's a lot of disabled people in the community."

Recommendation description

Explore a buddy or peer support program to strengthen well-being and support system navigation.

Theme: System Navigation
Proposed System Change Level: 2 and 3 (Creating new tools or resources, Working together better)

Why it's placed here: Requires program design and coordination; feasibility needs further assessment. Consider literature review of peer support extenders and/or networks, especially those that are volunteer based. Still requires framework, training, certification, finances, monitoring, and evaluation of outcome metrics.

ACTION STEPS

- Assess feasibility for peer-support. Define clear peer roles, boundaries, safety expectations, and training needs.
- Build a tiered peer structure that accommodates varying energy levels and offers modest compensation for participation.
- Pilot a matched buddy program and test lower-intensity options like phone calls or virtual visits, using thoughtful matching criteria. Funding and resources will be required to support vetting processes and accountability.
- Measure outcomes such as reduced isolation, improved service connection, and participant satisfaction to guide refinement.

Gaps and barriers making this change necessary

- **Isolation stemming from long-term, chronic illness.** People experiencing post-viral IACCs are isolated, have unmet needs and safety concerns. They may not have a trusted support person who is experienced with their needs or illnesses or someone to call for basic living needs challenges (e.g., the power goes out).
- **Lack of trust in formal systems of care.** People experiencing post-viral IACCs may have experienced harm in seeking care from clinics, hospitals, or emergency rooms. Lack of trusted connections in formal care systems leads to greater trust in peers who may have more knowledge about systems of care, resources, and "how to work the system" than workers within formal care systems.

- **Peer groups may not be able to fully support unique care needs.** Due to the nature of these illnesses, those with extreme energy limiting conditions may not be able to fully support others with the same energy limiting conditions.
- **One size does not fit all.** Individuals need to be knowledgeable of and/or understand unique experiences, cultures, and identities that intersect with specific care needs of those with post-viral IACCs.
- **Formal assistance systems of care may not be able to fully support needs.** Personal care assistants (PCAs) have restrictions on attending client medical appointments. The PCA staffing crisis leads to challenges in finding/building a consistent, trustworthy relationship. Individuals Community Living Supports (ICLS)|DHS) are insufficiently resourced/staffed and may not understand post-viral IACCs.

What success looks like (from multiple perspectives)

People with post-viral IACCs and their caregivers

- Buddies offer high quality care and support. They understand the specific needs, are a caregiver, or are people with post-viral IACCs.
- Peer network includes a variety of individuals with unique lived experiences, demographics, cultures, and identities.
- Clear understanding of how they can contribute support (especially if they also have energy limiting conditions).
- May be part of a network of supportive people who can be called upon for various types of support.
- A support system staffed by peers not professionals and are familiar with unique needs of those with post-viral IACCs.
- Buddies have time and capacity to step in a variety of ways, are invested in building a trustworthy relationship, and are compensated for their time. They are equipped, willing, and able to break down complex life tasks into “bite sized” steps.
- Care and support buddies perform a variety of tasks for home and community-based services. Tasks could include grocery shopping, applying for benefits, phone call check-ins, spending time in person, and socializing.

Formal care systems

- Peer programs are accessed and promoted within formal care systems. Formal care systems have knowledge and are able to connect those who would benefit from support.
- Formal care systems support moves beyond providing resource lists. Systems support connection to buddy programs and help match individuals based on their shared lived experiences.

Existing efforts and partners (state, local, others)

- Resources | Peer Mentoring Works
- Minnesota Home Help Navigation| #MEAction pilot (currently underway via grant from MDH): using peer experience and formal support
- HIV/AIDS Buddy programs | Action Wellness
- Certified Peer Specialists Program: Mental Illness | DHS
- Centers for Independent Living peer model (MCIL).
- Other peer-caregiver programs that offer reimbursable services (but may be different from buddy program).
- Buddy-to-Buddy Program | University of Michigan
- Campus Y: Best Buddies | Heel Life
- Expanding Behavioral Health Teams in Care Deserts With Community Health Workers and Peer Support Specialists

Focus Area: Formal Assistance

Recommendation 3: Invest in community health worker (CHW) infrastructure

> *"The fractured medical system puts an enormous burden on individuals who don't have the capacity to manage their own care."*

Recommendation description

Community health workers improve health outcomes by providing education, coaching, and advocacy. Specific tasks include assisting with care management, improving medication awareness, offering social support, and helping residents navigate complex social and health systems. This recommendation would call for investment and expansion of the community health worker workforce. That investment could include the following:

- Develop post-viral IACC-specific training for community health workers.
- Leverage and expand reimbursable care pathways to support community health worker services, including framing community health worker work as reimbursable homecare or navigation visits through insurance and related programs.
- Embed navigation support through reimbursable community health worker models.
- Support policies and investments that sustain and scale community health worker infrastructure beyond authorization, including funding and long-term viability.

Theme: System Navigation, Access to Assistance, and Policy Formation

Proposed System Change Level(s): 2, 3, 4, and 5 (Building new tools and resources, Working together better, State level policy change or expansion, State level behavioral change or accountability)

Why it's placed here: Training requires development of resources or adaptation of existing resources. Expanding reimbursable care pathways and policy investment requires advancement of existing roles through coordination across systems, alignment with state policies, and accountability for implementation and reimbursement.

ACTION STEPS

- Align stakeholders and define system fit. Convene community health worker leaders, state agencies, and payers to clarify current roles, reimbursement pathways, and system gaps. This may require policy change to expand community health worker scope and allowable services under Medicaid/state programs.
- Develop and standardize post-viral IACC community health worker model. Create training, role definition, and referral workflows tailored to post-viral IACC needs. Map access points and embed into clinical/community pathways.
- Pilot and test delivery models. Launch pilots assigning community health workers to post-viral IACC patients. Test multimodal engagement (phone, virtual, in-person) and refine based on access and outcomes.

- Identify and remove reimbursement barriers. Analyze coding, supervision, and documentation constraints. Propose fixes to enable billing and integration. This likely requires policy and/or payer rule changes (e.g., Medicaid reimbursement, billing codes).
- Build and execute sustainability strategy. Develop return on investment case and payer-facing brief. Align workforce development and partnerships to scale community health worker navigation long-term. This may require legislative appropriation or policy support for sustained funding.

Gaps and barriers making this change necessary

- **Fractured medical and care systems place burden of navigation on individuals.** People with post-viral IACCs need access to multiple systems of support to meet complex care needs. These care/health systems don't communicate well and require individuals to navigate support and solutions on their own.
- **People with post-viral IACCs are left to be "general contractors" of their own care**. This coordination and connection responsibility requires energy and stamina that isn't reliably available to people with energy limiting conditions. In some cases, it could cause further damage/harm to health.
- **Individuals lack access and awareness of community health worker support.** Community health workers may not be a well-known resource in patient care settings. People who are newly sick or just starting to understand their post-viral disability may not know what's out there—what their condition is, what resources exist, who to ask for help, or where to even start.
- **The CHW workforce is currently insufficient to meet the needs of people with post-viral IACCs.** While CHW roles closely align with the types of support required, meaningful investment is necessary to fully integrate these positions and ensure they function as a consistent resource. CHWs will require specialized training to effectively support people with post-viral IACCs. CHWs are not embedded across all systems, will need to be anchored within community health organizations.
- **Community health workers need expanded reimbursement, insurance, and policy support.** Reimbursement limitations create workforce shortages for CHWs and restrict their ability to support individuals with post-viral IACCs. Legislative changes are needed to authorize CHW reimbursement as healthcare providers. CHWs also cannot deliver certain services without a home-visit assessment ordered by a licensed clinician, and they require the ability to code patient needs and diagnoses for billing. It is unclear how many of these challenges are true systemic barriers versus coordination gaps between health providers and community organizations
- **Need to navigate obstacles with health insurance**: Clarification is needed to understand who is eligible to receive care and how to ensure sufficient hours are provided and covered by health insurance.

What success looks like (from multiple perspectives)

People with post-viral IACCs and their caregivers

- Support systems are knowledgeable of post-viral IACCs and proactively provide options for high quality, person-centered resources.
- People know what resources are available, such as community health workers, and where to find them. Additional examples include being familiar with SNAP benefits and knowing where to apply for benefits if they need food support.
- Supports should meet the unique needs of the person (home visits are not always the desired resource). Assistance should include other accessible ways to support navigation (e.g., phone, email, text).
- People have easy access to resources and community health worker support. People with post-viral IACCs easily get ongoing home visits from a community health work as soon as possible. Insurance pays for the community health worker and the community health worker serves them in a way that is accessible to them including doing no harm from lengthy assessments.
- All Minnesotans with post-viral IACCs are offered community health worker support when needed.

Employers

- There is improved communication about workplace insurance benefits to support care by community health workers.

Existing efforts and partners (state, local, others)

- Minnesota Community Health Worker Alliance
- Community Health Worker Initiatives | MDH
- Community Health Worker Billing and Reimbursement | MDH
- Developing A Sustainable Plan for Community Health Workers in Minnesota | Minnesota Community Health Worker Alliance
- Expanding Behavioral Health Teams in Care Deserts with Community Health Workers and Peer Support Specialists | SAMHSA
- Washington state’s forthcoming community health worker module on long COVID

Focus Area: Formal Assistance

Recommendation 4: Online resource centers: Materials expansion targeting social service professionals

Recommendation description

Enhance existing online resource centers to support social services professionals (e.g., medical social workers, community health workers, case managers, support group facilitators, etc.) interacting with this population to provide more curated information on post-viral IACCs.

Theme: Support Systems
Proposed System Level(s): 1, 2 and 3 (Understanding what already exists, Building new tools and resources, Working together better)

Why it's placed here: Requires resource mapping, content curation, and coordination, but not new policy.

ACTION STEPS

Identify individuals for a resource mapping work group to:

- Identify where social service professionals (medical social workers, community health, case managers, support group facilitators) turn to for post-viral IACC related material.
- Connect with social service professionals to understand gaps in resources needed to support the people they serve.
- Developing specific recommendations for enhanced or improved materials/information.

Gaps and barriers making this change necessary

- **Lacking a comprehensive list of resource sites and offerings.** Comprehensive mapping of existing resources including self-help tools, support group existence, and research-based information would uncover what resources are lacking.
- **Information access for social service professionals.** Social service professionals, often positioned to be trusted resources to people with lived experience, may not know where to turn for comprehensive and accurate information about IACCs, nor might they know what specific steps they can take or connections they can make to support those individuals.
- **Lack of information benchmarks.** What should people in supporting roles be expected to know — or find — to be of genuine support to people with IACCs?

What success looks like (from multiple perspectives)

People with post-viral IACCs and their caregivers

- Social service providers treat people with post-viral IACCs and their caregivers with understanding, respect, and validation of their symptoms and limitations.
- People with post-viral IACCs and their caregivers receive accurate, relevant, and clearly explained information or referrals from social service professionals.

Community organization site hosts

- An expanded, well-curated list of post-viral IACC resources would be available attached to existing resource centers.
- Organizations understand the needs, assets, and resources of each community.
- Web traffic from social service professionals steadily increases.
- Feedback from users provides useful information for future improvements/additions.

Social service professionals

- People in supporting service roles know where to find well-curated, easy-to-navigate resource sites to help those they assist.
- People in supporting service roles have a baseline understanding of post-viral IACCs and the challenges faced by those affected, enabling them to communicate with compassion and respect.

Existing efforts and partners (state, local, others)

- Disability Hub MN
- PACER Center: Champions for Children with Disabilities
- Disability Minnesota
- Resourceful Community Resource Guide
- Findhelp: Browse Social Services in Minnesota

Focus Area: Formal Assistance

Recommendation 5: Strengthen infrastructure between community, health, and formal assistance systems of care

Recommendation description

Strengthen the connective infrastructure between nonprofits, health systems, insurers, and the state to improve access to formal assistance.

Theme: Access to assistance
Proposed System Change Level(s): 3 and 4 (Working together better, State level policy change or expansion)

Why it's placed here: Essential first step could include exploring partnerships or leveraging relationships with others working in this space. Further infrastructure development will require additional resources.

ACTION STEPS

- Convene and co-design cross-sector infrastructure**.** Engage health systems, community organizations, and people with lived experience to jointly design referral and navigation systems with shared ownership and governance.
- Map gaps and standardize coordination. Identify breakdowns in referral pathways. Establish shared criteria, minimum datasets, and a curated, high-trust resource directory.
- Pilot and validate closed-loop referrals**.** Test tracked, confirmed, and followed referral models. Define and measure quality indicators for connection, access, and usefulness.
- Build sustainable coordination capacity**.** Fund backbone infrastructure and require compensated community participation in system design and implementation. This may require policy/funding changes to support ongoing coordination and governance.

Gaps and barriers making this change necessary

- **Lack of funding for infrastructure.** Funding infrastructure for building networks is not prioritized or missing altogether.
- **Inadequate technology for referrals, accountability, and follow-up.** Websites trying to connect people with community organizations are inadequate, referrals may not be reliable. Data sharing challenges prevent communication between care systems.
- **People with post-viral IACCs may not know how to access programs.** Individuals still need to make a connection and know how to "get into the front door" to receive services.
- **Missing voice and direction of the community and people with lived experiences.** Community voices are a "second thought" (initiatives that are happening are working from the top down), and the voices of those most impacted are not being heard.
- **Lack of compensation.** Uncompensated community advisory boards prevent individuals from supporting/putting feedback direct to the system.

- **Care systems are not coordinated.** Power imbalances due to resources and funding inequities exist between health systems and community-based organizations. Infrastructure is often lacking between health systems and nonprofits, is not well-implemented, or is not sustained. Dedicated resources are needed.
- **Wrong measures of success.** Need to shift success norms away from *quantity of patients* towards *quality of services* and/or *improved lives* based on input from those served.

What success looks like (from multiple perspectives)

People with post-viral IACCs and their caregivers

- Experience smooth, coordinated transitions across and between systems of care in partnership with the person served. This includes coordinated transitions from hospital to home or to community-based services, ensuring that home health, personal care assistance, and accessible transportation are arranged at discharge.
- Systems start by asking about needs and then match those needs with high quality referrals.

Formal assistance organizations

- Grant funding accountability/reports/feedback mechanisms consider stories and community voice — qualitative impact (not just “counts”).
- Accountability structures elevate community voice through qualitative reporting and compensated community advisory boards.
- Partnerships between payers, clinics, and community-based organizations operate equitably, supported by shared tools, integrated technology, and open information exchange.
- Financial and operational models shift from fee-for-service to more sustainable service models.
- Strong, overlapping relationships among navigators, social workers, case managers, CHWs, and other support roles enable coordinated assistance.

Existing efforts and partners (state, local, others)

- Resourceful Community Resource Guide
- Building Bridges Between Health Care and Community | Stratis Health
- Community-Clinical Linkages | MDH
- HIV/AIDS care — integrative initiatives among agencies and nonprofits. Supported by grants, funding sources, and public health departments.
- Grant applications and reports that reflect stories and are community input driven.

Focus Area: Formal Assistance

Recommendation 6: Telehealth and remote assessments

"We need to make sure that telehealth isn't just an option, that it is actively being offered to everybody, not just a thing that if you know how to request it, you can get."

Recommendation description

Expand low-barrier access to assistance by recognizing telehealth and remote assessments for healthcare and formal assistance as essential modes of care for people with post-viral IACCs.

Theme: Access to assistance
Proposed System Change Level(s): 4 (State level policy change or expansion)

Why it's placed here: Requires coordination and alignment across providers, payers, and systems. May need additional resources, policies, or legislation for formal adoption.

ACTION STEPS

- Assess access and define system gaps**.** Inventory where telehealth is working and identify policy, payer, technology, and eligibility barriers, especially for Medicaid and rural populations. This may require policy change to address coverage and access inequities.
- Advance policy and standardize expectations**.** Develop a policy brief. Promote telehealth as a proactive care option. Explore guidance recognizing remote access as an accessibility accommodation. This likely requires policy/regulatory changes (reimbursement, modality rules).
- Pilot and implement telehealth models**.** Test remote functional assessments and benefits navigation. Build provider guidance on appropriate modality use (phone, video, async, in-person).
- Expand access and awareness**.** Partner with organizations to increase broadband/device access. Create patient-facing resources on telehealth rights and how to request remote care.
- Measure impact and optimize**.** Track uptake, show rates, patient burden reduction, and satisfaction to refine models and support scaling.

Gaps and barriers making this change necessary

- **Need to expand virtual assessment:** Virtual assessments are not accepted for accessing various disability benefits, programs, or services.
- **Funding and costs to service provision prevent access.** Telehealth is not always reimbursed by insurance. The cost for providers to provide telehealth make it unaffordable for clinics who would provide services.
- **Legislative or system care policies that cap or reduce options for telehealth care.** During the COVID pandemic there were legislative actions that allowed increased telehealth care (video/telephone), but these were reduced or eliminated as the pandemic eased.

- **Broadband access and expense of high-speed internet reduce options for some people to reliably use telehealth.** Telehealth is limited for individuals who cannot afford high speed internet, and for individuals in who may not have broadband connection needed for virtual telehealth appointments.
- **Internet not considered a utility**. If internet were considered along with similar subsidies as a utility, access would increase.
- **Inadequate knowledge of post-viral IACCs and care needs.** Care professionals who lack understanding of post-viral IACCs may be less proactive in advertising their telehealth services as an option for care.
- **Policy system roadblocks.** Restrictions in providing telehealth across state lines create challenges in accessing quality services.

What success looks like (from multiple perspectives)

People with lived experience of post-viral IACCs

- Functional assessments conducted via telehealth are an acceptable means of qualifying for programs, including those that offer home and community-based services.
- All healthcare providers/health systems proactively offer telehealth. Telehealth is offered and available without needing to be requested. Patients experience fewer workarounds to get these services.

Formal assistance systems

- Policies incentivize and promote telehealth. State mandates telehealth care as an accessible mode of care/services for people with disabilities.
- Subsidies are available to Minnesotans to support internet access and provide increased access to telehealth/virtual services. State could provide subsidies to individuals needing this level of care to support access.

Existing efforts and partners (state, local, others)

- The Impact of Telehealth Adoption on Patient Outcomes: A Systematic Review: Study showing positive impacts on telehealth, especially for people with chronic diseases like cancer and barriers to accessing care including rural health systems.
- Consult with clinics and health systems that automatically offer telehealth appointments during the scheduling process for certain appointments.
- PCs for People — a nonprofit that provides hotspots.

Focus Area: Formal Assistance

Recommendation 7: Support accommodation guidance and promote disability inclusion in schools and workplace

"Had I been believed that I was suffering through an illness at that time, there would have been…support for workplace accommodations or work from home."

"I wish that there was…more understanding, especially for kids in school. There needs to be accommodation for people dealing with post-viral situations, and the understanding that you really never know what body you're going to wake up to."

Recommendation description

- Restore and localize guidance for school and workplace accommodations related to post-viral IACCs.
- Increase awareness of post-viral IACCs in school and workplaces, promote disability inclusion and accommodations, and ensure consistent implementation of protections in Minnesota.
- Develop and disseminate employer and school-facing education modules focused on Americans with Disabilities Act (Americans with Disabilities Act (ADA)) Title I accommodations.

Theme: School and workplace accommodations

Proposed System Change Level(s): 1 and 3 (Understanding what already exists, Working together better)

Why it's placed here: Resources already exist. Some schools and employers are not aware, not interested, or have limited internal resources. Primarily involves information sharing and targeted outreach rather than new enforcement mechanisms.

ACTION STEPS

- Assess and curate existing guidance. Inventory and synthesize accommodation resources (e.g., Job Accommodation Network (JAN), Vocational Rehabilitative Services (VRS), Disability Hub, Centers for Independent Living (CILs)) into a localized, Minnesota-specific toolkit.
- Assess employer needs and baseline gaps. Engage employers, HR leaders, and workers with lived experience to identify knowledge gaps and barriers, and support development of and/or adaptation of training, tools, and resources.
- Assess school system needs and baseline gaps. Engage school leaders, HR leaders, and families with lived experience to identify knowledge gaps and barriers, and support development of and/or adaptation of training, tools, and resources.
- Synthesize legal and practical guidance. Translate Americans with Disabilities Act (ADA) Title I requirements and existing accommodation resources into clear, actionable guidance tailored to post-viral IACC realities (fluctuating, invisible disability).
- Develop targeted education and tools. Create modular training for school system staff, HR, supervisors, and small employers. Include practical accommodations, scripts, one-pagers, short and stigma-reduction guidance. Build companion clinician resource for documentation and referrals.

- Enable consistent delivery and use. Develop a train-the-trainer model so workforce and disability organizations can deliver guidance uniformly and at scale.
- Disseminate through trusted channels. Promote the toolkit via school districts, employer networks, state agencies, workforce systems, and healthcare providers to reach both employers and workers.
- Pilot, refine, and build referral pathways**.** Test with early-adopter employers and incorporate feedback. Provide clear referral maps for additional support (e.g., vocational services, community organizations).
- Sustain and continuously improve**.** Assign ownership for updates and track usage and user questions to refine content over time. This may require policy/funding support for ongoing maintenance and infrastructure.
- For more policy recommendations related to disability rights, see also: Policy Considerations.

Gaps and barriers making this change necessary

- **Disability discrimination and a culture of stigma.** Many employees still have a fear of sharing any health info because they feel they could be putting their jobs at risk. They may be less comfortable asking for accommodations. This may result in job performance challenges and lack of retention of good employees. Co-workers may stigmatize someone with an accommodation.
- **Reluctance to provide documentation.** Healthcare professionals unfamiliar with post-viral IACCs may be reluctant to provide necessary documentation needed for accommodations for school or workplaces. They may not be compensated for the time it takes to complete the paperwork or work with their patient’s employer.
- **Professionals within school systems (e.g., teachers, social workers, counsellors, nurses, etc.) are unfamiliar with post-viral IACCs** and therefore less aware of accommodations needed to successfully support students with post-viral IACCs.
- **Health conditions can limit the ability of individuals with PV-IACCs to self-advocate or pursue legal action if discrimination occurs.** They may have less time, energy, and resources, and may need to prioritize their health needs and rest.
- **Employers and school systems may lack knowledge of existing resources.** Students, caregivers, and employees aren’t being referred to existing resources (such as vocational rehabilitation services and their local center for independent living).
- **Post-viral IACCs and long COVID are often invisible conditions**. These conditions may not be obvious and fluctuate over time. Those with post-viral IACCs may relapse or remit, which is part of the disabling experience.

What success looks like (from multiple perspectives)

People with post-viral IACCs and their caregivers

- Individuals receive proactive, seamless accommodations and do not have to struggle or forego access to services, benefits, and supports.
- Individuals feel safe disclosing disability and accessing supports without stigma or penalty.

- Individuals are directly connected to navigation support and services (e.g., vocational rehabilitation, Centers for Independent Living, Medical Assistance, etc.) when appropriate and desired by them.

Employers and school systems

- Clear, accessible, and actionable information on post-viral IACCs and accommodations is widely available to schools, employers, and HR professionals, with direct pathways to support (not just static resource lists). Employers know where to go for guidance and can quickly access support.
- Employers (including small businesses) and school systems understand, validate, and proactively implement accommodations, including for cognitive impacts (e.g., brain fog).
- Disability inclusion is embedded in culture. Leadership signals support, and individuals feel safe disclosing needs without being treated as a burden.
- Small businesses have the knowledge and resources to offer accommodations to their employees.
- Flexible employment designs (e.g., part-time roles, flexible schedules, and remote options, reduced multitasking, and quiet environments, etc.) are normalized.
- Student IEPs and 504 plans consistently reflect appropriate accommodations, with coordinated support from educators, families, and school-based officials.
- Students are connected to supports to help them transition to the workforce.
- Employers can support for accommodations for cognitive conditions, which may include:
    - Flexible scheduling (work hours, project deadlines, etc.).
    - Written instructions, that can be referenced back to if forgotten, versus verbal instructions.
    - Reduced multitasking requirements.
    - Quiet work environments.
    - Remote work whereby someone can lay down while performing tasks is ideal, but perhaps not allowed based on the nature of the job.

State systems

- Toolkits are improved, made robust, and widely used to standardize and strengthen accommodation practices.
- Systems enable clear, connected pathways so employers, schools, and individuals can easily access navigation, services, and benefits.

Healthcare systems

- Healthcare professionals understand their role and actively support school and workplace accommodation plans.
- Healthcare professionals have the organizational support, tools, guidance, and compensated time they need to confidently provide timely, appropriate documentation (e.g., accommodation letters, impact on functionality) necessary for their patients to access workplace accommodations.

Existing efforts and partners (state, local, others)

- Americans with Disabilities Act (ADA) Minnesota | Metro Center for Independent Living
- Americans with Disabilities Act (ADA) | Great Lakes Center
- Job Accommodation Network (JAN) - employers and employees can call for guidance on getting or granting accommodations
- Disability Hub MN
- National Alliance for Healthcare Purchaser Agreements - now looking at relaunching a MN employer healthcare group.
- Employer Reasonable Accommodation Fund | Minnesota DEED
- Consider diabetes education or heart disease programs as examples
- Minnesota vocational rehabilitation services (VRS) modules. Vocational rehabilitation services can help people with disabilities not just find but retain employment through supports and accommodations.
- Documentation for Return to Work and Disability | MDH
- Pediatric Guide to Pacing | Long COVID Families
- Long COVID under Section 504 and IDEA Resource to Support Children, Students, Educators, Schools, Service Providers, and Families (PDF)
- The New "Invisible" Illness: How School Nurses Can Support the Nursing and Educational Teams for Student Success (PDF) | National Association of School Nurses
- Supporting Students with Long COVID: A Workbook for Disability Service Providers (PDF) | Inside Higher Ed
- Supporting a Student with Long COVID (PDF) | Kennedy Krieger Institute
- Supporting Children Living with Long COVID to Manage Their Energy with Pacing Penguins | Long COVID Kids

Focus Area: Health Outcomes

Recommendation 1: Disseminate formal CMSS (Council of Medical Specialty Societies) resources to primary care providers and specialists

> *“I had printed off some documents from the #MEAction Network, and the ME/CFS Clinicians Coalition. I'm doing the education…and I'm fighting with MDs like, ‘I have peer-reviewed medical studies that I can send you.’ You just have to defend yourself. That's not the relationship that you want to have with your doctor.”*

Recommendation description

Expand formal educational opportunities by disseminating existing CMSS Long OVID Resource Repository, focusing on both primary care providers and specialists who receive referrals. These evidence-based resources were produced via a federally funded collaborative effort that included a multidisciplinary panel of primary care, specialists, advanced practice providers, and patients.

Theme: Preparation for Healthcare Professionals
Proposed System Level: 1 (Understanding what already exists)

Why it’s placed here: Resources already exist and can be shared through established dissemination networks. The work primarily involves coordination and outreach rather than new development.

ACTION STEPS

- Inventory existing post-viral IACC-related CMSS resources. Note where resources are more/less prevalent and prioritize any major gaps. Where gaps are identified, seek alternative authoritative sources as supplementary materials.
- Explore opportunities to ensure there are adequate warnings around exercise-based rehabilitation and that guidance around pacing and energy management are emphasized.
- UpToDate (software used by clinicians that is a point-of-care medical resource to support clinical decisions) is widely used. Work with lead authors of post-viral IACC-related topics to assure integration of appropriate CMSS materials.
- Explore dissemination tactics with health systems and professional societies, such as embedding in CMEs, electronic health record (EHR)s, etc.
- Determine which of these resources would benefit health plans and their care managers and disseminate in an easy-to-use format, and/or with assistance from AI tools.
- Develop brief summaries as point of care resources that are easy to access and quick to digest, and/or consider use of AI search tools (some are already in production/pilot phase).

Gaps and barriers making this change necessary

- **Awareness challenges:** Resources exist, or are in development, but are not broadly known about. Not all primary care providers or specialists are aware of existing CMSS resources.
- **Clinician capacity:** Much of this stems from already severely limited capacity of clinicians from existing (and increasing) demands on their time. This is especially true for reviewing the primary literature on post-viral IACCs, which is an area of active research and published in multiple journals. Resources that synthesize and operationalize denser material are considered a more efficient use of limited time.
- **Design challenges:** Existing resources are dense, challenging to access, and difficult to use or navigate in real time.

What success looks like (from multiple perspectives)

People with post-viral IACCs and their caregivers

- Clinicians and advanced practice providers know of resources to support people with post-viral IACCs. This could be accomplished by embedding resources into Continuing Medical Education (CMEs).

Clinicians and healthcare providers

- Providers can quickly scan or search resources organized by key questions or topics.
- Providers have access to tools that allow them to find essential information in under 30 seconds, potentially supported by AI.
- Payors include these in their National Committee of Quality Assurance (NCQA)-mandated published guidelines/endorsements.

General

- Partner with lead authors for post-viral IACC-related topics on UpToDate.
- During the clinical encounter, clinicians and nurses with questions about identification or management of these conditions can quickly identify reliable guidance. This would help to make the most of the visit and reduce the burden on the patient to educate the provider, as is currently often the case.

Public health

- Diagnoses are made and documented appropriately and consistently, enabling more accurate disease monitoring and assessment at the population level.

Existing efforts and partners (state, local, others)

- Long COVID Resource Repository | CMSS (these resources will need to be assessed individually)
- Multidisciplinary collaborative guidance on the assessment and treatment of patients with Long COVID: A compendium statement | PM&R
- For Healthcare Providers: Post-COVID Conditions | MDH

- Long COVID Treatment Guide | RTHM
- Clinician’s Pacing and Management Guide for ME/CFS and Long COVID | Patient Led Research Collaborative
- Research, Clinical Care, and Education | Bateman Horne Center
- IACCI Living Guidelines Pilot

Focus Area: Health Outcomes

Recommendation 2: Unified clinical pathways and point-of-care clinical tools

> *"I was getting to the point where I could barely leave the house, and not because I didn't want to. We'd see one doctor, then we [would see] another doctor, then we get sent to another…it was just insane like, I was the hot potato."*
>
> *"I see a neurologist because of the POTS and stuff…I see a cardiologist for beta blockers. [It's] the multi-systemic illness, and it's hard to you know, find everything in one spot."*

Recommendation description

Develop and disseminate practical point-of-care tools, cross-specialty clinical pathways embedded into electronic health records (EHR) systems to help clinicians and nurses identify post-viral IACCs, support patients, and develop care plans.

Theme: Structural Improvement
Proposed System Level(s): 1, 3, 4 (Understanding what already exists, Working together better, State-level policy change)

Why it's placed here: Basic informational pathways are feasible, but integration and adoption require coordination across institutions and vendors. Tools exist in beta form, but implementation requires coordination, alignment, and potentially policy or funding support. Could start with pilot programs.

ACTION STEPS

- Develop a stand-alone point-of-care clinical tools roadmap that outlines where in the care pathway a tool might be accessed, by which care team member, and what information is needed. This outline would be used to incorporate existing tools, tools in development, and gaps in need of attention. This clinical care pathway would benefit from diverse input, including clinicians, nurses, people with lived experience, and medical informatics specialists.
- Leverage and assess existing validated tools (in-state and national) for integration into care pathways. Prioritize development only where gaps exist and pilot tools in widely used systems (e.g., EPIC) and make sure the tools aren't tied to one system, so they can be shared widely and updated with feedback provided by users.
- Pilot interlinked care processes in narrow, cross-specialty groups (e.g., neurology, endocrinology, and rheumatology) and publish findings.
- Consider models for telementoring within or across health systems so that providers can contact each other with questions (would need to consider privacy, reimbursement, etc.).

Gaps and barriers making this change necessary

- **Care is fragmented across specialties.** Post-viral IACCs affect multiple systems in the body simultaneously, but healthcare is often heavily siloed. Without a shared framework, patients with these conditions are often bounced between specialists who each see only their slice of the problem, with no shared framework for how to assess, diagnose, or treat the patient as a whole. This can lead to redundant assessments, harmful treatments, and patients falling through the cracks.
- **Making the current acute care model work.** Current models of care and reimbursement rely on primary care providers but also do not allow for adequate time during the patient encounter. Clinicians have little to no control over the care model.
- **Knowledge gaps due to limited exposure to people with post-viral IACCs.** Healthcare providers and clinicians have limited exposure to people with post-viral IACCs, making it difficult to retain detailed knowledge of diagnostic criteria, care protocols, or referral pathways. This contributes to inconsistent identification and management. At the same time, best-practice standards for these conditions are still emerging. Broader use of standardized care pathways and systematic evaluation of outcomes would both close knowledge gaps and accelerate learning across the care system.
- **Debunked research still leads to harm.** Poorly published trials from the past (i.e., PACE Trials) have been debunked but continue to shape care today. As a result, some clinicians may still be recommending interventions that evidence now suggests can worsen symptoms. More training around PEM is crucial.
- **Need for "active" resources.** While important, passive access to post-viral IACC informational resources isn't enough to change behaviors of providers. More "active" resources, embedded in current processes and systems (e.g., widely agreed upon progress notes for post-viral IACCs in electronic health records (EHR) systems), would make increase the likelihood of a more consistent care experience for people with lived experience and make it easier for providers to compare outcomes and learn what works.
- **Ongoing risks of standardization.** Post-viral IACCs are complex and affect multiple systems in the body. While there are potential benefits to standardizing pathways and algorithms, there will always be inherent risks that standardized approaches may make for worse outcomes for some patients.
- **Referral challenges.** Even with resources like this in-hand, there aren't enough specialists with expertise in post-viral IACCs. A pathway might correctly identify that a patient needs to see a specialist, but if those specialists have months-long waitlists or don't exist in the region, the pathway breaks down at that step. And, without a well-developed referral ecosystem, clinicians and patients may be tempted to opt for whoever is available rather than the provider that is most appropriate. This will need to be addressed, likely once further efforts to organize the resources are in place.
- **Specialty centers are few and are not accessible to many of the patients in need.** They are also not viewed as profitable/sustainable by healthcare systems.

What success looks like from various perspectives

People with post-viral IACCs and their caregivers

- The experience of obtaining a diagnosis and management plan is more standardized, consistent, and coordinated across systems.
- Diagnostic tests are not unnecessarily repeated for people with post-viral IACCs.
- People are screened for PEM and those with post-viral IACCs are no longer recommended graded exercises when not appropriate.

Providers

- Tools are integrated into electronic health records (EHR) systems, with special attention to embedding automatic triggers for clinicians and allowing clinicians and nurses to capture their decisions directly in the system.
- Findings are published in OpenEvidence and medical journals to help build credibility among historically hesitant academic audiences. Special attention is given to how publications/resources are accessed by secondary resources (e.g., AI tools).
- The experience of assessing, diagnosing, and care planning for the patient is more standardized for providers.
- Provider roles beyond just the clinician (e.g., pre-visit planning, rooming) use these resources to support the experience and diagnosis of people living with post-viral IACCs.
- Providers and clinics know about progress notes regarding post-viral IACCs and use them.
- Approaches to caring for people with these conditions are shared and become more widely available.
- There are facilitated options, such as telementoring via Extension for Community Healthcare Outcomes (ECHO) programs, to educate and empower clinicians on post-viral IACC diagnoses, pathways, and care.
- Longterm solutions include clinics un-siloing care to enable same-day, one-patient care across specialists, e.g., people with post-viral IACCs can access a management clinic for outpatient needs and another for inpatient needs, where a group of providers work together to address a single patient (in contrast to making multiple referrals to multiple areas). Consider starting with inpatient needs and/or virtually modalities.
- Support transition to home- or community-based services. When discharging patients with these conditions, health providers ensure they have at least home health setup, and ideally a personal care assistant (PCA), medical assistance (MA), and accessible transport.

Community organizations

- There is a breadth of partner organizations sharing new post-viral IACC point-of-care tools with their members, especially those incorporating point-of-care tools and those working on long COVID including, the Minnesota Department of Health, Minnesota Hospital Association, Minnesota Association of Family Physicians, Minnesota Nurse Practitioners, Minnesota Academy of Physician Assistants, American Physical Therapy Association-

Minnesota, Minnesota Occupational Therapy Association, and other specialty societies, clinical educators, and electronic health record (EHR) vendors.

Public health

- Diagnoses are made and documented appropriately and consistently, enabling more accurate disease monitoring and assessment at the population level.

Existing efforts and partners (state, local, others)

- Physical therapist in Minnesota who is doing comprehensive rehabilitation work with the American Physical Therapy Association (APTA).
- MDH, Stratis Health, and their Guiding Council of clinicians have been working on standardized progress notes for long COVID care and other electronic health record (EHR) tools to help streamline documentation, promote best practices, and ensure consistent tracking of symptoms and interventions over time. As of Spring 2026, these are ready to be piloted, and they are actively recruiting testers.
- There may be AI-supported tools coming to EPIC, UpToDate, and/or that could potentially be designed to complement the CMSS repository. Those tools could shortcut some barriers by streamlining the information and decision algorithms for providers.
- Clinicians and researchers across the country are designing and testing similar tools, including at Mount Sinai, the University of Texas Austin, Emory University, Mayo Clinic, University of Washington Medicine Shoreline, and more.
- Multidisciplinary care models developed by the AHRQ Long COVID Care Network | Agency for Healthcare Research and Quality
- See Enhancing Pediatric Long COVID Care Through Telementoring: Insights from an ECHO Program | PubMed

Focus Area: Health Outcomes

Recommendation 3: Education modules for allied health professionals and support staff

“The things that have affected me the most are incorrect use of physical therapy. For me, it was swim therapy that caused me to go to a multi-year bedbound crash. The way I explain it is when I started swim therapy, I could shower independently. When I ended swim therapy, I could not shower independently.”

Recommendation description

Develop education modules for allied healthcare professionals and students to improve understanding and support of post-viral IACCs.

Theme: Preparation for Healthcare Professionals

Proposed System Level: 2 (Building new tools and resources)

Why it’s placed here: This is primarily a content development effort that can leverage existing education and training infrastructure.

ACTION STEPS

- Prioritize a list of allied healthcare professions who would benefit from post-viral IACC education beyond clinicians and nurses. Identify high quality modules that exist and disseminate these.
- Where no modules can be identified, recruit subject matter experts, allied health professionals, and educational experts to design and build materials. People with lived experiences should be included in the development of these materials.
- Develop a dissemination package in partnership with state chapters of professional societies and others. Consider mandatory and voluntary options as well as integration into existing educational structures.
- Consider expansion to other healthcare professionals (i.e., nurses and pharmacists) and others who might be interested.

Gaps and barriers making this change necessary

- **Allied healthcare roles and support staff have a significant influence on care.** The complexity of post-viral IACCs means that in addition to engaging with their physician, a person with post-viral IACCs will likely interact with allied healthcare roles and support staff (physical/occupational/respiratory/speech therapists, mental health professionals, medical social workers, emergency room and urgent care staff, administrative coordinators, pharmacy technicians, nursing assistants, personal care attendants, dietitians, rooming staff, etc.) throughout their healthcare journeys. The cumulative effect of those interactions on a patient's sense of being supported – or dismissed – is significant.

- **Resources are often designed for only physicians.** There are resources for primary care physicians and specialists generally available. Targeting additional healthcare professionals and support staff will help broaden awareness and effective care for those with post-viral IACCs.
- **A history and culture of disbelieving people with post-viral IACCs.** Many people with post-viral IACCs have been disbelieved, dismissed, or misdiagnosed due to lack of clinician knowledge leading to delays in appropriate treatment or even causing further harm. This is especially true for people with intersecting marginalized identities such as people of color, women, and the LGBTQIA2S+ community. Educational modules should address this stigma as well as technical/medical aspects of post-viral IACCs.
- **Some healthcare professionals don't recognize they have a role to play.** Some allied healthcare professionals and support staff don't believe this issue is relevant to them, in part due to its relatively small scale.

What success looks like (from multiple perspectives)

People with post-viral IACCs and their caregivers

- Voices and experiences of those living with post-viral IACCs are reflected in educational materials (i.e., what living with these conditions looks like, feels like).
- People with lived experience are recruited to help inform resources, especially those with intersecting marginalized identities such as people of color, women, and the LGBTQIA2S+ community.

Allied healthcare providers and support staff

- Educational resources are prioritized to focus on roles with a higher prevalence of engaging with people with post-viral IACCs (e.g., physical and occupational therapists, speech language pathologists, mental health professionals, medical social workers).
- Allied health professionals are engaged through their respective state societies to increase visibility and potentially integrate into other professional development activities and trainings.
- Physical and occupational therapists are more informed about post-viral IACCs, knowledgeable of the latest research (and what has been debunked), and avoid using graded exercises with patients with post-viral IACCs when they are not appropriate/may cause harm.
- Support staff recognize ways in which they can improve the clinical experience for people with post-viral IACCs, such as masking, turning down lights/stimulation, using plain language, etc.

Public health

- Minnesota Department of Health explores opportunities for embedding post-viral IACC training requirements into existing grant making activities (e.g., exploring opportunities with the Medical Education Research Costs (MERC) program).

Existing efforts and partners (state, local, others)

- A doctor at Hennepin Healthcare has developed educational resources for physical therapy and comprehensive rehabilitation (e.g., overview of dysautonomia in a physical and occupational therapy context).
- The American Academy of Physical Medicine and Rehabilitation has a compendium of guidance that may have some overlap: Multidisciplinary collaborative guidance on the assessment and treatment of patients with Long COVID: A compendium statement. This is also in the Council of Medical Specialty Societies (CMSS) repository (*see Health Outcomes Recommendation 1: Disseminate Formal CMSS Resources for Primary Care Providers and Specialists*).
- ME/CFS Resources for Medical Students includes details about Anki Intensive Anki Critical Care flashcards. Anki is a free, open-source flashcard program that uses a spaced repetition system to learn and retain information.
- CentraCare has a quarterly collaborative conversations approach for their orthopedic sports medicine department, including Continuing Medical Education (CMEs) and Continuing Education Unit (CEUs). This model of case conferences that bring the entire care team together could be replicated for post-viral IACCs and include allied and support staff.
- Overview of the Impacts of Long COVID on Behavioral Health | Substance Abuse and Mental Health Services Administration

Focus Area: Health Outcomes

Recommendation 4: Annual Minnesota post-viral IACC clinical symposium

"We need a system in place for building knowledge among [healthcare providers] in this state."

Recommendation description

Host an annual Minnesota post-viral IACC clinical symposium to share emerging evidence, case studies, and treatment approaches.

Theme: Preparation for Healthcare Professionals
Proposed System Level(s): 1 and 3 (Understanding what already exists, Working together better)

Why it's placed here: Active hosting is a moderate lift, but passive dissemination and integration into existing conferences and learning opportunities is highly feasible.

ACTION STEPS

- Articulate a compelling vision for a Minnesota-hosted event about post-viral IACCs that is distinct, and not in competition with existing conferences.
- Prioritize a narrow set of audience(s)/outcomes for initial iterations and outline how the event could expand to include others if interest grows.
- Research potential dates that wouldn't conflict with existing conferences.
- Recruit partner(s) to support development/publication of white paper(s) from the event.

Gaps and barriers making this change necessary

- **Limited sustained attention.** Past efforts have tended to be one-time events, which capture a different kind of shorter-term attention compared to annual events focused on the topic. Annual events, conversely, help sustain attention.
- **Need for more localized gatherings.** Some versions of similarly focused, recurring events exist but they are international and/or virtual. This often makes it difficult to share information specific to the regional/state/local level, as well as limits opportunities for relationship building and collaboration.
- **Limited time among clinicians.** Clinicians have very limited time to attend professional development gatherings, increasing the need for any potential event to be high value.

What success looks like from various perspectives

People with post-viral IACCs and their caregivers

- People with post-viral IACCs and their caregivers are aware of the event and can encourage their health care and social service providers to attend, helping broaden its reach.
- Specific efforts have been made to broaden the audience (and engagement mechanisms) to include non-clinicians and people with lived experience of post-viral IACCs. These efforts help uplift the experiences and voices of people with lived experience, increasing trust in and belief of people with lived experience by healthcare providers.

Event success

- The event is state-specific in how it's organized and what is presented, but open to all to attend.
- Dedicated planning and sponsorship support (e.g., Dr. Ruby Tam's clinic, Mayo Clinic), including capacity for supporting key players in the field to lead and/or meaningfully participate.
- Event modality includes in-person and virtual opportunities to participate.
- Virtual components reduce costs and increase participation/expand who can participate (though it may reduce depth of participation) especially for those with post-viral IACCs who may not be able to attend in person.
- In-person components support relationship building and help spark opportunities for potential collaboration. This could include formats like poster sessions to widen participation.
- The event results in the publication of valuable whitepapers for the field (especially around structural issues) and consider ways to capture takeaways and resources in a "living resource" that updates after each iteration.
- Regular engagement about post-viral IACCs boosts awareness broadly, including among members of the media.

Healthcare providers and clinicians

- The symposium is organized/run by clinicians.
- High-priority topics (e.g., integrative medicine) help boost participation.
- Participation in the event satisfies Continuing Medical Education (CMEs).

Community organizations

- There is a breadth of partner organizations including, e.g., the Minnesota Department of Health, academic medical centers, specialty societies, and patient advocates.

Existing efforts and partners (state, local, others)

- Annual Long COVID International Conference | Academic Medical Education
- International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis IACFS/ME Conference
- Unite to Fight: Long COVID and Myalgic Encephalomyelitis Virtual Conference
- Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and Gulf War Illness International Conference
- Extension for Community Healthcare Outcomes (ECHO) Programs | Open Medicine Foundation and Bateman Horne Center
- Mast Cell Activation Syndrome (MCAS) International Conference

Focus Area: Health Outcomes

Recommendation 5: Person-centered clinical care

> *"There was a lot of bad advice. I was told since nothing's wrong, I can ignore my pain and fatigue, which is why I got bedbound years later because when you ignore the fatigue, you get worse."*

Recommendation description

Promote person-centered clinical protocols that validate lived experiences, integrate trauma-informed care, and reduce stigma and harm for post-viral IACCs.

Theme: Structural Improvement
Proposed System Level(s): 1 and 3 (Understanding what already exists, Working together better)

Why it's placed here: Protocols could be developed quickly and could include a few post-viral IACC specific recommendations. Implementation will require broader disease consideration, not just post-viral IACC.

ACTION STEPS

- Draft recommended post-viral IACC patient care standards for clinical and hospital settings. Recruit people with lived experience of these conditions to support these efforts with an emphasis on people with intersecting marginalized identities (such as people of color, women, and the LGBTQIA2S+ community) and those with hospitalization experience. Include the recognition of post-exertional malaise to avoid unintentional harm.
- Prioritize physical and occupational therapy for targeted engagement around draft patient care standards. Recruit leaders from within the physical and occupational therapy fields to co-present (with people with lived experience of post-viral IACCs) on the draft standards at relevant professional gatherings.
- Gather diverse participants from clinical and patient communities to discuss trauma-informed care and others patient-centered standards to review instances of successful implementation and recommend basic and advanced implementation protocols.
- Gather clinicians and people with lived experience to serve as representatives who can develop shared communication and other strategies that build therapeutic and trusting relationships that support self-efficacy of people with lived experience. This would be based on literature reviews and real-world experiences of challenges patients and clinicians face individually and collectively.

Gaps and barriers making this change necessary

- **Widespread ignorance of post-viral IACCs' existence.** Knowledge barriers can result in clinicians knowing less about these conditions than their patients. This is a vulnerable position for providers, and some resist this discomfort by not believing their patients and dismissing their symptoms as unimportant.

- **Documented patterns of disbelief.** People with post-viral IACCs consistently report deeply frustrating healthcare experiences, often reflecting cultures and attitudes in clinical settings that feel minimizing or dismissive of their lived experiences. In this way, the healthcare system has been part of the harm. This is especially true for people with intersecting marginalized identities such as people of color, women, and the LGBTQIA2S+ community.

- **Systemic barriers create compounding challenges for people with post-viral IACCs.** Healthcare systems were designed to deliver standardized, time-limited care, but like many complex conditions, post-viral IACCs require individualized assessment and coordination across multiple specialties. The siloed structure of healthcare makes that coordination difficult, increasing the risk of misdiagnosis and fragmented treatment. In the absence of system-level coordination, the burden of navigating and connecting care often falls to patients and their caregivers. This is a significant risk for post-viral IACC patients, whose symptoms (e.g., cognitive dysfunction, fatigue, and post-exertional malaise) can often make sustained self-advocacy extremely difficult.

- **Bright spots are limited in scale.** Some specialists with more knowledge of these conditions are well-regarded by people with lived experience and the broader post-viral IACC community (often playing a quasi-primary care provider role and helping address systemic barriers). But these providers are limited in how many patients they can serve, resulting in long wait lists and restricted access for many who need them. Many have also faced burnout.

What success looks like from various perspectives

People with post-viral IACCs and their caregivers

- People with post-viral IACCs and their caregivers are recruited to help inform standards, especially those that have experience being hospitalized for post-viral IACCs and those with intersecting marginalized identities such as people of color, women, and the LGBTQIA2S+ community.

- People are supported in their transition to home- or community-based services. Upon discharge, they have at least home health setup, and ideally a personal care assistance and medical assistance support and accessible transportation.

- People are screened for post-exertional malaise (PEM) are not automatically prescribed exercise therapy. Hospitalized patients are offered appropriate support such as feeding tubes when necessary.

- Self-advocacy is easier, especially in high-priority settings, such as educational institutions and hospitals.

Healthcare providers and clinicians

- Generally, providers believe patients with post-viral IACCs as reliable witnesses of their own lived experiences and catalogue those experiences to inform diagnosis, care planning, and evaluating effectiveness of therapies.

- There are clear hospital care recommendations available for post-viral IACCs.

- Providers are aware of and empowered to integrate trauma-informed care principles, such as:

  - Safety: physical and emotional
  - Trustworthiness/Transparency: building trust through open organizational decisions
  - Choice: empowering individuals to have a voice in their care
  - Collaboration and mutuality: partnering, leveling power differential
  - Empowerment: validating strengths and fostering skill building
  - Cultural, historical, and gender issues: moving past stereotypes to provide responsive care

Existing efforts and partners (state, local, others)

- Harvard's inpatient IACC group.
- "Do No Harm" Checklist Makes Care Safer by Design | Institute for Healthcare Improvement
- What is Trauma-Informed Care? | Trauma-Informed Care Implementation Resource Center
- Trauma-Informed Care: Evidence and Pragmatic Approaches | AAFP
- Health Care Homes | MDH

Recommendations for population-level monitoring, assessment, and evaluation

Population-level disease monitoring helps track impacts and health trends to inform public health responses. MDH has identified this set of data-focused recommendations to strengthen population-level disease monitoring, assessment, and evaluation to understand post-viral IACCs in Minnesota. These recommendations are intended to support the development of robust and sustainable systems for actionable, population-level monitoring and assessment.

The primary audience for these recommendations includes public health and population health professionals. However, inclusion of others, such as people with lived experience and partners in healthcare and communities, is essential for co-designing effective public health approaches overall.

Recommendation 1: Establish consistent case definition(s) for viral diseases, post-viral chronic conditions and related conditions

Recommendation description

Establish, promote, and revise (as needed) monitoring and assessment case definitions for infectious viral diseases, post-viral IACCs, and related conditions. Standardized population-based case definitions are the foundation of public health monitoring. This is particularly important for post-viral IACCs as this is an emerging area of health and public health, and because clinical diagnosis is symptom-based.

ACTION STEPS

- Adopt and/or align with consensus clinical definitions promoted by the Centers for Disease Control and Prevention and other expert professional and patient-led organizations, including National Academies of Sciences, Engineering, and Medicine (NASEM).
- Promote use of International Classification of Diseases, 10th Revision (ICD-10) coding by clinicians and healthcare providers.
- Participate in the development, adoption, and alignment of consensus-based, population-level public health monitoring and assessment definitions.
- Design and/or validate population-based monitoring and assessment definitions by data sources and, as needed, ensure validity for demographic and marginalized subgroups.

Gaps and barriers making this change necessary

- **Lack of consistent documentation of acute illnesses in the medical records.** Consensus definitions for viral infections based on diagnostic tests, self-reporting, or other methods need to be documented as they can vary by virus, data source, and the population being assessed.
- **Definitional challenges.** The clinical definition for post-viral chronic conditions such as long COVID is non-specific, broad, and shares symptoms and presentation with other chronic diseases.
- **Infrequent and inconsistent diagnostic coding.** Underdiagnosis and under-utilized documentation of viral disease and post-viral chronic conditions by healthcare providers mean that the diagnostic codes for viral infections and post-viral IACCs are not used frequently or consistently, even when the conditions are present.
- **There is a need for validation studies** of population-based case definitions of viral infections and post-viral IACC, including for related symptoms and conditions such as post-exertional malaise (PEM), myalgic encephalomyelitis (ME/CFS), and postural orthostatic tachycardia syndrome (POTS).

Existing efforts and partners (state, local, others)

- Long COVID Data and Reports | MDH
- The Public Health Approach to Long COVID | CDC
- Long COVID Surveillance Quick Reference Guide (PDF) | CSTE
- RECOVER COVID Initiative | NIH

Recommendation 2: Establish an essential set of objectives and core metrics to monitor and assess post-viral IACCs and related conditions

Recommendation description

Identify, prioritize, and validate objectives and indicators to equitably monitor, assess, and evaluate the health, social, and economic impact of post-viral IACCs in Minnesota.

ACTION STEPS

- Strengthen and maintain collaboration between public health infectious disease and chronic disease programs to identify, pilot, and establish post-viral IACC monitoring and assessment objectives and core indicators.
- Partner with federal, state, local public and Tribal health, and other stakeholder colleagues to review and recommend core population-based viral and post-viral IACC impact, outcome, and evaluation metrics, including recommendations for data sources and valid indicators.
- Collaborate with patient-led organizations and marginalized communities to design population-based indicators relevant to improving the knowledge, awareness, behaviors, and outcomes in their communities.
- MDH, researchers, and other public health institutions should conduct or support studies to validate and improve viral and post-viral IACC health, social, and economic outcome indicators.

Gaps and barriers making this change necessary

- **Assess impact and change over time.** Need for specific, measurable, actionable, reliable, time-bound, inclusive, and equitable objectives to assess post-viral IACC impact and change over time.
- **There is a need to identify and prioritize viral and post-viral IACC indicators.** This is challenging due to the large number of potential symptoms. It is also difficult because post-viral IACCs can be hard to diagnose validly. In addition, many protective and risk factors influence these conditions. Symptoms can fluctuate over time, which adds further complexity. Determining core outcomes across time periods is also necessary.
- **Need to identify and prioritize factors affecting daily activities** of living at home, work, and school, including social and economic outcomes.
- **Challenges in data collection and data sources** for ongoing monitoring and assessment of prioritized population-based indicators and metrics.
- **Definitions and validity of identified indicators vary**, especially by data source.
- **Barrier reaching stakeholder consensus.** Reaching stakeholder consensus on prioritizing and defining core metrics is a significant challenge.

- **Equity-driven metrics.** Identifying, designing, and prioritizing objectives and indicators that advance health equity and disability justice is needed.

Existing efforts and partners (state, local, others)

- Long COVID Data and Reports | MDH
- The Public Health Approach to Long COVID | CDC
- Long COVID Surveillance Quick Reference Guide (PDF) | CSTE
- RECOVER COVID Initiative | NIH

Recommendation 3: Implement epidemiology studies and ongoing monitoring systems to assess viral and post-viral IACC impacts, guide programs and policies, and assess progress toward post-viral IACC objectives

Recommendation description

Design, validate, implement, and use modernized, integrated, and sustainable viral and post-viral IACC population monitoring systems leveraging existing data sources while exploring new or additional systems. These systems should be timely, cost-effective, sustainable, and equitable. Data should be disaggregated by severity, race, ethnicity, gender identity, disability status, income, geography, and along other lines of potential disparity whenever possible.

ACTION STEPS

- Establish Minnesota advisory group to identify, prioritize, and facilitate the design and implementation of viral and post-viral IACC epidemiologic studies and monitoring systems.
- Collaborate with decision-makers to ensure sustainable viral and post-viral IACC monitoring and assessment resources, including workforce development and maintenance.
- Partner with researchers, public health, community organizations, and people living with post-viral IACCs to prioritize, design, and support implementation of epidemiology and evaluation studies and post-viral IACC monitoring systems.
    - Partnerships can be at the local, state, Tribal, or federal level.
    - Ensure long COVID and ME/CFS measures are routinely included in the Minnesota Behavioral Risk Factor Surveillance Survey.
    - MDH continues to interview over time Minnesotans who test positive for COVID-19 and other viruses that can cause long-term health problems.
    - MDH and Minnesota Electronic Health Records Consortium (MN EHRC) continue to explore impact of post-viral IACCs as documented in the medical record.
    - MDH conducts post-viral IACC economic analyses using the Minnesota All Payers Claims Database.
    - Conduct community-based qualitative and quantitative assessments of post-viral IACCs.
- Partner with researchers, health systems, healthcare insurers, and community benefit organizations to foster appropriate medical record documentation of viral infections, subsequent post-viral IACC diagnosis, ongoing management of the symptoms, and associated health outcomes.
    - Foster collection of indicators for limitations of daily activities, social needs, referral and receipt of support services, and measures to assess health equity and disability justice.
    - Implement feasibility pilots of electronic medical record clinical decision-making tools that promote accurate and timely documentation of post-viral IACC indicators.

Gaps and barriers making this change necessary

- **Need for sustainable funding and resources**. Insufficient funding prevents the implementation of epidemiologic studies and ongoing monitoring systems needed to assess viral and post-viral IACC impacts and track progress.
- **Need for clear system definition and prioritization.** Lack of clarity on how to define and prioritize post-viral IACC population-based systems limits the ability to meet monitoring, assessment, and evaluation objectives.
- **Need for adaptable system design.** Ensure systems are adaptable to emerging evidence and related conditions.
- **Need for integrated and modernized data systems** to support public-private infectious disease and chronic disease data monitoring systems.
- **Need for epidemiologic studies and pilot feasibility studies** to implement and improve viral and post-viral IACC monitoring and assessment data systems, including integration of these systems when appropriate.
- **Need for comprehensive data approaches.** Community assessment and monitoring systems should include both qualitative and quantitative data.
- **Challenge to ensure equity in system design and implementation.** Barriers to designing and implementing equitable monitoring and community assessment systems risk underrepresenting disproportionately affected communities.
- **Need for sustained workforce capacity and expertise.** Gaps in workforce development and retention hinder the design, implementation, analysis, interpretation and dissemination of post-viral IACC monitoring results.

Existing efforts and partners (state, local, others)

- Minnesota Electronic Health Record Consortium (MNEHRC)
- The Role of U.S. Public Health Agencies in Addressing Long COVID | American Journal of Preventive Medicine
- Long COVID Resources for Community Recovery | ASTHO
- Strategies and Innovations to Address Long COVID | ASTHO
- Building Stronger Programs to Address and Mitigate Long COVID Effects | ASTHO
- Community wraparound service organizations

Recommendation 4: Actively use monitoring and assessment findings to guide, implement, and evaluate post-viral IACC impact, interventions and policy responses

Recommendation description

Implement effective, equitable dissemination of findings to specific audiences, using tailored formats (reports, dashboards, traditional and social media, etc.) to guide and inform strategies and policies to prevent and control post-viral IACCs and related conditions.

ACTION STEPS

- Establish a Minnesota communication plan and network with partners to identify dissemination opportunities, key audiences, and communication strategies and materials.
    - Collaborative approach with partners to co-lead communication and dissemination strategies.
    - Engage national and other state-based partners to promote consistent messaging of post-viral IACCs and related conditions.
- Design and implement evaluation plan to assess impact and guide improvement in strategies.
- Foster stakeholder communication and dissemination of viral and post-viral IACC findings to their respective audiences and communities.
    - Coordinate messaging to ensure accuracy, consistency, and to build trust among stakeholder audiences (i.e., mitigate misinformation and misinterpretation of findings).

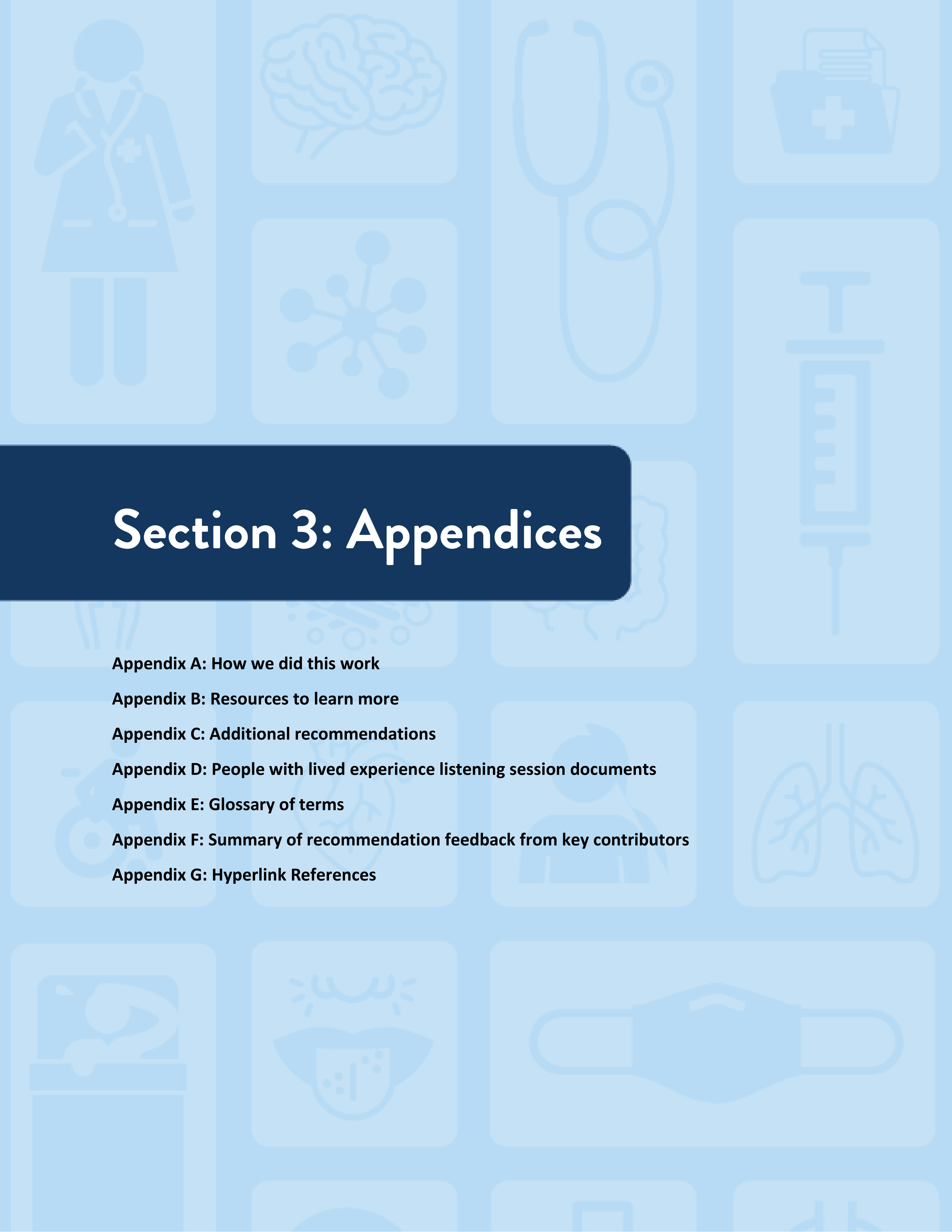
Gaps and barriers making this change necessary

- **Need for defined dissemination networks.** Absence of a coordinated network of key audiences limits the active and targeted dissemination of post-viral IACC monitoring and assessment findings.
- **Need for audience-centered communication strategies.** Communication efforts are not consistently tailored to specific audiences or co-designed with communities, reducing relevance, trust, and uptake of findings.
- **Need to embed health equity and disability justice in communications.** Communication design and dissemination strategies do not consistently integrate health equity and disability principles, limiting accessibility and inclusiveness.
- **Need to address misinterpretation and misinformation.** Lack of proactive communication approaches increases the risk of findings being misinterpreted, misused, or contributing to misinformation.

- **Need for routine evaluation of dissemination effectiveness.** Inconsistent evaluation of timeliness, reach, comprehension, and impact limits the ability to refine and improve dissemination strategies over time.

Existing efforts and partners (state, local, others)

- Long COVID Resources for Community Recovery | ASTHO
- Building Stronger Programs to Address and Mitigate Long COVID Effects | ASTHO
- Still Here: Communicating about Long COVID | Public Health Communications Collaborative
- Potential partnerships would include a broad range of collaborators, such as Minnesota Department of Health, state, local, and Tribal public health agencies; CDC and other federal institutions; patient-led advocacy organizations; media; health professional associations; health systems and insurers; the Minnesota Department of Human Services; businesses and employers; academic institutions; and community service organizations.



Section 3: Appendices

Appendix A: How we did this work

Appendix B: Resources to learn more

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Appendix D: People with lived experience listening session documents

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Appendix F: Summary of recommendation feedback from key contributors

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Appendix A: How we did this work

Overview of planning process

The Minnesota Department of Health (MDH) initiated this project to build upon work done by the Long COVID Program since 2021. MDH has convened healthcare providers, community organizations, and many partners, and surveyed Minnesotans with post-viral IACCs to understand the impacts of these conditions and related needs.

In 2023, MDH secured state funding to expand the work and support the development of a coordinated, statewide response for addressing long COVID and related conditions. This led to the need for an action-oriented roadmap to improve care and support for people in Minnesota living with post-viral IACCs and their caregivers.

The roadmap was developed between May 2025 and May 2026 through a structured, multi-phase process led by Management Analysis and Development (MAD) in partnership with MDH. MAD is the State of Minnesota's management consulting practice. The approach prioritized engagement with people with lived experience and cross-sector stakeholders, while grounding recommendations in existing data and system realities.

Project governance and steering committee

A project steering committee was established early in the process to guide overall direction and ensure alignment with stakeholder needs and system contexts. The committee included ten members selected for their expertise, lived experience with post-viral IACCs, and/or connections to broader networks across healthcare, employment systems, community-based organizations, and advocacy spaces.

MAD supported MDH in recruiting members, managing logistics, and facilitating meetings. The committee met twelve times over the course of the project. Members provided input on project design, reviewed emerging findings, helped prioritize recommendations, and contributed directly to the writing of this report.

This work was guided by Sins Invalid's 10 Principles of Disability Justice. People with post-viral IACCs were included as interviewees and as members of the work group and steering committee, where their input shaped the vision and influenced which recommendations were prioritized.

We adapted participation to support access (flexible timelines, multiple formats) and focused on the full impact of these conditions across health, daily life, and community systems. Priority recommendations identified by contributors with lived experience are summarized in Appendix F and are reflected across focus areas.

While final decisions remained within the project team and steering committee, this work moves toward more inclusive and connected system design grounded in lived experience.

Environmental scan and listening sessions

An environmental scan and a series of listening sessions were conducted by MAD between May and October 2025 to understand the current landscape of support, gaps, and system dynamics affecting Minnesotans living post-viral IACCs.

This phase included:

- **Review of existing data and resources:** Documents, materials, and reports provided by MDH and additional desk research were used to establish a baseline understanding of current challenges, services, and systems.
- **Listening sessions:** Interviews and focus groups with a total of seventeen people living with post-viral IACC's or their caregivers.

These activities identified key barriers, gaps, and opportunities across formal and informal systems of care. Findings from resource review and listening sessions were synthesized into internal summary reports and shared with the steering committee and work groups to inform early development of recommendations. A comprehensive version of these takeaways is included in Appendix D.

Engagement with people with lived experience

Engagement with people with lived experience and their caregivers was a core component of this project. In addition to listening sessions, people living with post-viral IACCs were engaged throughout the process. They held roles on the steering committee and within work groups, helping develop recommendations, and providing feedback on vision statements and recommendations in a final survey prior to publishing the report.

This approach sought to center real-world experiences and priorities, including barriers to accessing care, challenges navigating fragmented systems, and the need for more flexible and responsive supports.

Development of vision statements and recommendations

Roadmap vision statements were developed through an iterative process involving the steering committee and work groups.

Over several meetings, the steering committee defined and refined an overall vision, including desired future states and key opportunities for change across three focus areas: public life, formal assistance, and health outcomes. It's important to note that findings from listening sessions were analyzed and organized across these focus areas (see Appendix C).

From October 2025 through March 2026, MAD convened three work groups — one for each focus area — to translate findings into actionable recommendations. Each work group met four to six times and was responsible for:

- Reviewing and interpreting listening session findings and providing input on draft vision statements and goals.
- Developing and prioritizing recommendations, including identifying indicators of success and the key barriers that underpin and justify the need for each recommendation.

Recommendations were prioritized based on potential impact, feasibility, and their position along the system change framework, ensuring a balance between near-term system improvements and deeper, long-term transformation.

This phase of the roadmap development focused on collaboration across sectors and identifying actions that can move forward now, alongside those that will require longer-term system change.

Refinement and finalization

Final recommendations were synthesized into a comprehensive action roadmap between April and May 2026. MAD worked in close partnership with MDH and the steering committee to ensure the final product is clear, actionable, and aligned with identified priorities.

The steering committee also identified legislative priorities based on these recommendations and contributed to writing this report.

An early draft of the final recommendations was shared with individuals who participated in the listening sessions and workgroups. Their feedback informed final revisions of this document.

Appendix B: Resources to learn more

The Minnesota Department of Health was one of the first state health departments in the country to have a program and staff dedicated to long COVID and post-COVID conditions. In 2023, the State of Minnesota began funding the MDH Long COVID Program under law (Minn. Stat. §145.361). Program activities were expanded to include outgoing grants and contracts to organizations that serve communities disproportionately impacted by COVID-19, long COVID, and related conditions.

Minnesota-specific activities and data can be found on the MDH Long COVID Program website.

Inspiration for this roadmap: the Health+ Long COVID Human-Centered Design Report (PDF) published in November 2022. In particular, the report's opportunities framework heavily informed the selection of the three focus areas (health outcomes, formal assistance, and public life) used to organize our efforts.

Readers looking to learn more about any of the following are encouraged to start with the Health+ Report:

- The narratives and expertise of people with long COVID and what they want and need to live better, healthier lives.
- An ideal treatment journey or set of steps for seeking care for long COVID, and the pain points and barriers that often prevent treatment from occurring.
- Research takeaways and recommendations at the national level.

#MEAction: A national advocacy organization dedicated to improving the lives of people with ME/CFS and long COVID, with an active chapter in Minnesota. The organization's work centers on elevating patient experience and driving systemic change through community-based research, medical education initiatives, legislative advocacy, and organizing efforts that build networks of support and leadership across the ME/CFS and long COVID communities. Resources include:

- Resources for understanding and communicating about ME/CFS and long COVID.
- Community-driven research, educational resources, and tools for engaging clinicians and health systems.
- Advocacy strategies and policy priorities at the national and state levels.
- Opportunities for connection, organizing, and involvement through #MEAction's national and Minnesota-based activities.

Resources for all audiences and implementers are listed throughout this roadmap under each recommendation under "Existing efforts and partners." Here are a few highlights that may be broadly useful:

- Long COVID Resources and Support | MDH
- A Long COVID Definition | National Academies

- IACC Resource Guide | Infection Associated Chronic Conditions Initiative (IACCI)
- Resource Hub | Long COVID Justice
- Long COVID Guide for Social Security Disability Claims (PDF) | SSA
- ME/CFS Guide for Social Security Disability Claims (PDF) | SSA
- IACC Resource Guide | Infection Associated Chronic Conditions Initiative (IACCI)
- ME/CFS | Long COVID Justice
- 10 Principles of Disability Justice
- Job Accommodation Network (JAN)
- Long COVID | Washington State Department of Health
- Long COVID Resources for Community Recovery | ASTHO
- Long COVID Education, Engagement, and Care Management | CMSS

Resource recommendations from the ME/CFS community

The project team received the following resource recommendations from key contributors from the ME/CFS community. Please note that these resources are not medical advice and are for information sharing only. MDH does not endorse or take responsibility for the content of the forums, books, or websites below, nor do they necessarily reflect the opinions of MDH. However, we felt it was important to make information available, especially given the lack of support for people with these conditions.

Organizations / Forums & Blogs

- Bateman Horne Center – a center dedicated to dedicated to improving diagnosis, treatment, and support for people with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), fibromyalgia (FM), Long COVID (post-acute sequelae of SARS-CoV-2 infection, PASC), and other related chronic conditions.
- COVID-19 Longhauler Advocacy Project
- Health Rising – an organization providing information to people with Long COVID, ME/CFS, and fibromyalgia.
- HHV-6 Foundation – an organization dedicated to promoting and funding research on HHV-6, a virus linked IACCs.
- How to Get On – a self advocacy guide for anyone home-bound or bed-bound in the US.
- Phoenix Rising – a website and daily subscription-based email providing support for patients with ME/CFS.
- Science for ME – Where science and the ME/CFS community meet.
- Self Help – CFIDS & Fibromyalgia Self Help (online courses, library, store).
- Solve ME/CFS Initiative – a research and advocacy organization dedicated to ME/CFS.

- ME/CFS | Stuff That Works – a communal space for patients to discuss treatments and ask questions.

Provider Lookups

- ME/CFS Find a Doctor Tool | #MEAction

Diagnostic Criteria

- ME | International Consensus Criteria
- ME/CFS | Canadian Consensus Criteria
- ME/CFS | Institute of Medicine 2015 Diagnostic Criteria
- Long COVID - 2026 ICD-10-CM Diagnosis Code U09.9: Post COVID-19 condition, unspecified

Conferences

- Centers for Disease Control and Prevention - Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Stakeholder Engagement and Communication (MECFS-SEC).
- Chronic Fatigue Syndrome Advisory Committee (CFSAC) Meetings.
- IACFS/ME Biennial Conference
- ME/CFS Working Group | NANDSC-NIH
- Annual Long COVID International Conference | Academic Medical Education

Videos and personal stories:

- Unrest, a Sundance documentary winner by Jennifer Brea, an ME/CFS patient
- Suspended Animation, story of college student Mia Anderson with ME/CFS
- Voices from the Shadows, a film on ME/CFS

Books

- An Interior Life by Bill Hope
- Chronic Fatigue Superhero by Michael Towers
- The Sound of a Wild Snail Eating by Elisabeth Tova Bailey
- Your Symptoms Are Real: What to Do When Your Doctor Says Nothing Is Wrong by Dr. Benjamin Natelson
- The Long COVID Survival Guide | The Experiment

Appendix C: Additional recommendations

Each work group generated more recommendations than could be fully developed within the time and resources available for this project. In some cases, additional expertise or perspectives would have been necessary to generate a productive, actionable recommendation. As a result, the steering committee prioritized a subset of recommendations for work groups to explore more deeply based on consideration of feasibility, need, stakeholder interest, alignment with existing efforts, and potential impact. The recommendations that were not developed more fully are included here to reflect the breadth of ideas raised and to offer a foundation for future work related to post-viral IACCs.

Ideas for further exploration: Public life

Opportunity Area	Potential Future Recommendations for Public Life
General public awareness	• Provide tools to help parents/caregivers recognize symptoms common to conditions • Create and promote education ambassadors - a bank of education ambassadors to provide various kinds of education or outreach, managed by a centralized advocacy group • People with post-viral IACCs and their caregivers have ready access to reliable resources to support advocacy for their care and can easily share those resources with their healthcare providers and others supporting their care needs to strengthen clinical and systems support knowledge of post-viral IACCs
Support systems	• Fund staffing to provide statewide education and resource support • Personal assistance through healthcare systems - Expand access to more navigators/care coordinators • Expand resource list - build out resources, including resources where people get health information that may not be related to post-viral IACCs specifically but could be part of outreach • Create an underrepresented needs framework • Hub center - identify and create space for caregivers to have access to each other and ideas for supporting each other in daily life
School and workplace accommodations	• Administrator resource hub - provide information and tools about rights, policies, and supports to inform administrators about necessary accommodations

Ideas for further exploration: Formal assistance

Opportunity Area	Potential Future Recommendations for Formal Assistance
Access to assistance	• Expand access by redesigning eligibility pathways away from diagnosis dependent eligibility • Leverage and expand reimbursable care pathways • Develop a self-referral model to support low barrier access to assistance • Shift formal systems that require entry into one system for access to another to support low barrier access to assistance
System navigation	• Resource hub: Increase visibility of available resources that support access to care
School and workplace accommodations	• Build employee facing workplace-specific skills/capacity building • Build capacity through training, credentialing, and continuing education

Ideas for further exploration: Health outcomes

Opportunity Area	Potential Future Recommendations for Health Outcomes
Preparation for healthcare professionals	• Expand formal educational opportunities: Certification and professional curriculum • Coordinate the collection and sharing of information relevant for healthcare providers • Conduct outreach, provide incentives to drive participation in formal educational opportunities
Post-viral IACC research	• Establish a post-viral IACC research consortium that connects academic institutions, clinics, and patient communities to coordinate studies and share data • Develop a post-viral IACC research agenda to expedite projects/grant opportunities
Structural improvement	• Coordinate statewide support networks linking primary care teams with specialists, ensuring access to real-time clinical support across Minnesota • Develop a central hub for information and resources for providers • Expand the avenues and number of providers equipped to provide care for people living with post-viral IACCs

Appendix D: People with lived experience listening session documents

Despite facing significant barriers within systems not designed to support them, people living with post-viral IACCs demonstrate remarkable strength, autonomy, and persistence —continually educating themselves and their providers, advocating for appropriate care, and supporting one another. Their deep knowledge and lived experience offer invaluable insight for improving healthcare systems in ways that could benefit all Minnesotans.

This summary shares key themes from a series of listening sessions with individuals living with post-viral IACCs and their caregivers and was used to guide working groups in developing recommendations. Initially separated by focus area, the insights have been combined here for a comprehensive overview.

Methods

Participants were recruited through a survey shared with MDH grantees, the guiding council, and networks connected to the steering committee and MDH. Ninety-five individuals responded, 21 were selected for participation. Participants were provided VISA gift cards for their time.

Thirteen individuals living with post-viral IACCs or their caregivers took part in listening sessions or interviews. Participants were asked about key moments in their care and support journeys, resources they used, gaps they encountered, and priorities for improving systems that affect their health and well-being.

Responses were reviewed and grouped into three categories representing the focus areas for the road map—public life, formal assistance, and health outcomes. From there, common themes were identified to inform the findings and recommended priorities in this summary.

Listening session insights – Public life

Gaps of knowledge and awareness of these conditions

Participants shared that **widespread misunderstanding of chronic fatigue/energy limiting conditions** leaves them feeling dismissed and misunderstood. The name itself, they noted, makes the illness sound mild — like being tired — rather than a serious, debilitating condition. Because of this, many said they felt pressure to keep going or "push through," even when doing so made them sicker.

- "When he was diagnosed after 4 years, the doctor comes in, he goes, I've looked at your file, I know what you have, you have chronic fatigue syndrome, there's no test, there's no treatment, there's no cure, but they're doing research. And I couldn't believe that came out of his mouth. I said, don't tell me my sick kid has something that sounds like he needs a nap, a spurious chronic fatigue syndrome. It's often been said that it's like calling Alzheimer's chronic forgetfulness syndrome. It's just a horrible name."
- "Stigma is so rampant in this. I was a young adult who fit the bill of good health with a low BMI, no previous health problems, so when I went in, the quick and easiest path was to say it's psychosomatic and you're just stressed out."
- "They've rebranded it as chronic fatigue syndrome, as though it makes you sleepy and doesn't destroy your entire central nervous system. It's not fatigue. I ran 20 miles on 2 hours of sleep, 6

weeks before I got sick, and that level of tired does not even compare to my baseline level of energy now."

- "When I got sick, I ended up in the hospital. I was in college as a 20-some-year-old. I was sent home with no diagnosis, no advice, no nothing. Had to drop out, go lay on my parents' couch for the summer. I tried to recover, tried to figure out why I couldn't even walk around the block. Fast forward I went back to school, tried to finish my classes, took me twice as long as anybody else, 8 years to finish an undergrad degree, went to graduate school, because I didn't know what else to do. And I ended up… getting sicker and sicker and sicker. Life was unmanageable, and I kept searching and searching and searching for medical care."

Participants frequently discovered the name and nature of their condition on their own — often through documentaries, online communities, or peer networks — after years of medical dismissal or uncertainty. **Self-diagnosis and community knowledge-sharing played a crucial role** in helping them understand their illness and find validation when formal healthcare systems failed to do so.

- "I made my own self-diagnosis because I accidentally watched the documentary *Unrest*…when I watched that film, I was like, there's actually a name for what I have. Because before that it was chronic fatigue syndrome. I thought, [chronic fatigue syndrome] is just a garbage can diagnosis, it doesn't mean anything, and no doctors take it seriously, and they dismiss you if you say you have it."
- "I didn't know I had ME/CFS until I saw Jen Brea's film, *Unrest*. I think what's really remarkable about that film is it provides such a great visual of what ME/CFS looks like for someone."
- Figuring out that there was something called myalgic encephalitis, and then encephalomyelitis, and then figuring out that there was a support network, which I immediately contacted, and then started getting into Facebook groups and forums where I could connect to others and gather more information because I didn't even know about Mayo Clinic or that there were other people locally."
- "I got my information about everything from finding an online community. They were all like, hey we've had this disease and we're not getting better. And there were folks there from ME/CFS Alliance and they were like…welcome to the club. I started piecing together things like electrolytes and to check with the doctor for POTS."

Caregiver strain and critical support

Participants emphasized the **essential role of caregivers in supporting basic survival**, daily functioning, and gradual recovery for people with severe post-viral illness. Caregivers provided intensive physical assistance during periods of extreme debilitation, ongoing practical support for daily needs, and facilitated social and cognitive engagement as health improved. These supports were crucial for both immediate survival and long-term wellness.

- "If I hadn't had a caregiver there with me, who, you know, was my husband. I don't think I would have made it, and you know, not to sound extreme, but of course, he helped with everything. He brought me food, he carried me to the bathroom for the first 18 months… And being at a point where you realize, like, if the house is burning down, I'm just gonna die, because I can't, like, get myself…I can't make myself do this. My body will not work."

- “My husband shops for groceries for [our son], brings groceries every other week now. It used to be once a week. We provide rides to him if he needs it. He's well enough now to come to our house every Sunday and play Dungeons & Dragons with neighbor kids he grew up with.”
- “We're in a lot of communities, or I'm in them, he doesn't have the bandwidth to do it. He can't read a book because he can't concentrate without crashing. Very sound sensitive, lives with earplugs and noise cancelling headphones. He has gut issues. He can eat about 20 foods, that includes spices. When he did that in 2018, he just made a massive jump in wellness.”

Caregivers and family members described **profound emotional strain, fractured relationships, and exhaustion** as they navigated the demands of supporting a loved one with post-viral chronic illness. Many spoke of feeling powerless to help, stretched thin by caregiving and work responsibilities, and isolated as relationships eroded under sustained stress and uncertainty.

- “As a caregiver, as a parent, as a mother, I want to fix them. You know, you can't fix them.”
- “For me and for my family, definitely my job, my work at my actual paying job has suffered. My relationship with my husband has been strained because he's doing everything at our house, right? Because I'm not there to help with the dog, or the chores, or whatever.”
- “I know my dad's relationship with his wife, has been very strained. Our parents are divorced. My mom and dad are divorced. All of our relationships are basically at their breaking point.”
- “I was living with my parents, and my parents didn't want to take care of me… [they] cared but they were burned out…. I had very little community involvement.”

Social isolation and shrinking public life

Participants described profound social isolation resulting from their illness. Many have lost close friendships, missed major life milestones, and experienced shrinking social worlds as the physical and cognitive demands of maintaining relationships became overwhelming. For some, everyday social participation is no longer possible, leading to deep feelings of grief and disconnection from community life.

- “He was doing community college and living at home, getting straight A's, and loving it…so that's always sad, I just think of moments of loss for him. That's how I would picture it. Moments of loss for him. Moments of loss for our family.”
- “Even with close friends, as a person with the condition. Spending time with them, you get exhausted. And so your world really shrinks.”
- “No one who is mentally healthy is choosing to lay in bed with literally no stimulation, wearing adult diapers, drinking baby food that's watered down so you can drink it through a straw. Just no one is choosing that life and whether it's a physical thing or not, people deserve support.”
- “It is isolating to be sick like this… because of the sort of energy requirements of meeting people in person and showering and all that stuff that you have to do to see people in person. It is significantly more isolating. Everyone who has long COVID is excluded from public life forever at this point unless something very significant changes. They're either excluded from it, or they're participating at great personal risk. I've improved enough over the last year that I can have folks over occasionally. We mask and stuff, but I've seen my friends maybe 10 times in the last 3 years. I've left the house for medical appointments and nothing else since June of 2023 basically.”

Listing session insights – Formal assistance

Disbelief, denials, and delays within formal assistance systems

Participants consistently described barriers within various supportive systems that are not designed to accommodate the realities of chronic, fluctuating illness. Many participants **experienced repeated humiliating denials, appeals, and years-long delays** when applying for disability or personal care assistance. Participants shared that programs frequently reject claims on the basis of “subjective” or “unverifiable” symptoms.

- “I ended up going through the short-term disability process through [my employer’s] short-term disability, then on to long-term disability was which was a horrific and very stressful event… and I was ultimately denied long-term disability. Then [I went] through the state disability system which I was also denied for that too. In fact, when I came to talk about my symptoms and how they were affecting me, and how sick I was, during my appeal the judge said, ‘you need to quit exaggerating.’ It was a very humiliating process and made me almost sicker to the point where I was no longer able to work.”
- “I don’t know if you've looked at any of the stipulations that short- and long-term disability providers have, but most of them explicitly exclude subjective diagnoses, like chronic fatigue, as qualifying conditions, which is insane.”
- “We tried to get him Social Security Disability Insurance and he would have gotten it because he was under 22 when he was diagnosed. And he was turned down, the appeal was turned down, because they don't have any tests that prove anything is wrong with you.”
- “I became eligible [for Social Security] when I couldn't work. And eventually, five and a half years later, that disability insurance is finally kicking in.”
- “I qualified for a PCA because I did the mentors assessment, and I think we were waiting from spring to spring until we moved into the assisted living. I think it was a year that we were on a waitlist for a PCA, and we never got one.”

Forced into poverty to qualify for help

Participants described **benefit systems that require them to exhaust financial resources** so they can qualify for support. They reported being forced to deplete savings, limit assets, or stop working to qualify for assistance — forcing them to decide between living in poverty or worsening their health.

- “It's ludicrous that I had to work at all. I was really, really sick. But the disability system is designed to force you into poverty before it will pay disability benefits and then keep you there and frankly, the choice that I had to make between my health or do I spend every single cent that I have, and then end up getting $2,100 a month in SSDI, which is not even enough to pay for rent. So, I'm just gonna keep working until I can't, and I think that's the choice a lot of people make because they don't want to be forced into poverty to receive medical care.”
- “He had started a Roth account when he was in high school and working, right? Because we're like, let's get you to start being a money saver! And when he got SSI, he was applying he had to get rid of that, because you can only have $2,000 at any time. It's not like he can go work, but he got that, so he got something.”

- “After I got sick, in late 2022, I was just trying to push through because I didn't know how I would survive without a paycheck. I continued to do that for a couple years, and then…my workplace [became] really, really stressful and…I got much, much sicker to the point where my body couldn't work. I took a little bit of time off and now I'm trying to work part-time, but [I’m] really struggling.”

Participants with employer-provided benefits described systems that made it difficult to maintain coverage — **insurers denied or delayed claims**, creating financial strain and jeopardizing their recovery.

- “The biggest struggle that I've had was with private disability insurance that was covered by my job. They have been fighting us and not paying for five and a half years. I received Social Security disability fairly early on. But the private disability insurance has been a nightmare. And our family was lucky. Because that didn't bankrupt us but if we had been under different circumstances, we could have lost the house. They put pressure on you. They put pressure on you, and they put pressure on you, and then you're incentivized to settle at pennies on the dollar.”

They described **employer policies that forced them to return to work before they had recovered** in order to maintain eligibility — decisions that often worsened their health and deepened financial strain.

- “L had really great healthcare benefits, they took their FMLA, family medical leave… because they were having trouble working, they were able to take some time off work and then have some time working part-time and actually receive salary continuance through work. They were working somewhat part-time, on and off and then their salary continuance ran out. In order to qualify for another round of salary continuance they needed to go back to work for 7 days. So, they went back to work full-time…and that exertion, we think, is one of the things that kicked off this really, really bad episode, where they had to take some unpaid leave and then basically have gone on long-term leave.”

Participants described **exhausting bureaucratic processes** that require advanced legal or administrative know-how — skills many did not have the energy or capacity to manage while sick. Many spent months or even years appealing denials, correcting system errors, or fighting to keep essential benefits and coverage.

- “[Their] employer terminated their health insurance on May 31st this year with no prior warning. Luckily, I had already started the process of trying to get L on medical assistance. We wanted to get L some care through the state because we've been there 24 hours a day for more than a year and we're just all burning out. But then their private health insurance was terminated, and I had until August 1st, which is when the COBRA deadline was, to figure it out. I think I finally got medical assistance approved July 28th or something just days before the deadline. So that was wonderful, and that was retroactive back to June 1st, so L had continuous coverage, and I was able to go back and get their doctor's appointments and prescriptions paid for.”
- “My disability went through, but I didn't know anything about that process, and I had to do it largely on my own, you know, reading legal textbooks. Learning is it better to forego an in-person hearing? Is it better to push for a virtual hearing? How to essentially write your own legal questions. I had to do that on my own. If there had been resources at the beginning, that would have made my life a heck of a lot easier as a sick person.”

- "What if we needed to get L to a doctor's appointment to get an MRI? We would need medical transport, and it would need to be stretcher transport. And so, it's not Metro Mobility, which you have to be in a wheelchair. So, I called a Department of Human Services fee-for-service line, and I spoke to a woman who either was having a really bad day, or should not be in customer service, because she was screaming at me for 10 minutes. I was like, I'm just interested in knowing whether medical assistance covers medical transport stretcher transport. And I think the short answer is she doesn't know. And I'm like, well, who do I call? And she's like, this is the line that you call. I'm like, but you don't know the answer, so who do I follow up with? And she just was like yelling, 'I've already told you!'"
- "I talked to someone in the State Medical Review Team (SMRT), office, when I was really upset about it, and she was like, I'm so sorry, I can't help you, but you might want to talk to the county commissioner, so I called [the commissioner's] office and talked to some of her staff and maybe her, actually, and then she, referred me to the state ombudsperson…and that ombudsperson looked into it and was like, yeah, I think that we've been telling people the wrong thing…so we're gonna get them to change some of their I don't know, documentation or something."

Barriers to care within formal assistance systems

Participants described major barriers navigating formal systems meant to help and support people with post-viral IACCs. Across experiences, they emphasized financial strain, inequitable access to care, burdensome benefit processes, and the urgent need for assessments for accommodations that acknowledge fluctuating illness and chronic disability.

Participants reported that **access to essential treatments** often hinge on insurance providers or government program limits. Even when providers prescribed necessary care, insurance denials and reclassification of chronic maintenance as "non-essential" left those with post-viral IACCs paying substantial out-of-pocket costs.

- "The number one thing that most of us experience is that if we've had it long enough, there's an overwhelming out-of-pocket cost for all the supplements and all the treatments. The state of Minnesota will cover a certain number, but then they start calling it maintenance if you don't get better, and with a chronic condition, you don't get better, but you can maintain function and increase your function if you can get access to acupuncture, and for me, chiropractic [care] and massage."
- "The issue with getting prescriptions has not been my providers, it's been the insurance company. Specifically, one of the gut-related things I have, there is a very specific antibiotic that is used for that. It is extremely expensive, and insurance does not want to pay for it."

Participants highlighted **deep systemic inequities**. Those without savings, employment benefits, or personal networks are excluded from essential care due to prohibitive costs. Financial strain led some participants to delay or forgo treatment entirely, while others made personal sacrifices to preserve access to life-sustaining supports.

- "I was not able to legally marry my partner, because it would mean losing access to so many of those important resources and programs. So, yeah marriage equality for the disabled is also a huge, huge issue."

- “For me, I had a little nest egg of finances that I accrued through at least my professional career of working for 5 or 6 years. But a lot of people don't have that…people go homeless. That's a reality of this illness when it's been marginalized to the sidelines of medicine. There's just, there's very little access to support services.”
- “[This illness] required a lot of research and resources on my own. Resources that have cost my family tens of thousands of dollars, literally tens of thousands of dollars, in order to provide me treatment. Some of it is covered by insurance, but much of it isn't. That's just not an option for a lot of people in the community.”
- “L had really good short-term disability, salary continuance, they were able to get donated leave from coworkers and keep getting money. So I don't know if there's anything that would be better in that situation, but it would be great if everyone's employer offered those kinds of programs, if everyone had a long-term disability insurance policy that would pay out like L's is paying. I think L's employer is pretty good.”

Barriers to essential accommodations

Participants emphasized the critical importance of accommodations — across workplaces, schools, medical systems, and home environments — to prevent harm and support stability. When accommodations are denied or unavailable, individuals face worsened symptoms and exclusion from education, employment, and community life.

Securing formal accommodations often hinges on provider documentation. Participants reported that provider disbelief, lack of diagnosis, or unfamiliarity with post-viral IACCs frequently blocked their access to essential accommodations needed for work, school, or home.

- “Had I been believed that I was suffering through an illness at that time, there would have been at least protections of either support for workplace accommodations or work from home.”
- “I just continued to miss so much school, and, you know, about half of my classes in, 10th and 11th grade, and it was very, very difficult to, even though I did, you know, have a doctor's note for the chronic migraines, it was very difficult to find any kind of support from the school, you know, from my counselor, from my teachers. I continued to struggle with this, although at least in college, I, you know, could take a part-time course load, and I did that. But, you know, I struggled without any, knowledge or, you know, support for ME/CFS in particular, and, when I finally received it, was about in 2018, I was 28 years old.”
- “I needed help for workplace accommodations, and the MD was like, ‘you're not gonna get that from me.’ And so, you're kind of drowning, and you're asking for a life preserver, and they're taking it away. We just fought for everything on our own.”

Participants reported that **inadequate housing accommodations compromised both daily mobility and safety**. Limited space and inaccessible features made it difficult to use mobility aids, complete basic tasks like laundry, or safely evacuate in an emergency.

- “Some of the big problems are I'm in a one-bedroom unit and I have a lot of big mobility aids, a lot of stuff that takes up space. My medications take up so much space. So that's why I was wanting to do a two-bedroom. They also have in-unit washer-dryer. There is a laundry room in my building, but I can't go. It stresses me out too much. I've tried, and I can't do it. I have a scooter, wheelchair, cane, walker, bariatric walker if I want to go on a walk. The cane is fine for short trips. But anything longer than half a block, I need something else, something more supportive. And it takes 10-15 minutes to get the stuff out sometimes, because of how just small the apartment is, there's no space to maneuver anything. So, there was just multiple reasons I requested the accommodation, and I'm really hoping it works. Even though I really don't want to move again. It would solve my issues with this apartment, it would solve all of them, pretty much all of them."

- "We are worried about in an emergency how would we get L out? And then, if L were to improve to the point where they could be in a wheelchair, they would still be housebound because we wouldn't be able to get them down the stairs."

Listening session insights – Health outcomes

The health outcomes section reflects participants' answers to questions related to moments or experiences that stood out in their illness journey, gaps in Minnesota systems and care, and priorities for improving systems of care and support for people with chronic conditions.

Major themes of their responses included:

- Lack of provider preparation and knowledge of post-viral IACCs
- Misdiagnosis, dismissal, and stigma experienced by people with these conditions, especially for those with marginalized identities
- Harmful or inappropriate medical advice or treatment
- Fragmented systems and barriers to care
- Critical need for accommodations

Participants' priorities included:

- Mandatory education for providers
- Specialty centers and interdisciplinary models for care in Minnesota
- Public awareness campaign
- Investments in research

The following summarizes listening session participants' experiences, and their recommended priorities related to health outcomes.

Lack of provider awareness and preparation

Participants in the listening sessions described a systemic lack of provider preparation to support people with post-viral infection–associated chronic conditions (post-viral IACCs), resulting in patient harm through misdiagnosis, dismissal, and delayed care. Many experienced seeing healthcare providers who have **little to no formal training on these conditions**, leaving the providers uncertain and unprepared to diagnose or offer treatments.

- "There's 3 or 4 MDs I would trust in this state. When people reach out to me and they're struggling, those are the 4 names [I give], and their waitlists are booked."
- "The average doctor has no clue, unless their life has been touched by it."

- "Every specialist I've seen other than the ME/CFS provider just kind of explicitly said, I do not know what to do for you."
- "We became convinced that L had, mast cell activation syndrome, and the primary care physician was like, I am not comfortable diagnosing that, I'm not comfortable prescribing the medications. She [said], that's too far outside my expertise, sorry."
- "I had printed off some documents from the #MEAction Network, and the ME/CFS Clinicians Coalition. I'm doing the education…and I'm fighting with MDs like, 'I have peer-reviewed medical studies that I can send you.' You just having to defend yourself. That's not the relationship that you want to have with your doctor."

Nearly all participants described experiences of being **disbelieved, dismissed, or misdiagnosed** due to lack of provider knowledge about post-viral IACCs which often led to them attributing their symptoms to a psychological illness or another problem.

- "My symptoms were dismissed as just a migraine or anxiety."
- "The first doctor I saw said I had depression."
- "First, I went to my endocrinologist because I'm trans. I said, I can't even walk, I can't get out of bed, I don't know what's wrong with me. He goes, you're not gonna like my answer. I said, what? Stress. You're feeling stressed, just like we all are. I said, nope, bye."
- "When I got sick, I was 44 years old, and everywhere I went, every doctor wanted to tell me I was in menopause, and that that's what was wrong with me. And I'm like, you know, I just had a baby last year, I've had all my hormones checked, I'm not in menopause."
- "We just saw a neurologist on Friday and the provider did not believe us. He was like, yeah, I'm not gonna help you because you haven't had an MRI. I was like, how are we going to get him to an MRI. [He] couldn't handle the sound of it, it's just not possible. So, we're definitely still having people dismissing the condition."

Biases in society and healthcare can make experiences of disbelief or harmful misdiagnosis **more common and more difficult for people with marginalized identities**, especially when it comes to race and gender.

- "During my hospitalization… my parents, who had to advocate on my behalf, had to carefully balance and tiptoe around the white doctors' and nurses' egos and portray themselves as 'non-aggressive brown people' or 'compliant immigrants'… if they didn't and were too forceful, I would experience retaliation and further neglect and abuse. Even when I could [self-advocate], I had to perform the same tiptoe around a landmine… and still was abusively retaliated against numerous times."

The lack of knowledgeable providers contributed to a **roulette-type experience** in provider treatment recommendations and quality of care, sometimes even within the same institution.

- "If I go to [health system], it's a huge hub, right? There is gonna be a very different experience if I get [provider name], who did fellowship at Bateman Horn Center in Salt Lake to understand these conditions, or if I get [provider name] that doesn't know these illnesses, it is going to be incredibly different."

- "[Health system] has [doctor name], who's phenomenal. But they just do diagnoses, they don't treat. So, it has been frustrating for people in the community. At least you won't be gaslit if you get the right person. But they [also have another] program down there that is a gaslighting program, it's unbelievable for patients. You can't have [people like us] do exercise, graded exercise, where you do a little and then you just keep increasing the amount. That is false information. That [came from] faulty research that was put out in 2012."

Harmful or inappropriate medical advice or treatment

Participants recounted debilitating consequences of receiving inappropriate medical advice due to providers not understanding the nature of these illnesses. Specifically, advice instructing patients to ignore symptoms, "try harder," or "push through." For many participants, attempting to follow incorrect advice drove them into further, more severe disability, such as becoming bedbound after undergoing physical therapy.

- "If you get a nurse practitioners or a medical doctor that does not understand post-exertional malaise and energy-limiting debility, then [you are] put in harm's way, because that's what harmed me. They told me to try harder, they told me to push. That drove me into further disability because I didn't have the courage to admit that they don't know, and when they don't know, that becomes an ugly affair."
- "The COVID infection that started all this was November 11th of 2022. And I started seeking medical care for it probably, I think it was February 2023 and then ended up starting physical and occupational therapy. But the first major crash that I had… that first 'I am too tired to chew episode' was following a PT session."
- "The things that have affected me the most are incorrect use of physical therapy. For me, it was swim therapy that caused me to go to a multi-year bedbound crash. The way I explain it is when I started swim therapy, I could shower independently. When I ended swim therapy, I could not shower independently."
- "There was a lot of bad advice. I was told since nothing's wrong, I can ignore my pain and fatigue, which is why I got bedbound years later because when you ignore the fatigue, you get worse."
- "I was in a clinical trial for a new chronic migraine drug. Normally, they screen people in clinical trials to make sure they don't have any other conditions, and I didn't realize that I also had fibromyalgia and ME/CFS, because I [was not diagnosed]. After that trial, everything got so much worse, I became 70% bedbound."

Participants shared that provider doubt and lack of preparation resulted in severe **trauma and harm during hospitalizations**, including unsafe discharge planning where a critically ill individual was nearly released without a safe transport or care plan.

- "I experienced very severe neglect and discrimination at that hospital. I had very severe symptoms, like severe sinus tachycardia, stroke-like symptoms, or TIA symptoms. I lost the ability to swallow. I lost the ability to speak. I also had intermittent full-body paralysis. This is the kind of very, very severe end of what ME/CFS patients experience. Despite the severity of my conditions, I was not taken seriously at all…they said, it's okay, she can get a little malnourished."

- “The doctor said on a Friday afternoon L's actually fine and we're just gonna discharge them today. And I was like, what do you mean? They can't walk: they need a hospital bed. They live on the second floor of an apartment building. Do I have to just carry them to my car? What do you mean you're discharging them? And my cousin's a nurse, so I called her, and I'm freaking out, and she's like, they can't discharge without a safe discharge plan. L doesn't have a safe place to go. You don't have a hospital bed, you don't have medical transport, you can say no. And so, I was able to fight with this doctor who wanted to just drop L on the street on a Friday. And he agreed to wait until Monday so that I could get a social worker, caseworker, to help with medical transport. We still didn't have a safety plan in place in terms of emergencies. I really don't think we should have been discharged. But I was able to delay enough that we got a hospital bed, we got medical transport, L was stretcher transported back to their apartment and carried back up to the bed. And we haven't done any other doctor's appointments out of the house since then. They've just been bedridden since then.”

Barriers in system design and navigation

Participants overwhelmingly shared experiences with an inaccessible, fragmented healthcare system that was unprepared to support people with post-viral chronic conditions. Patients are subjected to a “hot potato” experience, constantly bounced from one siloed doctor to another, leaving the sick person or their caregiver to act as the primary, uncompensated care coordinator. This coordination task is rendered impossible by debilitating symptoms like severe fatigue and cognitive dysfunction.

- “I was getting to the point where I could barely leave the house, and not because I didn't want to. We’d see one doctor, then we [would see] another doctor, then we get sent to another…it was just insane like, I was the hot potato.”

In search for appropriate care, respondents shared about reliance on specialists or traveling sometimes very long distances for care.

- “I’m in the Northwest Metro, there's no providers in this area that have knowledge of these [conditions], how can we change that?”
- “There really weren't any doctors in Minnesota yet that were treating or even identifying post-viral illness. For me, I had to travel out to Stanford University in Palo Alto, California.”

This continuous battle to find care leads to **demoralization and despair**, with participants stating it is, “not even worth trying” to pursue medical help, as the effort causes an illness crash and rarely yields constructive results.

- “I just felt like it's not even worth trying to pursue medical help because just to get to the appointment itself is so exhaustive that I'm gonna have a crash after going to see the doctor, and when I get there they're not gonna have anything to help me anyway.”
- “It was so demoralizing. Doctors don’t realize you bring your best self to that appointment.”
- “If they say everything's okay, that’s going to influence how you approach that situation. Where I walked in, I said, hey, I think something doesn't feel right, here’s the 3 symptoms I have. That physician at [health system] essentially told me to get out of the room, meaning you're fine, your blood came back great, you're just stressed…this is now your problem, this isn't our problem. And think of how that influences how I share that out with my family. Like, I essentially having to share with my loved ones I just paid a physician to tell me that I'm crazy.”

Required self-advocacy and patient/caregiver educators

Participants and their caregivers overwhelmingly secured their care by being strong self-advocates for their own needs and care options, often navigating frustrating barriers to help while being very sick.

- "Somebody from #MEAction who had the phone number of an ME specialist called the specialist on my behalf more recently, within the past 2 years, and got me into Mayo Clinic. I can say I've never had better medical care in my life. Never had more thorough medical care, never had to not worry about money, because they said, 'Don't worry about it, we're going to diagnose you' and [they] got me into a clinical trial, which I've never had access to before because apparently you have to see the right doctors in order to even get into a clinical trial."

In some cases, success hinges not on the competence of the system, but on finding individual providers who are "willing to listen and learn" from the patient, even if the patient must supply the necessary research and information.

- "One benefit [my son] had is the family practice doctor we went to never doubted he was sick… he was always willing to listen and try. We would say, here's the research, we want to try this drug, and he was always willing to try, but it was us providing the information."

Needed accommodations for care

Participants highlighted needing critical accommodations to keep themselves safe, reduce harm, and avoid further exacerbating their illness while seeking care. Priority accommodations included masking requirements in public and medical settings (to protect immunocompromised patients from reinfection), flexibility to manage sensory sensitivities (bright lights, loud noises), and options for virtual visits, and mobile medical resources/house calls for those too ill to leave home safely.

- "Imagine going to a doctor's office, you're immunocompromised, you're wearing a mask, and no one else is wearing a mask, because not even doctors have to wear a mask anymore. Like, I wish there was an option you could check that said, please [wear] a mask, because I would like you to be masking around me."
- "There needs to be more flexibility and availability to have people coming into the home for checkups, for nursing care, you know. For a lot of those things. I don't think folks understand how difficult it is sometimes just to get out of the house, let alone if you're the only person. You can't drive when you're in that situation. It's very dangerous, and I know many of us, out of cost restriction don't want emergency services because of the price tag attached to that, so it'd be great if there was more mobile medical resources."
- "We've had a positive experience with L's primary care physician, who's a really thoughtful, kind person who is always trying to work on what's gonna help L. She did lots of virtual visits. She's actually been out and done a house call at L's apartment and someone else from her practice has also come and done a house call, if not once, maybe twice. That's really helpful stuff."
- "Those of us who are so sick cannot go running around to a million different doctors and a million different appointment."
- "When you're that sick, I really wish doctors understood [how hard it is] for a person who's really sick with a post-viral condition to get an appointment made, number one. And two, [the challenge to] get there because we're making appointments for a future date, and you never know what body and brain you're gonna wake up with. The day before the appointment maybe I can get up

and shuffle around the house and do a little of this and that. Then on the day of the appointment, I can't walk or I'm in extreme pain, or whatever the case may be. For me, one of my issues is I randomly get hives, and my throat swells up and I never know what it is I'm reacting to I just have elevated MCAS, histamine stuff now, post-COVID."

Listening session recommendation priorities – Shared

The following recommendation priorities were shared across two or more focus areas.

Mandatory education for care providers

- "[Practitioners] believing [people with these conditions] and knowing that it exists, you're already ahead of your colleagues."
- "If Minnesota Department of Health could do anything, they could do mandatory education. They could push to get it on the boards that doctors have to take to be certified as physicians to have questions."
- "One of them is the medical education piece. The medical piece has to be there. But the other piece is, how do you treat people? How do you treat people well? How do you listen? How do you understand the narrative? How do you read the pieces of the story and understand and diagnose, not necessarily having to take any tests with this particular illness?"

Public health campaigns to address stigma and increase recognition

- "There needs to be a massive educational campaign to let the health providers know that [post-viral IACC's] exist. That it's real and how hard it is, what the patients have to go through just to see [health providers] and be part of that system."
- "We need a health system in place for building knowledge amongst [medical providers] in this state."

Provide more comprehensive and inclusive care

- "We need more comprehensive [support]. We need people who can show up if you need to go get a ride to the doctor. The PCA model is not working for a lot of us. If you don't have a family member who loves you and cares for you, or you don't have a community that you can draw from to be a PCA person, those people are treated badly in this program, or they can't find anyone else at all to work with them."
- "As a trans person, I have another barrier to getting just some random person from an agency to come work with me in very intimate ways. The idea of a buddy program is an ideal solution. It'd probably have to be multiple different types of programs for serving slightly different sets of needs and communities. I think about the queer community, I think there's a lot of people that want to volunteer to do stuff, and there's able-bodied people in the community, and there's a lot of disabled people in the community."
- "Why can't we set up a situation where somebody's paired with somebody who can help with shopping, help with taking you to a community event, or help with taking you to a doctor appointment, or help go pick up something for you if you're not feeling well enough that day. Just be a check-in presence, so if you're depressed, you're not just falling off a cliff into an abyss."

Improvements to supportive care systems and policies

- "There are a list of conditions where State Medical Review Team (SMRT) can get expedited. ME/CFS and long COVID should be expedited, especially homebound or bed bound individuals with ME/CFS."
- "Home and community-based services assessment needs to be revised to [include] questions that acknowledge that some of us have fluctuating chronic conditions that are disabilities. The way they ask the questions, it's binary A or B, on or off, yes or no. They have me get up and say, let me see you walk. I'm like, what you don't understand is, I can walk right now across the room. See me on a day when I can't even get up off the couch. See me on a day when I'm counting and saving energy so that I can either get to the bathroom the appropriate number of times or maybe make some food and eat. And then I don't even have enough energy to eat the food after I make it. They don't understand these conditions and the questions exclude us by the nature of the way they ask the questions. So we don't get assessed for enough hours."

Providing accommodations for safe and accessible living environments

Participants emphasized the importance of **safe and accessible living environments** tailored to their functional needs and preferences. Features such as air conditioning, in-unit laundry, mobility space, **reliable transport, and food programs meeting safe dietary needs** were described not as conveniences but as health-preserving necessities.

- "Some people want to be in a group home. They feel better, you know, it does them better to be in a more social environment. Some people want to be in an individual home, and they should have that, be it a studio, or one bedroom, or whatever they need to have enough space to move around. People with mobility issues or chronic fatigue… should have space for their wheelchair whenever they need it."
- "Handicap parking. That should just be a no-brainer for everybody, because walking is exertion. Anything is exertion. Not just physical. Mental, emotional, visual, auditory, all of those."
- "There's this Lyft pass from ConnectAbility you can use, and I found out that you are not supposed to use it if you go to a doctor's appointment because MA Transport is supposed to be doing that service. That's very frustrating because I've used MA Transport for about a year... I missed appointments, I was waiting over an hour on multiple occasions, they were late. Lyft has issues, but it's a lot better."
- "It's important that I stay here because I have laundry in my unit, so I don't have to be exposed to things when I'm doing laundry. I have central air conditioning, and since I don't sweat anymore, that is more of a necessity than a nice to have. And my apartment is oriented in such a way that I don't face the sun, which is nice because my light sensitivity is pretty mortifying a lot of the time. A lot of folks with POTS basically lose the ability to regulate their body temperature, and so air conditioning is…a medical necessity for a lot of folks like us."
- "Meals on Wheels is a great option and I'm happy it's covered by the waiver. The problem is you have a lot of people who are sick from viral infection also have food sensitivities. A lot of people have MCAS, mast cell activation syndrome, a lot of people, and they can't eat something like that. Personally, I feel like that you should be able to customize it, or even just have it where they give you a 3-week supply of stuff, like. 3 weeks' supply of pre-made mashed potatoes, or a dinner size seasoned chicken. Nothing tastes good when you do it in a little plastic or cardboard container."

Transparent and inclusive statewide information sharing regarding post-viral IACCs

- “I'd love to see more movement on these [guiding council] meetings that are held every other month with MDs. What are [they] talking about? What material's being shared? We don't have any insight on that.”
- “[Colorado] had these bi-monthly guiding council meetings…with their Lieutenant Governor, the Colorado Department of Health, CU Health, Denver Children's, and then patients and researchers all gathered at a roundtable. And it was a public roundtable, where they spoke about what the state is doing, here's what the researchers and the MDs are seeing, here's what the patient needs are, and it was a public avenue where they were able to livestream it.”

Listening session recommendation priorities – Formal assistance

The following recommendation priorities related to the formal assistance focus area were elevated by participants in listening sessions.

Address income limits for benefits

- “I think spending needs to be looked at. When I was in my assisted living, I could not pay the full amount of rent. I had to get government help to pay rent. And I was only legally allowed to keep $125 a month because all my money went to rent. No one can survive on $125 a month without family support. No one.”
- “Not having a limit on how much disabled people can have in savings. Giving disabled people $600 a month to live off of and then not really allowing them to have more. If they have a job that could kick them off of disability, but disability doesn't do enough to even pay rent, or utilities, and then you have to worry about food and medication?”

Address denials in insurance coverage

- “We need to address insurance company stipulations that short- and long-term disability providers have [that] explicitly exclude subjective diagnoses, like chronic fatigue as qualifying.”
- “If there was a penalty for them for denying [coverage] so there's an incentive for them not to do that. If [insurance] can spend a dollar today, or a dollar in a year they're gonna spend a dollar in a year. There's no penalty [for insurance to deny coverage].”

Providing school and workplace accommodations

Participants described a wide range of **workplace and educational adjustments**—from flexible scheduling to remote work and modified workloads. They emphasized that understanding the unpredictability of post-viral conditions is essential to meaningful inclusion.

- “I had to leave my professional career, in 2018 then, after a medical leave, after I realized I could not sustain employment. There were no accommodations. I couldn't lead my team, with not being in person, and so…I had to take a medical leave.”
- “I'm very fortunate, to be able to…work remotely. I never thought I'd be able to work again at all. I couldn't. My brain was really badly affected. And I'm very fortunate that I have been able to find a position where I can work remotely. But I work from bed. I have to stay on an incline for a large part of the day so that I can get enough blood to my brain to be able to think. And when I have

rough days, I have the ability to kind of pull back and do more independent work rather than engaging. Engaging with people takes a lot of energy, even over a screen. And some days it's just not there…"

- "I wish that there was kind of more understanding, especially for kids in school. There needs to be accommodation for people dealing with post-viral situations, and the understanding that you really never know what body you're gonna wake up to. It becomes difficult to kind of pre-plan. It'd be nice if there was an understanding of that, so that if we had made a commitment, and then you're not able to do it, people understand you're not trying to flake on them or be non-reliable, but you just have to make those accommodations."

Listening session recommendation priorities – Health outcomes

The following recommendation priorities related to the Health Outcomes focus area were elevated by participants in listening sessions.

Interdisciplinary care models/specialty centers

- "I see a neurologist because of the POTS and stuff, but I don't have small fiber neuropathy, really, so what are they gonna do? I see a cardiologist for beta blockers. [It's' the multi-systemic illness, and it's hard to you know, find everything in one spot."
- "We need a home, so we need a center of excellence in Minnesota. So, what that means is it would [be]a place that you can perform clinical care, carry out translational research, and that engages with education and training and outreach. So, Mayo Clinic is trying to spearhead that in Rochester. Is there any way MDH can help support those efforts?"
- "I'm a patient representative with the National Institutes of Health Recover Initiative for studying long COVID. Minnesota, we don't have a site. The nearest site is in Sioux Falls, South Dakota. We need to have a home here."

Research

Participants shared about the need for more research to advance treatments and cures for post viral chronic conditions to the same degree as other research efforts have done for HIV/AIDS and cancer.

- "I want a cure for this. I would do anything. I would give anything. We don't expect people with cancer, and with Parkinson's, and with Alzheimer's, to accept that their illness as part of life and not try to do anything about it and the federal offices for conducting that kind of medical research [for long COVID and ME/CFS] don't exist anymore. I don't know the extent to which Minnesota can do anything about that, but like, you know. HIV/AIDS is a manageable chronic condition at this point, and that took 40 years and billions and billions of dollars in investment. And that is what it is going to take for illnesses like this, and a diagnosis of ME/CFS is just as serious as cancer, or Alzheimer's, or Parkinson's, or MS."
- "We should try to find a sterilizing vaccine for COVID. We should try to find some kind of prophylactic you can use for short periods of time so that it's relatively safe. You know, we could encourage masking, we could encourage vaccination, we could but it just, like the notion that the state or anyone at this point is going to put more money into COVID mitigations [is unlikely]."

Listening session summary tables

The following tables were developed to give members of the Public Life, Formal Assistance, and Health Outcomes workgroups a quick overview of the listening session summaries in the prior section. They were reviewed during meetings to help shape recommendations. Because workgroups met separately and covered overlapping topics, some themes and quotes appear in more than one table.

Public life

Major Themes	Summary Description	Illustrative Quotes	Connections to Other Major Themes
Gaps of Knowledge, Stigma, and Misdiagnosis	Widespread public and medical misunderstanding, fueled by stigmatizing condition names (e.g., "chronic fatigue syndrome"), makes the illness sound mild, leading to patient dismissal and pressure to "push through." Patients often rely on self-diagnosis and peer networks for validation after years of medical dismissal.	"It's often been said that it's like calling Alzheimer's chronic forgetfulness syndrome. It's just a horrible name." \ "I made my own self-diagnosis because I accidentally watched the documentary Unrest…"	**Health Outcomes:** Stigma is directly caused by the **Lack of Provider Preparation**, which leads to misdiagnosis and dismissal. **Formal Assistance:** Stigma is a root cause of the **Disbelief, Denial, and Delay** faced when applying for benefits based on "subjective" symptoms.
Social Isolation and Exclusion from Public Life	The debilitating nature of the illness, which requires extreme energy conservation, results in profound social isolation, loss of friendships, and exclusion from public life. Many miss major life milestones because the physical demands of maintaining relationships or leaving the house become overwhelming.	"Even with close friends, as a person with the condition. Spending time with them, you get exhausted. And so your world really shrinks." \ "Everyone who has long COVID is excluded from public life forever at this point, unless something very significant changes."	**Formal Assistance:** Isolation is amplified by the **Failure of Supportive Care Models** (PCA), and the unreliability of transport, which prevent the homebound from engaging with the outside world.

Major Themes	Summary Description	Illustrative Quotes	Connections to Other Major Themes
Caregiver Strain and Critical Support	Caregivers (family members, spouses) are essential for basic survival (carrying the patient, fetching food) and are forced to provide intensive, uncompensated physical and practical assistance. This support creates profound emotional strain, fractured family relationships, and exhaustion for caregivers.	"If I hadn't had a caregiver there with me... he carried me to the bathroom for the first 18 months..." \ "My relationship with my husband has been strained, because he's doing everything at our house, right?"	**Health Outcomes:** Caregivers frequently act as the uncompensated **care coordinator** due to system fragmentation. **Formal Assistance:** Strain is exacerbated by the **Forced into Poverty to Qualify** theme, requiring families to bear financial burdens that disability payments do not cover.
Barriers to Necessary Accommodations (Housing/School/ Work)	Accessing necessary accommodations for work, school, or safe living environments is often blocked because providers lack knowledge or disbelief, preventing necessary documentation. Inadequate housing (e.g., no mobility space, inaccessible stairs/laundry) severely compromises daily safety and health, making movement nearly impossible.	"I needed help for workplace accommodations, and the MD was like, 'you're not gonna get that from me.'" \ "We are worried about in an emergency how would we get L out?"	**Health Outcomes:** This theme links directly to the **Lack of Provider Preparation**, as providers' refusal to document disability creates systemic exclusion. **Formal Assistance:** This is a core part of the **Barriers to Essential Accommodations** theme, emphasizing the need for features like central AC, handicap parking, and mobility space.
Priority Recommendation for Public Life Improvements	**Public Health Campaigns and Transparency:** Launch a massive educational campaign to legitimize post-viral IACCs as "real" illnesses, increase public knowledge, and counteract the severe stigma. Also, ensure transparency by making state-level information sharing (like guiding council meetings) public and accessible.	"There needs to be a massive educational campaign to let the providers know that [post-viral IACC's] exist. That it's real and how hard it is..." \ "[Colorado] had these bi-monthly guiding council meetings... and it was a public avenue where they were able to livestream it."	**Foundational priority:** This recommendation is necessary to address the root causes of **Stigma (Public Life), Misdiagnosis (Health Outcomes), and Denial of Claims (Formal Assistance).**

Major Themes	Summary Description	Illustrative Quotes	Connections to Other Major Themes
Recommendation for Public Life Improvements	**Comprehensive and Inclusive Care Models:** Develop alternative and more comprehensive support models, such as **"buddy programs,"** where individuals are paired with someone to help with social needs, shopping, and check-ins. This addresses the failure of the current Personal Care Assistance (PCA) model and combats social isolation.	"The idea of a buddy program is an ideal solution." \ "Just be a check-in presence, so if you're depressed, you're not just falling off a cliff into an abyss."	This is a direct response to **Social Isolation (Public Life)** and the **Failure of Supportive Care Models** in Formal Assistance, offering a necessary alternative for those who need social support.
Priority Recommendation for Public Life Improvements	**Mandatory education or licensure requirements for providers** are crucial. Establishing **Interdisciplinary Care Models/Specialty Centers** (Centers of Excellence) is needed to streamline treatment. Substantial **Research** funding is required to advance cures and legitimize the conditions.	"If Minnesota Department of Health could do anything, they could do mandatory education." \ "We need a home, so we need a center of excellence in Minnesota."	**Foundational priority:** These structural reforms are essential to solving the problems across all three journeys: improving diagnosis (**Health Outcomes**), providing documentation (**Formal Assistance**), and offering long-term hope, which helps mitigate **Social Isolation**.
Priority Recommendation for Public Sector Reforms	**Accommodations for Safe Living:** Ensure accessible housing features, including sufficient space for mobility aids, in-unit laundry, and central air conditioning (as a medical necessity for temperature regulation). Also ensure features like handicap parking are readily available.	"Central air conditioning... is more of a necessity than a nice to have." \ "Handicap parking. That should just be a no-brainer for everybody, because walking is exertion."	Addresses the **Barriers to Essential Accommodations** (Public Life), specifically mitigating health risks associated with conditions like POTS (Health Outcomes).

Formal assistance

Theme	Summary Description	Illustrative Quotes	Connections to Other Major Themes
Disbelief, Denial, and Delay in Formal Assistance	Supportive systems (disability, insurance) are not structured for chronic, fluctuating illness, leading to pervasive denial of claims based on symptoms being deemed “subjective” or “unverifiable.” This results in humiliating appeals, repeated denials, and years-long delays for essential support, sometimes forcing people to become sicker until they are unable to work.	“Most [disability insurance policies] explicitly exclude subjective diagnoses, like chronic fatigue, as qualifying conditions, which is insane.” \ “During my appeal the judge said, ‘you need to quit exaggerating.’"	**Health Outcomes:** Provider disbelief and lack of diagnosis blocks access to necessary documentation for benefits. **Public Life:** This experience contributes to feelings of stigma.
Forced into Poverty to Qualify	Benefit systems are designed to force sick individuals into poverty by requiring them to exhaust savings, limit assets (e.g., $2,000 cap for SSI), or stop working entirely to qualify for support. Monthly disability payments (like SSDI) are often insufficient to cover basic expenses like rent.	“The disability system is designed to force you into poverty before it will pay disability benefits and then keep you there.” \ “No one can survive on $125 a month without family support. No one.”	**Public Life:** Financial precarity severely exacerbates caregiver strain.
Burdensome Bureaucracy & Inequitable Access	Navigating the bureaucratic process for benefits is exhausting and complex, requiring the sick individual (or caregiver) to manage appeals, read legal textbooks, and correct system errors alone for months or years. Inequitable access means those without private funds or strong networks are excluded, sometimes necessitating extreme personal sacrifices, such as forgoing marriage, to preserve access to life-sustaining programs.	“I had to do it largely on my own, you know, reading legal textbooks.” \ “I was not able to legally marry my partner, because it would mean losing access to so many of those important resources and programs.”	**Health Outcomes:** The exhaustion caused by fighting bureaucracy mirrors the experience of being passed from one provider to the next and the system fragmentation in healthcare, where the patient must coordinate everything while too ill to do so.

Theme	Summary Description	Illustrative Quotes	Connections to Other Major Themes
Failure of Supportive Care Models & Assessment	Existing care models like Personal Care Assistance (PCA) are often ineffective due to long waitlists and difficulty finding caregivers. Additionally, formal assessments utilize binary questions that fail to measure the severity or fluctuating and unpredictable nature of post-viral IACCs, leading to under-assessment and denial of necessary support hours.	"Home and community-based services assessment needs to be revised to [include] questions that acknowledge that some of us have fluctuating chronic conditions." \ "The PCA model is not working for a lot of us."	**Health Outcomes:** The system's failure to account for fluctuation is a barrier in both assistance and health systems; the unpredictable nature of the illness also makes keeping medical appointments extremely difficult. **Public Life:** Ineffective models heighten caregiver strain and contribute to social isolation.
Barriers to Essential Accommodations (Housing/Work /Transport)	Accessing accommodations (workplace, school, or housing) is often blocked because provider disbelief or lack of knowledge prevents necessary medical documentation. Inadequate housing (lack of mobility space, inaccessible laundry, lack of central AC) compromises health and safety. Essential services, like MA Transport, are unreliable, and food programs are inflexible for common sensitivities (MCAS).	"I needed help for workplace accommodations, and the MD was like, 'you're not gonna get that from me.'" \ "Central air conditioning... is more of a necessity than a nice to have."	**Health Outcomes:** The need for AC and temperature regulation in housing is directly linked to the need for accommodations for care due to comorbid conditions like POTS. **Public Life:** The lack of accessible environments and reliable transport directly enforces **social isolation** and exclusion from community life.
Priority Recommendations to Structural Reforms in Formal Assistance	**Address denials and income limits:** Remove or substantially raise limits on how much disabled people can hold in savings or assets**. Penalize insurance companies for denying necessary coverage** to create incentives for approving legitimate claims and end stipulations that exclude "subjective diagnoses."	"Not having a limit on how much disabled people can have in savings." \ "If there was a penalty for them for denying [coverage] so there's an incentive for them not to do that."	

Theme	Summary Description	Illustrative Quotes	Connections to Other Major Themes
Priority Recommendations to Structural Reforms in Formal Assistance	**Improve Care Systems and Assessments:** Assessments must be revised to include questions that specifically acknowledge and measure fluctuating chronic disabilities. **Expedite the SMRT process** for post-viral IACCs, particularly for homebound individuals. **Develop alternative support models**, such as "buddy programs," to provide comprehensive and inclusive care beyond the current PCA model.	"Home and community-based services assessment needs to be revised to [include] questions that acknowledge that some of us have fluctuating chronic conditions." \ "The idea of a buddy program is an ideal solution."	
Priority Recommendation to Structural Reforms in Formal Assistance	**Mandatory education or licensure requirements for care providers** are crucial to ensure foundational knowledge, enabling them to provide necessary documentation for accommodations and benefits. **Public health campaigns** are required to legitimize post-viral IACCs, counteract stigma, and improve recognition across all supportive systems.	"If Minnesota Department of Health could do anything, they could do mandatory education." \ "There needs to be a massive educational campaign to let the providers know that [post-viral IACC's] exist."	**Foundational priority:** Addressing provider ignorance and public stigma is essential for overcoming the barriers of **Disbelief, Denial, and Barriers to Essential Accommodations** in the formal assistance sector.
Priority Recommendation to Structural Reforms in Formal Assistance	**Provide accommodations:** Recommendations include ensuring accessible housing (sufficient space for mobility aids, in-unit laundry, and central AC as a medical necessity). Also recommended is customizing food assistance programs (like Meals on Wheels) to meet the safe dietary needs of individuals with sensitivities like MCAS.	"Central air conditioning... is more of a necessity than a nice to have." \ "The problem is you have a lot of people who are sick from viral infection also have food sensitivities."	

Health outcomes

Theme	Summary Description	Illustrative Quotes	Connections to Other Major Themes
Lack of Provider Preparation and Knowledge	Healthcare providers exhibit a systemic lack of formal training on post-viral infection–associated chronic conditions (post-viral IACCs), resulting in uncertainty, misdiagnosis, and an inability to offer treatment.	"The average doctor has no clue, unless their life has been touched by it." \ "Every specialist I've seen other than the ME-CFS provider just kind of explicitly said, I do not know what to do for you."	Connection to provider misdiagnosis, dismissal, and stigma. **Formal Assistance:** Provider disbelief and the lack of diagnosis **blocks access to the necessary documentation** required for securing accommodations and formal assistance/disability benefits. **Public Life:** Lack of professional knowledge fuels **widespread stigma** and public misunderstanding of the illness.
Misdiagnosis, Dismissal, and Stigma	Nearly all participants were disbelieved, dismissed, or misdiagnosed due to lack of provider knowledge, often having symptoms attributed to psychological illness (like anxiety or stress) or other problems (like menopause), delaying appropriate physical treatment.	"My symptoms were dismissed as just a migraine or anxiety." \ "When I got sick, I was 44 years old…every doctor wanted to tell me I was in menopause..."	
Harm from Inappropriate Medical Advice	Patients suffered debilitating consequences, including worsened disability, after receiving inappropriate medical advice to "try harder," "push through," or undergo incorrect treatments like graded exercise or physical therapy.	"They told me to try harder, they told me to push. That drove me into further disability because I didn't have the courage to admit that they don't know..." \ "For me, it was swim therapy that caused me to go to a multi-year bedbound crash."	**Public Life:** Advice reflects the pressure felt by patients to conform to expectations of health and productivity, often worsening their illness.

Theme	Summary Description	Illustrative Quotes	Connections to Other Major Themes
Systemic Fragmentation and Care Barriers	The healthcare system is fragmented, leading to the experience of patients constantly being bounced between siloed doctors. The resulting coordination burden falls onto the sick person or caregiver, rendered nearly impossible by severe fatigue and cognitive dysfunction.	"It was just insane like, I was the hot potato." \ "I just felt like it's not even worth trying to pursue medical help because just to get to the appointment itself is so exhaustive that I'm gonna have a crash..."	**Formal Assistance:** Patient's burden of coordinating care mirrors the **exhausting bureaucratic processes** required to fight for benefits and correct system errors. **Public Life:** The requirement for the sick person or caregiver to coordinate care contributes directly to severe **caregiver strain**.
Critical Need for Accommodations	Participants require critical accommodations to keep themselves safe while seeking care, including masking requirements (due to being immunocompromised), flexibility for sensory sensitivities (lights, noise), and virtual visits or mobile medical resources for those too ill to leave home.	"There needs to be more flexibility and availability to have people coming into the home for checkups, for nursing care..." \ "We're making appointments for a future date... you never know what body and brain you're gonna wake up with."	**Formal Assistance:** System failure (e.g., unreliability of MA Transport). **Public Life:** Themes of **social isolation** and housing/environmental accommodation needs (e.g., central AC as a medical necessity due to temperature regulation issues).
Priority Recommendations for Structural Health Reform	**Mandatory Education for Providers:** Mandatory education or licensure requirements are prioritized to ensure foundational knowledge of post-viral IACCs, ensuring providers believe and validate patient experiences and reduce patient harm.	"If Minnesota Department of Health could do anything, they could do mandatory education. They could push to get it on the boards that doctors have to take to be certified as physicians..."	**Foundational priority**: Addressing provider ignorance and public stigma is essential for overcoming the barriers of **Disbelief, Denial,** and **Meet Need for Critical Accommodations** for health sector.
Priority Recommendations for Structural Health Reform	**Interdisciplinary Care Models/Specialty Centers:** Participants recommended shifting towards interdisciplinary care models or establishing specialty centers ("Centers of Excellence") to manage the multi-system nature of post-viral IACCs.	"We need a home… a center of excellence in Minnesota… a place that you can perform clinical care, carry out translational research, and that engages with education..."	Creating centralized "homes" for care would address the fragmentation of the system and ensure comprehensive treatment for multi-systemic illnesses.

Theme	Summary Description	Illustrative Quotes	Connections to Other Major Themes
Priority Recommendations for Structural Health Reform	**Public Health Campaigns and Transparency:** Recommendations include a major public health awareness campaign to counteract stigma, legitimize post-viral IACCs, and increase knowledge among residents and providers. Transparent, inclusive statewide information sharing (e.g., public roundtables) was also suggested.	"There needs to be a massive educational campaign to let the providers know that [post-viral IACC's] exist. That it's real and how hard it is..."/ "[Colorado] had these bi-monthly guiding council meetings... and it was a public avenue where they were able to livestream it."	
Priority Recommendations for Structural Health Reform	**Research Investment:** Participants stressed the need for substantial research funding to advance treatments and cures for post-viral IACCs at a scale commensurate with other serious, life-altering diseases.	"A diagnosis of ME-CFS is just as serious as cancer, or Alzheimer's, or Parkinson's, or MS." \ "...[addressing HIV/AIDS] took 40 years and billions and billions of dollars in investment. And that is what it is going to take for illnesses like this..."	

Appendix E: Glossary of terms

- **Accommodation** – adjustments or supports that enable people with disabilities (and often broadened to include caregivers) to perform tasks, access opportunities, or fully participate in work, education, or other environments. Accommodations can include but are not limited to: flexible work schedules, remote schooling options, modified duties, or communication supports.
- **Allied Health Professionals** – Licensed or certified non-physician, non-nurse clinicians who provide diagnostic, therapeutic, rehabilitative, behavioral health, and supportive services, including but not limited to: physical and occupational therapists, speech-language pathologists, psychologists, and clinical social workers.
- **Care Algorithms** – Step-by-step clinical decision pathways designed to guide assessment, diagnosis, and management in a consistent, evidence-informed manner.
- **Care Team Members** – A broad term inclusive of many roles often found in the formal assistance sector, such as case managers, social workers, and support staff.
- **Clinical Pathways** – Standardized, multidisciplinary care plans that outline coordinated approaches for managing specific conditions across providers and settings.
- **Community Health Workers (CHW)** – Trusted, frontline public health workers who provide education, support, and system navigation within the communities they serve, often sharing lived or cultural experience with those they assist.
- **Disability Hub MN** – The Disability Hub MN is a free statewide network in Minnesota that helps people with disabilities – and their families and support networks – solve problems, navigate systems, and plan for the future. It is a "no-wrong-door" service, meaning anyone can contact it, and staff will either help directly or connect you to the right person or resource.
- **Disability Justice** – Disability justice is a movement-building framework that understands all bodies are unique and essential, and that all bodies have strengths and needs that must be met.
- **Electronic Health Record (EHR)** – a digital version of a person's medical history that is maintained over time and shared across healthcare providers to improve care quality and coordination.
- **Focus Areas** – The three biggest categories for organizing recommendations in the plan, these reflect major systems that influence the experiences, relationships, decisions, and resources of people living with chronic conditions. Focus areas in this report are public life, formal assistance, and health outcomes.
- **Health Equity** – Health equity is the state in which everyone has a fair and just opportunity to attain their highest level of health. Achieving this requires focused and ongoing societal efforts to address historical and contemporary injustices; overcome economic, social, and other obstacles to health and healthcare; and eliminate preventable health disparities.

- **Job Accommodation Network (JAN) –** The Job Accommodation Network (JAN) is a free, expert, and confidential resource that helps individuals with disabilities and their employers navigate workplace accommodations under the Americans with Disabilities Act (ADA), the Rehabilitation Act, and other disability-related laws.
- **Minnesota Centers for Independent Living (**MACiL**)** – a non-profit organization whose purpose is to advocate for a statewide network of independent living services and supports for Minnesotans with disabilities. The organization provides information about the eight Centers for Independent Living (CILs) across the state, which offer various services aimed at enhancing the independence of individuals with disabilities. See also Metropolitan Center for Independent Living.
- **Minnesota Electronic Health Record (MN EHR) Consortium** – The MN EHR Consortium is a public health partnership established during the early days of the COVID-19 pandemic. It brings together Minnesota's largest healthcare systems, the Minnesota Department of Health (MDH), local public health agencies, and researchers to pool medical data for real-time public health surveillance and research.
- **Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)** – A complex, chronic, multi-system disease characterized by profound fatigue that is not improved by rest, along with a worsening of symptoms following even minor physical or mental exertion (known as post-exertional malaise, or PEM). Other core symptoms include unrefreshing sleep, cognitive impairment ("brain fog"), and postural orthostatic tachycardia syndrome (POTS) orthostatic intolerance—difficulty staying upright.
- **Navigation / System Navigation / Care Coordination** – The ability to understand options, access services, and move effectively through health, social, and community systems.
- **Post-Exertional Malaise (PEM)** – A worsening of symptoms following physical, cognitive, or emotional exertion, or sensory overload, often delayed by hours or days, and a hallmark feature of several post-viral IACCs. PEM can present as extreme fatigue not improved by sleep, flu-like symptoms, cognitive impairment, pain, dizziness, visual disturbances, and more. It can last for days or much longer, and in some cases can permanently decrease baseline capacity, leaving people housebound or bedbound.
- **Postural Orthostatic Tachycardia Syndrome (POTS)** – POTS is a condition in which the body struggles to regulate blood flow and heart rate when moving from lying or sitting position to standing, a phenomenon known as orthostatic intolerance. POTS is a hallmark feature of several post-viral conditions and a type of dysautonomia, or dysfunction of the autonomic nervous system.
- **Post-Viral Infection-Associated Chronic Conditions (post-viral IACCs)** – broadly, this refers to lingering symptoms like chronic fatigue, cognitive impairment (brain fog), post-exertional malaise, pain, and immune dysfunction that persist after an acute viral infection. They are sometimes referred to as Infection-Associated Chronic Illness or named for the infection that triggered them (long COVID, post-COVID syndrome, etc.). May also be abbreviated as IACCs or PVCCs.
- **Public Health –** Public Health focuses on preventing disease, prolonging life, and promoting health through organized societal efforts. Core activities include disease surveillance, policy

development, health education, ensuring access to quality healthcare, and addressing environmental factors like clean air and water. (Frieden, 2020; Kass, 2011). Public health is different from, but complementary to, the work of medical care and human/social services.

- **Telehealth** – Delivery of healthcare or formal assistance services through phone, video, or other remote technologies.
- **State Medical Review Team (SMRT) –** The State Medical Review Team (SMRT) makes disability determinations for people not certified disabled by the Social Security Administration (SSA). SMRT is housed within the Minnesota Department of Human Services.
- **Support Groups** – Structured or semi-structured gatherings (can be virtual or in-person, synchronous or asynchronous) where people with shared experiences connect, exchange information, and offer mutual support.
- **Vocational Rehabilitation Services (VRS)** – The Vocational Rehabilitation Services is a state program that helps people with disabilities prepare for, find, and keep jobs, and live more independently.

Appendix F: Summary of recommendation feedback from key contributors

Purpose and background

In partnership with the Minnesota Department of Health, Management Analysis and Development (MAD) developed and administered an online survey to gather structured feedback from key contributors on draft vision statements and recommendations put forward for a statewide roadmap to improve the lives of people with post-viral infection associated chronic conditions (IACCs). This survey was the final step in developing the statewide roadmap. The survey was designed to capture high-level impressions and any significant concerns about the draft vision and recommendations before the roadmap was finalized. Respondents were informed that while **major changes or new recommendations would not be possible at this stage**, all feedback would be reviewed, summarized, and included in the final report appendices.

The work to develop the roadmap began with a series of focus groups and interviews with people with post-viral IACCs and their caregivers. They shared their experiences navigating complex and often difficult systems — and offered suggestions for what would have made those experiences easier, more manageable, or more supportive. Their input shaped the foundation of the roadmap. Details about this portion of the work are available in the appendices of the final roadmap report.

Summaries of the interviews with people with post-viral IACCs and their caregivers were provided to members of the steering committee and three workgroups (and are found in the appendices of the final report). These groups met throughout the project, using findings from these initial interviews to seed ideas and develop vision statements and recommendations supporting three areas of focus: Public Life, Formal Assistance, and Health Outcomes. Each workgroup centered their recommendations in one of three areas.

This survey gave those initial interviewees, workgroup members, and others involved in the eco-system supporting people with post-viral IACCs a chance to review and provide input on the draft vision statements and all focus area recommendations before the roadmap was finalized. Where appropriate, project team members incorporated this feedback into the final draft. All feedback from the survey is summarized in this document.

Readers are encouraged to consider the top recommendation priorities identified by these contributors, as well as their suggestions for how to put those recommendations into practice. Additional insights offered through the survey may inform future development of individual recommendations or similar roadmap efforts.

Methodology

Invitations to complete the survey were sent to over seventy individuals. The survey was open for two weeks in April 2026. To support accessibility, participants received unique login credentials allowing them to return to the survey over a two-week window rather than completing it in a single session.

Eighteen people completed the survey. The survey combined multiple-choice and open-ended questions. Multiple-choice questions gauged agreement with draft vision statements and surfaced priority recommendations within each roadmap focus area. Open-ended questions invited elaboration, identified gaps, and gathered suggestions for successful implementation.

An initial review of all responses informed direct edits to the roadmap. Respondent feedback prompted revisions to the vision statement to improve clarity and breadth. Identified gaps and suggestions were used to strengthen and clarify several recommendations in the final report. One respondent also contributed a list of resources that have been incorporated into the resource section of the final roadmap. This memo summarizes the high-level themes and findings across all respondents.

Note: Between the survey launch and the finalization of the roadmap, several revisions of the recommendations were made to improve clarity, plain language, and specificity throughout — including merging and renaming of several recommendations. Where relevant, this summary indicates whether recommendation language shifted in the final roadmap. Those who provided survey feedback may notice these differences in the final roadmap from the draft language they reviewed in the survey.

Vision statement feedback

Respondents viewed the draft vision statements favorably. When asked how well the statements reflected a better future for people with post-viral IACCs, the majority said they did "very well," three respondents said "extremely well," and one said "somewhat well."

Half of respondents offered written comments. Feedback included: suggested edits to strengthen the depth of the vision, notes about missing elements or areas needing greater clarity, copy editing suggestions, and positive affirmations of the direction and tone. This input was reviewed by members of the steering committee and directly informed revisions to the vision statements in the final roadmap draft.

Priority recommendations and other considerations

Public life

Respondents were asked to select their top two priorities from the Public Life recommendations. The two most frequently selected were:

- **Online resource centers** (selected by 12 respondents)
- **Public awareness campaigns** (selected by 9 respondents)

The remaining recommendations — Define, assess, and enhance navigator role (8) and Support group expansion (5) — also received notable support. Several respondents noted it was difficult to limit their selections to two given the importance of all recommendations in this area.

What respondents found unclear or missing:

Respondents identified several areas needing greater clarity or expansion across the Public Life recommendations. These included: overly complex language in several recommendations, particularly around the navigator role and support group expansion; the need for public awareness efforts to actively address stigma, misinformation, and media narratives through partnerships with local and statewide outlets; gaps in accessibility for people with the most severe illness, including housebound and bedbound individuals, across resource centers, support groups, and navigator services; insufficient attention to children and teens with post-viral IACCs and their families, including school-based supports; questions about how people with lived experience will be meaningfully involved and compensated in implementation; and opportunities to build on existing infrastructure from established networks for other infection-associated chronic conditions rather than starting from scratch.

Formal assistance

Respondents were asked to select their top two priorities from the Formal Assistance recommendations. The two most frequently selected were:

- **Invest in Community Health Worker (CHW) infrastructure** (selected by 10 respondents)
- **Disability recognition in navigation systems** (selected by 8 respondents; renamed "Enhance disability recognition across formal assistance assessments and systems" in final report)

The remaining recommendations, Telehealth and remote assessments (6) and Strengthen infrastructure between community, health, and formal care (5), also received notable support, suggesting broad interest across this section.

What respondents found unclear or missing:

Across the Formal Assistance recommendations, respondents flagged several areas needing greater clarity or expansion. These included: language that was difficult to parse or interpret, particularly around disability recognition and assessment; the need to more explicitly name the full range of post-viral IACC disability, including fluctuating capacity, cognitive impairment, and severe presentations; gaps in support for caregivers, children, and families; missing enforcement and implementation pathways for disability rights and employer education; and overlap between several recommendations that may benefit from consolidation.

Health outcomes

Respondents were asked to select their top two priorities from the Health Outcomes recommendations. The two most frequently selected were tied:

- **Education modules for ancillary health professionals** (selected by 10 respondents; renamed "Education modules for allied health professionals and support staff" in final report).
- **Point-of-care clinical tools** (selected by 10 respondents; merged with "Unified clinical pathways…" and renamed "Unified clinical pathways and point of care clinical tools" in final report).

The remaining recommendations, Patient-centered clinical standard (6) and Unified clinical pathways and care algorithms (5), also received meaningful support. Several respondents noted it was difficult to select only two, given the importance of all recommendations in this area.

What respondents found unclear or missing:

Respondents identified several areas needing greater clarity or expansion across the Health Outcomes recommendations. These included: confusing or overlapping language between recommendations; the need for harm avoidance, especially around graded exercise therapy, to be made explicit throughout clinical tools, pathways, and education modules; gaps in reaching emergency department, urgent care, nursing, and mental health providers through education efforts; insufficient attention to people with the most severe presentations, including housebound and bedbound patients; the importance of vetting linked clinical resources individually rather than broadly endorsing them; structural barriers in primary care reimbursement and time constraints that education alone cannot address; and questions about who will lead and deliver education, how existing community-created materials will be incorporated, and how the work will remain accountable to affected communities, including people from marginalized groups.

A list of specific suggestions to expand and support recommendations is provided at the end of this document.

Suggestions to support successful implementation

Respondents offered substantive suggestions about what would be needed to move the roadmap from strategy to action. Themes that emerged across responses are summarized below.

Accountability, ownership, and measurable outcomes. Respondents consistently identified the absence of clear ownership, timelines, and measurable success indicators as a significant risk to implementation. Suggestions included developing a phased implementation plan with defined milestones, establishing a standing advisory body to review progress on a regular basis, and building-in public reporting on outcomes, including patient-reported outcomes. Without these structures, respondents cautioned that the roadmap risks becoming a well-written document that does not change outcomes for people with post-viral IACCs.

Sustained engagement with people with lived experience. Respondents stressed that people with lived experience must be meaningfully involved throughout implementation, not only in early development. This includes ensuring accessible and compensated participation, building in accountability to affected communities, and recognizing that lived and professional experience are not mutually exclusive.

Clearer, more actionable recommendations. Several respondents noted that the current recommendations are too vague to implement or measure and may be vulnerable to being deprioritized as a result. Respondents also flagged the need to explicitly address cultural and systemic barriers — including deeply held attitudes about rest, pacing, and use of social services — that will shape how recommendations are received by systems and the public.

Building on existing infrastructure. Respondents recommended conducting a thorough assessment of what already exists before creating new systems — including patient-led organizations, disability community networks, and existing educational resources. Several noted that people with post-viral IACCs are better served by working in coalition with the broader disability community than in parallel to it, and that lessons from other health crises — such as the HIV/AIDS response — offer useful models.

Statewide data, surveillance, and research partnerships. Respondents identified a gap in statewide prevalence and outcomes data, and recommended disaggregating data by severity, race, income, and geography to identify disparities. Suggestions included building research partnerships with Minnesota institutions, integrating post-viral IACC content into medical and nursing school curricula, and exploring the development of Centers of Excellence for multidisciplinary clinical care and research.

Funding, feasibility, and cost-effectiveness. Respondents acknowledged the current resource-constrained environment and encouraged prioritizing recommendations with the greatest potential for impact. Several noted that unmet chronic care needs drive costly acute care utilization, and that framing recommendations around cost savings may strengthen the case for investment. Respondents also identified missing incentive and enforcement mechanisms for key system stakeholders.

Terminology and naming. At least one respondent raised a concern about the use of "post-viral" as a descriptor throughout the roadmap, noting it is not broadly accepted nationally or by patient communities, and recommending alignment with "infection-associated" language used by the National Academy of Medicine. This was framed as both a scientific accuracy concern and a matter of trust and credibility with affected communities.

Conclusion

The feedback gathered through this survey reflects both strong support for the direction of the statewide roadmap and a deep investment in its success from people who know this work best. Respondents expressed high agreement that the draft vision statements reflect a better future for people with post-viral IACCs, and their input directly improved the final draft which underscores the importance of engaging this community throughout the process.

All recommendations were valued, and clear priorities emerged across all three focus areas — Public Life, Formal Assistance, and Health Outcomes. Despite the small sample size, consistent patterns in respondent priorities offer meaningful directional guidance for where to start in implementation planning.

Qualitative feedback also strengthened the final roadmap. Respondents identified areas where recommendations needed clearer language, greater specificity, and stronger attention to the full range of post-viral IACC experiences, and where able, their feedback was incorporated into the final draft.

Looking ahead, respondents were candid that a well-written roadmap is not enough. **Successful implementation will require clear ownership, realistic timelines, measurable outcomes, and the sustained and meaningful involvement of people with lived experience.** This feedback reflects not only what contributors believe should happen, but their commitment to seeing it through.

Detailed suggestions for expanding recommendations

Several survey respondents provided detailed suggestions on how to expand or build onto specific recommendations for implementation. Not all details were incorporated into the final report, so they are provided here as they were shared by survey respondents.

Public life

Public awareness campaigns

- Launch a statewide post-viral IACC public education campaign that includes short videos, lived experience storytelling (stories or testimonials to humanize the issue), interviews with patients - caregivers - clinicians - researchers - leadership (State or Federal-level leaders), infographics, radio spots, podcasts, YouTube videos or social posts. This public education campaign could focus on post-exertional malaise (PEM), disability accommodations, prevalence, and stigma reduction. The campaign could highlight annual observances as well (ME/CFS Awareness Day/Month, Long COVID Awareness Month, Dysautonomia Awareness Month).
- Create a specific public awareness effort around PEM, with visuals or storytelling that centers on activity → crash → days/weeks to recover. MDH could partner with trusted voices on anything public awareness-related, including CIDRAP, Univ. of MN, Mayo Clinic to establish even more credibility and reach. Also centering real patient stories, short videos or profiles of Minnesotans living with a post-viral IACC of before/after impact, invisible symptoms, pacing realities could be a powerful lever. These short videos could be Instagram-reel short (30-60 seconds) or short YouTube videos.
- A Seminar Series public awareness campaign (similar to RECOVER Initiative), where MDH could select specific aspects of post-viral IACC to impact: different communities to highlight, on specific research aspects (both UMN and Mayo Clinic are involved with research), clinical care pathways (similar to ECHO series), economic impact, employment / workforce impact, family / caregiver impact, etc.
- Any public messaging should include prevalence and severity (bedbound, housebound, employment loss), the pediatric reality (kids and teens are affected too), and the long diagnostic delays and common misdiagnoses (anxiety, depression, deconditioning).
- Include education institutions as a target audience for public awareness campaign.
- Increase in public awareness can also be helpful if state legislature was also involved such as proclamation and awareness days, introducing a bill to encourage medical professionals to take CE on Infection Associated Chronic Illnesses and conditions. Having these types of CEs promoted on licensure boards (nursing, medical) would also be helpful in increasing awareness.

Online resource centers

- Online Resource Centers, should include: clear guidance on PEM and activity intolerance, how to support clients who cannot attend in-person appointments, how to document functional limitations for disability, accommodations, and benefits - scripts and examples for describing symptoms in non-medical settings, guidance on fluctuating capacity (good days ≠ recovery), information on homebound/housebound populations, how to avoid retraumatizing or dismissive interactions and a section specifically for case managers, county workers, and social workers who often have no training on post-viral IACCs.

Support group expansion and coordination

- Options for low-stim, low-energy participation (camera off, chat-only, asynchronous), groups for housebound/bedbound people, facilitators trained in trauma-informed, disability-informed approaches.
- Groups for caregivers and parents of pediatric patients, coordination with existing patient-led groups.

Define, assess, and enhance navigator role

- One recommendation is a statewide post-viral IACC care navigation hotline, that would help with finding/coordinating care, finding providers, disability paperwork, and social services. This would helps patients find knowledgeable post-viral IACC clinicians, disability resources, pacing/PEM education and community supports. A statewide referral pathway aided by the navigator role, so patients and clinicians know where to access appropriate care, including telehealth and home-based options, would be vital.
- Need to include training on PEM, pacing, and energy budgeting; understanding of disability systems (SSDI, SSI, Medicaid, MA-EPD, workplace accommodations); knowledge of home-based care options; awareness of how to help people who cannot travel; support for people who are cognitively limited (brain fog, processing issues); navigation for school accommodations (504 plans, IEPs); navigation for employment protections (ADA, FMLA); understanding that many patients cannot make phone calls or attend in-person meetings; a trauma-informed approach — many patients have been dismissed or harmed in medical settings.

Other recommendations

- Public understanding of PV-IACCs is shaped not only by clinical and social systems but also by media narratives. Accurate, stigma-free coverage is essential for reducing misinformation, improving early recognition, supporting community awareness and ensuring accurate information reaches Minnesotans. Would also be great to see MDH form and continue partnerships with local and statewide media outlets to increase accurate, accessible coverage of PV-IACCs, and have that be an implementation step under #1 - Public Awareness Campaigns. I would encourage MDH to incorporate partnerships with these local and statewide media throughout the roadmap. Including guidance for ethical reporting, public-awareness campaigns, and collaboration with journalists would strengthen the Public Life section and support the broader goals of early recognition, equitable access, and community understanding. As we know, media can strongly shape how communities, employers, and even clinicians interpret these conditions. Some local media members that have shown a keen interest in reporting on post-viral IACCs in Minnesota so far include Renee Cooper and Ellen Galles of KSTP, Jeremy Olson of Star Tribune, Jill Burcum of Star Tribune (Editorial Board), Esme Murphy and Erin Hassanzadeh of WCCO, Cathy Wurzer and Nina Moini of MPR, Sarah Boden of CIDRAP, Anja Wuolo of Sun Post, and Chloe Peter of Southwest Voices.

- Additionally, it would be great if MDH reached out to these media members before June 2nd's Statewide Conversation and for any future developments with the roadmap. These media opportunities can help counter outdated or harmful narratives. Lastly, partnering with some select national media like The Sick Times (Betsy Ladyzhets and Miles Griffis) would be really helpful with high reach, as we saw how that advocacy helped last May in defending MDH's retained funding (and how The Sick Times reporting helped rally the community with this reach). This can also help with policy influence and credibility with lawmakers and health systems.

Formal Assistance

Disability recognition in navigation systems (renamed in final report)

- Help with standardized disability documentation, as well as helping create templates for doctors writing disability letters and functional limitation language.
- Any expanded efforts in Disability Recognition in Navigation Systems needs to explicitly include: Recognition of PEM as a disabling functional limitation, not "fatigue"; Episodic and Fluctuating capacity as a legitimate disability pattern; Housebound and bedbound patients as a priority population; Cognitive impairment (processing speed, memory, executive function) as a barrier to accessing services; the need for low stim, low demand communication options (email, text, asynchronous); Recognition that many cannot attend in person assessments.

Buddy program / peer support

- Options for extremely low-capacity participation (camera off, chat only, asynchronous); Peer supporters trained in PEM aware, harm reduction approaches; Support for caregivers and parents of pediatric patients; Matching based on severity (housebound folks need peers who understand that reality); Avoiding "motivational" or "activity building" framing that harms post-viral IACC patients.

Invest in community health worker (CHW) infrastructure

- CHWs must be trained in: PEM, pacing, and energy budgeting; How to support people who cannot travel; Home based care pathways; Disability documentation and benefits navigation; Trauma informed communication (many have been dismissed or harmed in care settings); How to work with people with cognitive limitations.

Strengthen infrastructure between community, health, and formal assistance systems of care

- From lived experience, my recommendations: warm handoffs, not "here's a link"; cross agency communication that doesn't require the patient to be the project manager; shared understanding of PEM across systems; integration with existing patient-led orgs, not reinventing the wheel; support for people who cannot navigate multiple portals or phone trees.

Telehealth and remote assessments

- Telehealth should be a default option, not an exception; remote functional assessments that don't require exertion; asynchronous options for people with cognitive limitations; home based assessments for severe patients.
- Strongly endorse support for telehealth, home-based care, and remote service models, which is so vital for post-viral IACC.
- Telehealth is discussed but discussing the importance of establishing other tele services - like tele tutors for children who are unable to attend school regularly.

Promote disability rights and employer-facing education-modules (renamed in final report)

- MDH could help guidance for schools, workplaces, and disability services - through post-viral IACC / PEM aware accommodations, return to school/return to work guidance, and templates for 504 plans and workplace accommodations.
- Would recommend including pediatric-specific guidance for clinicians and schools, including accommodations, homebound instruction, and family-centered support.
- Any education modules need to center clear guidance on PEM and activity intolerance; examples of reasonable accommodations (flexible hours, remote work, reduced cognitive load); education on fluctuating disability; warnings against harmful "graded exposure" or "building tolerance" approaches; support for workers who cannot predict their capacity day to day.
- Missing: Seek and implement beneficial ways to enforce/incentivize and educate employers (both public AND Private) to practically accommodate persons with disabilities in general, post-viral IACC disabilities.

Support and promote accommodation guidance at the state and local level (Merged with "Promote disability rights and renamed in final report)

- Standardized guidance for schools, workplaces, and public programs; templates for letters, documentation, and functional descriptions; guidance for county workers and case managers; clear language on pacing and PEM; accessibility for people who cannot attend in person.

Reorient assessments and requirements to access formal assistance (Merged with "Disability recognition…" and renamed in final report)

- Assessments that do not require physical exertion; recognition that "activities of daily living" fluctuate; options for written or asynchronous assessments; shorter, paced interviews; no penalties for inability to attend in person; recognition that cognitive impairment affects paperwork completion.
- Use of existing assessment tools that allow for fluctuating functional capacity with this illness can help encourage faster implementation. Suggestions by Bateman Horne's Clinical Care Guide Include: Good Day/Bad Day Questionnaire, PROMIS Fatigue and Cognitive Dysfunction Questionnaire, SF-36 (Rand-36) Functional Assessment Scale, or FUNCAP (55 for more detail, 27 if the patient needs shorter assessment due to capacity limitations).

Bridge formal and informal systems of care (Merged with "Strengthen infrastructure between community, health, and formal assistance…" in final report)

- From lived experience: support for caregivers (including unpaid family caregivers); guidance for people who rely on informal care because formal care is inaccessible; integration with home based services; recognition of the burden on households when the patient cannot perform basic tasks; support for people who live alone and cannot rely on informal care.
- Consideration with referral pathways that very likely the first referral by an ME/CFS unaware provider is to psychiatric/mental health providers. We must also educate psychiatric/mental health professionals on ME/CFS to reduce psychiatric misdiagnoses.

Other formal assistance recommendations

- Create pathway for IACCs patients to obtain caregiver assistance through Social Security Disability or statewide service for people disabled by IACCs.
- We need to also include education for educators and schools. Children can be greatly affected by long covid and struggle with getting resources through schools as the lack of education, understanding and awareness is not there.
- Also addressing resources for families with kids with long covid as the parents are now struggling with caring for their child and remaining employed. Looking at resources for families of medically fragile children that are already in place and expanding those resources to families of children with post-viral IACCs.

Health Outcomes

Education modules for ancillary healthcare professionals (Renamed in final report)

- Recommend that MDH help develop and mandate CME-accredited trainings for Minnesota clinicians. MDH could host or co-host CME webinars with national post-viral IACC experts that would include partnering with the U.S. ME/CFS Clinician Coalition, Bateman Horne Center, Solve ME/CFS Initiative, Dysautonomia International, Patient-Led Research Collaborative, Mayo Clinic, and the University of Minnesota. These CME modules could be focused on diagnosing post-viral IACCs, managing PEM / PEM recognition, and disability documentation. The CME-accredited provider trainings could be for primary care, pediatrics, and emergency departments.
- Curricula development and training. MDH work with the U of M, collaborate with faculty, staff, and patients/patient advocates to make sure that there is content available in courses for new and existing practitioners.
- These modules must include: PEM as a defining feature, not "fatigue"; how to avoid harm (no graded exercise, no "build tolerance," no pushing through symptoms); recognition of fluctuating disability; cognitive impairment and how it affects communication, consent, and care; how to provide low stim, low demand care; how to support housebound and bedbound patients; trauma-informed approaches (many patients have been dismissed or harmed in care settings).

- In order to get information to students, ME action and Solve ME this year have brought to our attention that we need to get questions on ME/CFS and other post-viral IACCs on the medical and nursing exams. If they are on medical board exams, it means it needs to be taught in school as part of the curriculum.

Disseminate formal Council of Medical Specialty Societies (CMSS) resources to clinicians

- Clear warnings against exercise based rehabilitation; guidance on pacing and energy management; recognition of severe and very severe patients; clinical red flags (orthostatic intolerance, dysautonomia, cognitive dysfunction); how to document functional limitations for disability and accommodations.
- For CMSS I would say the committee should not use or link to their full set of resources but examine each resource and determine which are most useful. I'm aware of a few resources they've included, such as the Long COVID Compendium, with its regretfully poor section on exercise. UpToDate, same basic principles apply: caveat emptor. The most respected source, or the one with the most authors is unfortunately not always the best source of patient-centered, best-practice information.

Point-of-care clinical tools (merged with “Unified clinical pathways” in final report)

- These tools must include: PEM screening questions; short, low cognitive load assessment formats; guidance for clinicians on how to avoid triggering PEM during visits; Decision trees that do not default to exercise or “graded exercise”; orthostatic intolerance screening (NASA lean test, symptom based alternatives); medication cautions (e.g., drugs that worsen dysautonomia or fatigue); home based care option. Point of care tools must be designed for clinicians who have no background in post-viral IACCs.
- Recommendation to Add text such as: Educate providers regarding use of new ICD 10 Codes for ME/CFS and Long Covid to ensure proper tracking of patients for broad patient analysis/formal counts to improve care and funding moving forward.
- In developing care plans, for example in the scope of nursing, having examples of appropriate nursing diagnoses and interventions that are appropriate for the severity of the patient could be helpful as guidance to create a more patient oriented treatment plan.

Annual Minnesota post-viral-IACC clinical symposium

- Partnering with the patient community and lived-experience experts to help identify potential facilitators or participating members. There may also be opportunities to collaborate with Minnesota-based health associations for physicians, residents, and medical students in this too (MMA, MAPA, MN AAP, MN Nurses Association, etc.). The post-viral IACC Clinical Symposium should include clinicians, researchers, and patient experts from the ME/CFS, Long COVID, POTS / Dysautonomia, MCAS field and more. Would recommend MDH to partner and collaborate with CIDRAP, University of Minnesota, and the Mayo Clinic.
- Ideally, there would be representation at this Symposium from state leadership — for example, the Lieutenant Governor, as seen in other states — or from the Health Commissioner.

- Patient led panels; training on severe and very severe patients; sessions on PEM, pacing, and harm reduction; cross disciplinary training (primary care, neurology, cardiology, PT/OT, mental health); practical clinical pathways, not just research updates.
- Would also recommend case-based learning (“what went wrong / what worked” / "what needs work") in the Symposium, and practical sessions: of how to manage PEM / how to support function with a post-viral IACC.

Unified clinical pathways and care algorithms (renamed in final report)

- These pathways must include: a PEM first framework; pacing as the foundational management strategy; recognition of fluctuating function; guidance for managing orthostatic intolerance and dysautonomia; home based and telehealth options; clear “do not do” lists (no GET, no forced activity, no “reconditioning” protocols); pathways for severe and very severe patients Unified pathways must protect patients from harmful or outdated care.

Patient centered clinical standard (Do No Harm Protocols) (renamed in final report)

- These must include: Explicit harm reduction principles; No exercise based rehabilitation for PEM affected patients; Short, paced visits with breaks; Asynchronous communication options; Avoiding unnecessary testing that triggers PEM; Protocols for preventing post visit crashes; Guidance for clinicians on validating and supporting patients; Care algorithms that start with post-viral IACC informed management, not generic chronic illness care.
- Help fund & accelerate available medical system equipment, training and procedures to support patients with post-viral IACCs throughout the state (Tilt-Table Tests, 2-Day CPETs, etc.). I had to travel to California for a 2-Day CPET - we need more in Minnesota to able to understand PEM, research studies, clinical trial involvement, and if applicable, disability purposes - disclaimer being those well enough to complete without harm.
- MDH can help build and support statewide clinical guidance for post-viral IACCs, including recognition of PEM and harm-avoidance in rehabilitation.
- Patient Care standards must also include information related to Severe and Very Severe ME/CFS as this group is typically not able to access care because of the severity of illness. This population is also under represented in research.
- When Engaging PT and OT, the consideration of hEDS comorbidity need to be included in education and implementation. A large amount of the post-viral IACC patient population has this diagnosis and it requires different considerations and strategies when implementing PT/OT interventions.
- Communications strategies would be a great spot for post-viral IACC aware mental health professionals to lend their expertise as they have extensive experience in communication strategies, trauma informed care and therapeutic relationships due to the nature of their practice. If done by someone not experienced with post-viral IACCs it could inadvertently cause harm (i.e. providing suggestions that aren't tailored to the ME/CFS patient could lead to PEM for the patient).

Other recommendation for health outcomes

- MDH could help develop a Minnesota post-viral IACC provider directory that is publicly accessible and updated annually. This list could include primary care, specialists, PT/OT familiar with PEM and pediatric providers. Right now the Guiding Council just lists the participating clinics and health systems, but this community has learned that doesn't guarantee a provider in that system will be knowledgeable on post-viral IACCs. We need a public, accessible provider directory.
- Education, pathways, and tools are common interventions for attempting to raise awareness of clinicians or to encourage a condition to be considered as part of the differential diagnosis process. The missing piece appears to be how the intended change in practice approach can be incorporated into the current acute care focused model of care and reimbursement. Primary care is the backbone for much of this, but clinicians often work within models that do not allow for the time needed to address conditions such as post-viral IACC. The clinicians have little to no control over the model.
- Working with medical boards and certification groups is key here. Many providers (especially non-doctor providers like NPs, PAs) get the majority of their CEUs from their professional organizations (I.E NAPNAP, AANP, etc.). Partnering with these groups to provide CEU modules on post-viral IACCs is imperative in helping inform medical providers. Include nursing organizations that provide nurse CEUs as well. Consider required CEUs for state license renewal for nurses and PAs, NPs.
- Primary care providers were addressed but also include Emergency Department (ED) staff. Many patients with post-viral IACCs can end up in the ED at times of crisis and the lack of education in the ED can lead to gaslighting, misdiagnoses, and harm vs providing care that helps stabilize the patient until they can see their regular provider. It is important to include ED providers and also urgent care providers.

Appendix G: Hyperlink References

Below is a collection of all hyperlinked resources and references inserted throughout this roadmap document, in alphabetical order.

10 Principles of Disability Justice (https://sinsinvalid.org/10-principles-of-disability-justice/)

A Guide to Reducing Coverage Losses Through Effective Implementation of Medicaid's New Work Requirement from the Center on Budget and Policy Priorities (https://www.cbpp.org/research/health/a-guide-to-reducing-coverage-losses-through-effective-implementation-of-medicaids#determining-exemptions-cbpp-anchor)

A Long COVID Definition | National Academies (https://www.nationalacademies.org/read/27768)

AHRQ Long COVID Care Network | Agency for Healthcare Research and Quality (https://www.ahrq.gov/coronavirus/long-covid/care-network.html)

American Physical Therapy Association (APTA) (https://www.apta.org/)

Americans with Disabilities Act (ADA) | Great Lakes Center (https://adagreatlakes.org/)

Americans with Disabilities Act (ADA) Minnesota | Metro Center for Independent Living (https://mcil-mn.org/services/ada-minnesota/)

Bateman Horne Center (http://www.batemanhornecenter.org/)

Book: An Interior Life by Bill Hop (https://billhope.com.au/an-interior-life)

Book: Chronic Fatigue Superhero by Michael Towers (https://a.co/d/098xpQY8)

Book: The Long COVID Survival Guide - The Experiment (https://theexperimentpublishing.com/catalogs/fall-2022/long-covid-survival-guide/)

Book: The Sound of a Wild Snail Eating by Elisabeth Tova Bailey (https://a.co/d/0dT1YvsF)

Book: Your Symptoms Are Real: What to Do When Your Doctor Says Nothing Is Wrong by Dr. Benjamin Natelson (https://a.co/d/01zu9nRE)

Buddy-to-Buddy Program | University of Michigan (https://available-inventions.umich.edu/product/buddy-to-buddy-program)

Building Bridges Between Health Care and Community | Stratis Health (https://stratishealth.org/customized-solutions/building-bridges-between-health-care-and-community/)

Building Stronger Programs to Address and Mitigate Long COVID Effects | ASTHO (https://www.astho.org/topic/toolkit/2026/building-stronger-programs-to-address-and-mitigate-long-covid-effects/)

Campus Y: Best Buddies | Heel Life (https://heellife.unc.edu/organization/bestbuddies)

Certified Peer Specialists Program: Mental Illness | DHS (https://mn.gov/dhs/people-we-serve/adults/health-care/mental-health/programs-services/cps.jsp)

Clinician's Pacing and Management Guide for ME/CFS and Long COVID | Patient Led Research Collaborative (https://patientresearchcovid19.com/clinicians-pacing-and-management-guide-for-me-cfs-and-long-covid/)

CMSS resources (https://cmss.org/programs-and-resources/long-covid-resource-repository/)

Community Health Worker Billing and Reimbursement | MDH (health.state.mn.us/communities/commhealthworkers/employers.html)

Community Health Worker Initiatives | MDH (health.state.mn.us/communities/commhealthworkers/index.html)

Community-Clinical Linkages | MDH (health.state.mn.us/communities/healthcarelinks/index.html)

Comprehensive Guide to LC | C19LAP | COVID-19 Longhauler Advocacy Project (https://www.longhauler-advocacy.org/2024cglc)

Conference: Annual Long COVID International Conference | Academic Medical Education (https://academicmedicaleducation.com/programs/4th-long-covid-international-conference-2026)

Conference: CDC - ME/CFS Stakeholder Engagement and Communication (MECFS-SEC) Meetings (https://www.cdc.gov/me-cfs/events/index.html)

Conference: IACFS/ME Biennial Conference (https://www.iacfsme.org/)

Conference: Mast Cell Activation Syndrome (MCAS) International Conference (https://ismcas.org/2026-ismcas-annual-conference/)

Conference: ME/CFS Working Group | NANDSC-NIH (https://www.ninds.nih.gov/about-ninds/who-we-are/advisory-council/nandsc-working-group-mecfs-research)

Conference: Unite to Fight: Long COVID and Myalgic Encephalomyelitis Virtual Conference (https://www.rehacare.com/en/media-news/emag/business/international-long-covid-me-cfs-conference)

COVID-19 Longhauler Advocacy Project (https://www.longhauler-advocacy.org/)

Developing A Sustainable Plan for Community Health Workers in Minnesota | Minnesota Community Health Worker Alliance (https://mnchwalliance.org/sustainable-planning-for-chws/)

Disability Hub MN (https://disabilityhubmn.org/)

Disability justice definition (https://sinsinprocess.squarespace.com/blog/disability-justice-a-working-draft-by-patty-berne#:~:text=A%20Disability%20Justice%20framework%20understands,bodies%2C%20but%20because%20of%20them.)

Disability Minnesota (https://mn.gov/disability-mn/)

“Do No Harm” Checklist Makes Care Safer by Design | Institute for Healthcare Improvement (https://www.ihi.org/library/blog/do-no-harm-checklist-makes-care-safer-design)

Documentation for Return to Work and Disability | MDH (health.state.mn.us/diseases/longcovid/providers/work.html)

Employer Reasonable Accommodation Fund | Minnesota DEED (https://mn.gov/deed/business/financing-business/eraf/)

Enhancing Pediatric Long COVID Care Through Telementoring: Insights From an ECHO Program | PubMed (https://pubmed.ncbi.nlm.nih.gov/40077880/)

Extension for Community Healthcare Outcomes (ECHO) programs (https://pubmed.ncbi.nlm.nih.gov/40077880/)

Expanding Behavioral Health Teams in Care Deserts with Community Health Workers and Peer Support Specialists (PDF) SAMHSA (https://library.samhsa.gov/sites/default/files/advisory-expanding-behavioral-health-teams-care-deserts-pep26-07-001.pdf)

Fibromyalgia, ME/CFS, and Related Conditions Facebook Support Group (http://www.facebook.com/groups/FibromyalgiaMN)

Findhelp: Browse Social Services in Minnesota (https://www.findhelp.org/find-social-services/minnesota)

For Healthcare Providers: Post-COVID Conditions | MDH (health.state.mn.us/diseases/longcovid/providers/index.html)

Getting Ready to Talk about Long COVID with Your Child’s Doctor (PDF) - RECOVER (https://drive.google.com/file/d/1piHTuHF_HC6kwG2-p91f0IFUzStoOEMI/view)

Good day/Bad day questionnaire (PDF) | Bateman Horne (https://batemanhornecenter.org/wp-content/uploads/filebase/education/top_resources/Good-Day-Bad-Day-Questionnaire-Fillable-V3-6_6_2022.pdf)

Guidance on “Long COVID” as a Disability Under the Americans with Disabilities Act (ADA), Section 504, and Section 1557 | HHS.gov (https://www.hhs.gov/civil-rights/for-providers/civil-rights-covid19/guidance-long-covid-disability/index.html)

Health Care Homes | MDH (health.state.mn.us/facilities/hchomes/index.html)

Health equity definition | CDC (https://www.cdc.gov/health-disparities-hiv-std-tb-hepatitis/about/index.html)

Health Rising (https://www.healthrising.org/)

Health+ Long COVID Human-Centered Design Report (PDF) (https://health.gov/sites/oash/files/2025-01/healthplus-long-covid-report.pdf)

Healthcare Appointment Checklist for Long COVID| CDC (https://www.cdc.gov/covid/media/pdfs/2024/07/COVID-19-fact-sheet-post-appointment-checklist-c.pdf)

HHV-6 Foundation (https://hhv-6foundation.org/)

HIV/AIDS Buddy programs | Action Wellness (https://www.actionwellness.org/volunteer/buddy-program/)

Home care services | Minnesota DHS (https://mn.gov/dhs/people-we-serve/people-with-disabilities/services/home-community/programs-and-services/home-care.jsp)

How to Get On (https://howtogeton.wordpress.com/)

IACC Resource Guide | Infection Associated Chronic Conditions Initiative (IACCI) (https://www.iaccinitiative.org/iacc-resource-guide)

IACCI Living Guidelines Pilot (https://invisibleillness.crowdicity.com/hubbub/communitypage/23445)

Individuals Community Living Supports (ICLS) | Minnesota DHS (https://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=DHS-293369)

Job Accommodation Network (JAN) (https://askjan.org/)

Long COVID - 2026 ICD-10-CM Diagnosis Code U09.9: Post COVID-19 condition, unspecified (https://www.icd10data.com/ICD10CM/Codes/U00-U85/U00-U49/U09-/U09.9)

Long COVID | Pima County, Arizona (https://www.pima.gov/2253/Long-COVID)

Long COVID | Washington State Department of Health (https://doh.wa.gov/emergencies/covid-19/long-covid)

Long COVID Data and Reports | MDH (health.state.mn.us/diseases/longcovid/data.html)

Long COVID Education, Engagement, and Care Management | CMSS (https://cmss.org/programs-and-resources/long-covid-education-engagement-and-care-management/)

Long COVID Guide for Social Security Disability Claims (PDF) | SSA (https://www.ssa.gov/disability/professionals/documents/EN-64-128.pdf)

Long COVID Resource Repository | CMSS (https://cmss.org/programs-and-resources/long-covid-resource-repository/)

Long COVID Resources and Support | MDH (health.state.mn.us/diseases/longcovid/resources.html)

Long COVID Resources for Community Recovery | ASTHO (https://www.astho.org/topic/infectious-disease-prevention/long-covid-resources-for-community-recovery/)

Long COVID Surveillance Quick Reference Guide (PDF) | CSTE (https://cdn.ymaws.com/www.cste.org/resource/resmgr/infectiousdisease/Long_COVID_Surveillance_Quic.pdf)

Long COVID Treatment Guide | RTHM (https://www.rthm.com/resources/blogs/long-covid-treatment-guide)

Long COVID under Section 504 and IDEA Resource to Support Children, Students, Educators, Schools, Service Providers, and Families (PDF) (https://www2.ed.gov/about/offices/list/ocr/docs/ocr-factsheet-504-20210726.pdf)

MDH Long COVID Program (health.state.mn.us/diseases/longcovid/index.html)

MDH, Stratis Health, and their Guiding Council of clinicians (health.state.mn.us/diseases/longcovid/providers/guiding.html)

#MEAction (https://www.meaction.net/)

ME | International Consensus Criteria (https://www.meresearch.org.uk/research/international-criteria/)

ME | Stuff That Works (https://www.stuffthatworks.health/myalgic-encephalomyelitis)

ME/CFS | Canadian Consensus Criteria (https://www.meresearch.org.uk/research/canadian-criteria/)

ME/CFS | Institute of Medicine 2015 Diagnostic Criteria (https://www.cdc.gov/me-cfs/hcp/diagnosis/iom-2015-diagnostic-criteria-1.html)

ME/CFS | Long COVID Justice (https://longcovidjustice.org/me-cfs/)

ME/CFS Find a Doctor Tool | #MEAction (https://www.meaction.net/find-a-doctor)

ME/CFS Guide for Social Security Disability Claims (PDF) | SSA (https://www.ssa.gov/disability/professionals/documents/64-063.pdf)

ME/Long-COVID Justice (https://longcovidjustice.org/me-cfs/)

Metropolitan Center for Independent Living (https://mcil-mn.org/)

Minn. Stat. §145.361 (https://www.revisor.mn.gov/statutes/cite/145.361)

Minnesota Centers for Independent Living (MACiL) (https://www.macil.org/)

Minnesota Community Health Worker Alliance (https://mnchwalliance.org/)

Minnesota Dystonia Support Group | Dystonia Medical Research Foundation (https://dystonia-foundation.org/living-dystonia/support-groups/3459/minnesota-dystonia-support-group/)

Minnesota Electronic Health Record Consortium (MNEHRC) (https://mnehrconsortium.org/)

Minnesota Home Help Navigation| #MEAction pilot (https://help.meaction.net/)

MN Disability Hub (https://disabilityhubmn.org/)

MnCHOICES | Minnesota Department of Human Services (https://mn.gov/dhs/partners-and-providers/news-initiatives-reports-workgroups/long-term-services-and-supports/mnchoices/)

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National Alliance for Healthcare Purchaser Agreements (https://www.nationalalliancehealth.org/)

Open Medicine Foundation (https://www.omf.ngo/)

OSHII/SHIP (health.state.mn.us/about/org/hpcd/oshii/index.html)

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PACER Center: Champions for Children with Disabilities (https://www.pacer.org)

Pediatric Guide to Pacing | Long COVID Families (https://longcovidfamilies.org/wp-content/uploads/2024/02/Pediatric-Guide-to-Pacing-2.pdf)

Phoenix Rising (https://phoenixrising.me/)

Post-COVID recovery & COVID-19 patient forum | Mayo (https://connect.mayoclinic.org/group/post-covid-recovery-covid-19/)

RECOVER COVID Initiative | NIH (https://recovercovid.org/)

Resource Hub | Long COVID Justice (https://longcovidjustice.org/resources/)

Resourceful Community Resource Guide (https://www.weareresourceful.org/)

Resources | Peer Mentoring Works (https://peermentoringworks.org/resources/)

Science for ME (https://www.s4me.info/)

Self Help (https://cfsselfhelp.org/)

Sins Invalid’s 10 Principles of Disability Justice (https://sinsinvalid.org/10-principles-of-disability-justice/)

Solve ME/CFS Initiative (https://solvecfs.org/)

State Medical Review Team (SMRT) (https://mn.gov/dhs/people-we-serve/people-with-disabilities/health-care/health-care-programs/programs-and-services/smrt.jsp#:~:text=The%20State%20Medical%20Review%20Team,the%20Social%20Security%20Administration%20(SSA))

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Understanding Long COVID: Implications for Family Physicians’ from the American Academy of Family Physicians (https://www.aafp.org/pubs/fpm/issues/2024/1100/long-covid.html)

UpToDate (https://www.wolterskluwer.com/en/solutions/uptodate/clinical-decision-support)

Vocational Rehabilitation Services (VRS) (https://mn.gov/deed/job-seekers/disabilities/)

Voices of Long COVID (https://www.youtube.com/playlist?list=PLPTBJ6591fPLHdI6MFDf5gZKANZUcEDxF)

What is Trauma-Informed Care? | Trauma-Informed Care Implementation Resource Center (https://www.traumainformedcare.chcs.org/what-is-trauma-informed-care/)