Long COVID Guiding Council: Project Accomplishments to Date and Plan for Future Work

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Since January 2023, the Minnesota Department of Health (MDH) and Stratis Health have been convening the Minnesota Long COVID Guiding Council of primary and specialty care clinicians to determine the types of supports and resources needed by clinicians and health systems across Minnesota to care for patients with long COVID. Visit MDH: For Health Care Providers: Post-COVID Conditions: Guiding Council for a list of participating organizations.

Long COVID is a new and emerging condition that can have a significant impact on a person's health and quality of life. An estimated 5-30% of people with COVID-19 will experience long COVID symptoms for weeks, months, or sometimes years after the acute phase of their infection. Failure to address long COVID can have serious consequences for patients impacted by the condition, hence the recognition by clinicians and health care systems is imperative in ensuring that patients receive appropriate care.

Overall, this group has identified that primary care clinicians will need support from their health systems to help identify and care for patients with long COVID. It is not enough to educate clinicians or put the entire burden on them to determine how they care for long COVID patients. The health systems need to proactively ensure that their clinicians have the supports and resources necessary to identify and care for patients with long COVID. However, for health systems to be effective partners in this work, greater prioritization of long COVID is needed.

The following is the timeline of Guiding Council's work that shows progress over time – where we've been and where we might be going.

Where we've been

Phase 1: Exploring the need for long COVID guidance and a universal definition of long COVID

Guidance. Long COVID presents challenges for clinicians: there is not yet a universal clinical definition, severity and duration varies from person to person, and the evidence to support diagnosis and treatment is minimal and actively evolving. To address this issue, the initial goal of the Guiding Council was to develop a guidance for diagnosis and management of long COVID and/or at minimum establish universal definition.

After an environmental scan of current guidelines and evidence and individual conversations with the Guiding Council members, it was determined that a guidance may not be value-added given the preponderance of national and international guidelines, with the American Academy of Physical Medicine and Rehabilitation PASC Consensus Guidance the U.S. Department of Veterans Affairs Whole Health System Approach to Long COVID (PDF) being the most

comprehensive. Some clinicians involved with the long COVID clinics are also using literature and guidance related to myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) because of the overlap in clinical presentations. UpToDate has made significant updates to their content on long COVID and seems to be a "go to" reference on diagnosis, treatment, and management for primary care clinicians.

Universal definition. The Guiding Council did not agree on a universal definition of long COVID, as there are valid definitions by the U.S. Centers for Disease Control and Prevention (COVID-19: Long COVID or Post-COVID Conditions), World Health Organization (Post COVID-19 condition [Long COVID]), and the United Kingdom's National Institute for Health and Care Excellence (COVID-19 rapid guideline: Managing the long-term effects of COVID-19) that members are using. Some members of this group preferred to have flexibility to choose a definition that best fit their patient population's clinical needs.

Long COVID pathway. Instead of focusing on developing a guidance or agreement on universal definition, the Guiding Council identified a need to fill in the gaps where the current evidence is unclear or insufficient in the long COVID care pathway that includes identification, diagnosis, management, recovery, and return-to-work to support primary care clinicians. This led to a recommendation for Phase 2 of the work to focus in part on how health systems can support primary care clinicians to 1) identify patients with long COVID in primary care by testing two screening questions with willing and interested clinicians, and 2) develop a resource for primary care providers to ease determination of and documentation for workplace accommodations/return-to-work requests.

Phase 2: Long COVID care pathways (identification, diagnosis, management, and return to work)

Workgroup 1: Developing and testing two screening questions to identify people with potential long COVID

Three primary care clinicians from the Guiding Council representing community health care, a medium-sized, Minneapolis-based health care system, and a large health system from Greater Minnesota tested a two-question screener to identify people with potential long COVID symptoms.

Results: 43 total screens found an almost equal split between those who said they had COVID-19 verses those who indicated they had not had COVID-19. Of those who said they had COVID-19, 11 were back to pre-COVID level of health; 9 had lingering symptoms (those patients were either being managed or didn't necessitate further follow up). Overall, the pilot did not identify more severe patients.

Feedback indicated that the questions were clear and understandable to patients and seemed to easily integrate into clinician's workflow.

Clinicians who conducted the pilots have been proactive about educating themselves and their patients about long COVID, and therefore may not be representative of clinicians more broadly. There may be a need for a larger cohort to make a more rigorous pilot study.

Workgroup 2: Long COVID Disability: Documentation for Workplace Accommodations

A package of resources for clinicians was developed in collaboration with Guiding Council members, ADA Minnesota, the Job Accommodation Network, employers, and people with lived experience. Resources include a fillable letter template, bank of common workplace accommodations for people with long COVID, and suggested links and resources for after-visit summaries and patient education. The workplace accommodations documentation resource is almost final and ready for use. MDH and the Guiding Council will continue exploring how health systems can incorporate the resource into their existing clinical workflows and electronic health records systems and consider opportunities to evaluate effectiveness and feasibility of use in the clinical setting.

Where we might be going

Phase 3 planning: Understanding and responding to needs related to long COVID

The Guiding Council's work to date indicates that this topic is a high priority for the members who have existing and well-structured long COVID programs. Many members express an interest in continuing and expanding the Guiding Council as a "learning network" among clinicians and other health care providers, however, the broader community of primary care and health systems have not indicated an urgency to prioritize long COVID.

Beyond healthcare, long COVID remains a public health issue:

- As COVID-19 continues to circulate indefinitely, some who are infected or reinfected will experience long-term complications, resulting in increased health care utilization and costs and loss of quality of life.
- Given the prevalence of long COVID among working-age adults, disability due to long COVID has and will continue to impact the workforce.
- People with long COVID are still facing barriers to accessing quality care. Patient advocates have a lot of interest in this topic.
- The COVID-19 pandemic had a disproportionate impact across communities, worsening health disparities across our state. Long COVID may further exacerbate these disparities.

Additionally, in 2023, the Minnesota Legislature identified long COVID as a priority area and has appropriated funding for the MDH Long COVID Program to address this issue. Minnesota now has an opportunity to lead in the understand and addressing of long COVID at the population level and inform efforts of other states seeking to do similar work.

As we look toward the next phase of work to understand and respond to the needs of health care providers, their health systems and leaders, and their patients, it will be important to gauge how conversations about long COVID have shifted among clinicians and their organizations over the last year. It is imperative that the work continues to be grounded in evidence and best-available practices, and that it supports health systems to make changes that will improve care of people with long COVID.

A few different ideas have solidified that could bring greater attention and foster interest, including evidence briefs to help bridge gaps in understanding of long COVID and post-infectious chronic conditions, an expert knowledge network for clinician mentorship/advice, and pilot projects to test systems-level changes that would improve identification and follow up care for people with long COVID and to test the workplace accommodations resource. Finally, we must incorporate equity as a focus as we test strategies to address structural barriers for underserved populations with long COVID.