m1 DEPARTMENT
OF HEALTH

Beginning a Long-Term Community Partnership: A Case Study of the Long COVID Community Voices Workgroup

In partnership with the Long COVID Program and the Center for Health Equity

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Introduction

In 2021, the Center for Health Equity at the Minnesota Department of Health (MDH) partnered with Wilder Research with the goal of infusing community perspectives into its COVID-19 health equity efforts. After some initial discussion, MDH decided that Wilder would support the Long COVID Program in the development of a community advisory group, called the Long COVID Community Voices Workgroup.

With this case study, we hope to share insights about how MDH can support community partnerships as a strategy for achieving health equity outcomes. To date, learnings include how to begin and build relationships with potential partners, the nuances of prompting and facilitating co-creation with community partners, the importance of intersectionality and recognizing multiple perspectives in partnership efforts, the complexities of navigating conflicts of interest with partners, and how contracting and business procedures can impede emergent or time-sensitive partnership opportunities.

The Long COVID Community Voices Workgroup is a partnership of community-based organizations interested in offering community perspectives to help guide MDH's long COVID work. Current and past members of the workgroup include:

- African Immigrant Community Services (AICS), represented by Abdirizak Diis, Mohamed Ahmed, and Pamela Zeller.
- CAPI (formerly the Centre for Asian and Pacific Islanders), represented by Mayly Xiong, Giselle Ramirez, Keo Phomsoukha, and Sarah Xiong.
- Hispanic Advocacy and Community Empowerment through Research (HACER), represented by Rodolfo Gutierrez.
- Metropolitan Center for Independent Living (MCIL), represented by Adrienne Wilcox, Jenni Schwartz, Kelly Krantz, and Michelle Vrieze.
- Southeast Minnesota Center for Independent Living (SEMCIL), represented by Rosalie Eisenreich.
- Stairstep Foundation, represented by Alfred Babington.

As part of MDH's Long COVID Program, Kate Murray and Jay Desai convened the workgroup for the first time in June 2022. In 2024, Lindsey Theis and Emerson Wheeler were hired to support the Long COVID Program, including efforts with the workgroup. Via the Center for Health Equity, Lovel Trahan, Ann Zukoski, and Mia Robillos offered critical support throughout the workgroup's lifespan. MDH staff Julie Hoff, Ashley Fell, and Kathy Como-Sabetti provided epidemiological expertise at multiple points to inform the workgroup's discussions.

Ryan Ander-Evans from Wilder handled workgroup logistics and served as the lead author for this case study. By providing logistical support like making agendas, taking notes, and coordinating meetings, he used an embedded researcher approach to gather and interpret data for this report. Beyond logistics, he contributed to the workgroup by sharing his experiences with community partnerships and strategizing with MDH staff about how the workgroup might function and grow. His role resulted not only in longitudinal data about how the workgroup helped direct MDH's long COVID efforts, but also a nuanced understanding of the dynamics involved in starting a partnership between a state agency and community-based organizations. He hopes this case study offers a tangible example to MDH staff people of how their colleagues prioritized community perspectives in the state's response to an emergent public health issue.
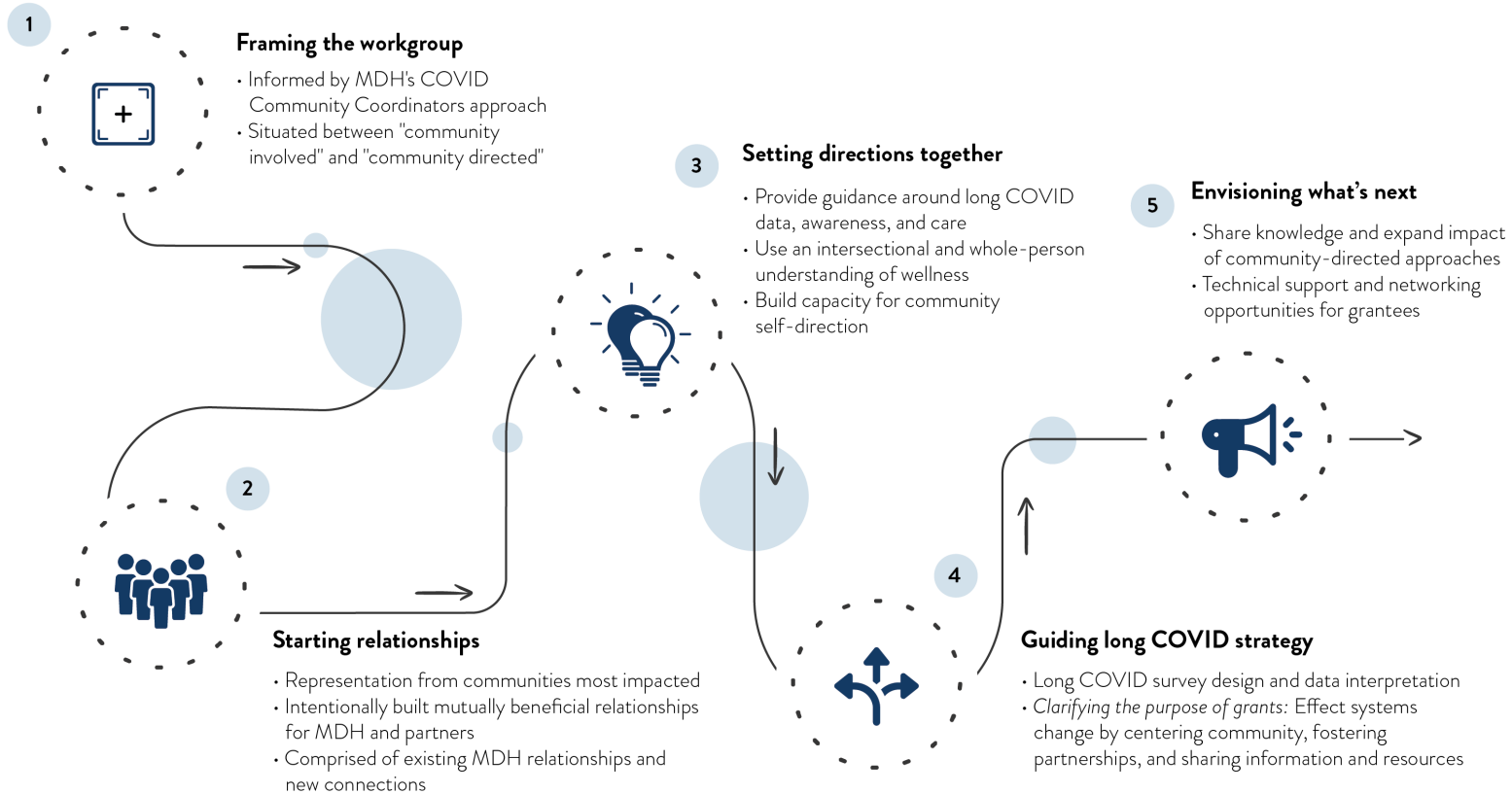
To jumpstart the writing process, in early 2024 Ryan hosted four co-theming sessions with MDH staff including Jay, Kate, Lovel, Ann, and Mia. In these meetings, he asked for reflections and memories of each phase of the workgroup's lifespan to date. He structured the case study based on these conversations.

Quotes from these co-theming sessions are cited as "co-theming meeting notes." Ryan also took notes at workgroup meetings with community partners (cited as "workgroup meeting notes") and planning meetings with Jay and Kate and, at times, Lovel, Ann, and Mia in which we discussed progress with the workgroup and strategies for moving its work forward (cited as "planning meeting notes"). To inform the development of the workgroup, in 2022 Ryan conducted a literature review about best practices for institution-community partnerships with a public health focus. He found additional secondary data while writing the case study, such as Governor Walz's recommendation to fund MDH's long COVID efforts. Secondary data sources such as these are cited where pertinent.

1. Long COVID Community Voices Workgroup annotated timeline

Long COVID Community Voices Workgroup
Annotated timeline (2021-2024)

1

Framing the workgroup
- Informed by MDH's COVID Community Coordinators approach
- Situated between "community involved" and "community directed"

3

Setting directions together
- Provide guidance around long COVID data, awareness, and care
- Use an intersectional and whole-person understanding of wellness
- Build capacity for community self-direction

5

Envisioning what's next
- Share knowledge and expand impact of community-directed approaches
- Technical support and networking opportunities for grantees

2

Starting relationships
- Representation from communities most impacted
- Intentionally built mutually beneficial relationships for MDH and partners
- Comprised of existing MDH relationships and new connections

4

Guiding long COVID strategy
- Long COVID survey design and data interpretation
- *Clarifying the purpose of grants:* Effect systems change by centering community, fostering partnerships, and sharing information and resources

← 2022 — 2023 — 2024 →

June
First workgroup meeting

March
Long COVID survey in the field

May
Legislative funding allocated for long COVID

June-Sept.
Contract gap

Sept.
In-person planning meeting

June
Workgroup began helping interpret survey data

Beginning a Long-Term Community Partnership:

A Case Study of the Long COVID Community Voices Workgroup

Framing the workgroup within MDH's long COVID efforts

The Long COVID Community Voices Workgroup started with a need and an opportunity. The need was the gradual recognition of long COVID in people's lives and our health systems. The opportunity was three-part: MDH's inclination to pursue a community partnership approach to addressing long COVID, partners' long history of community-based public health work, and the CDC's COVID-19 Health Disparities grant program, which helped to fund initial stages of MDH's long COVID health equity work. Chronic Disease & Environmental Epidemiology Manager Jay Desai framed motivations for the workgroup as, "How do we do a better job of engaging communities around our long COVID response?" (co-theming meeting notes, 1/17/2024).

In mid-to-late 2021, we had a handful of meetings to explore how a community partnership approach might help MDH accomplish health equity goals around long COVID. By January 2022, Long COVID Program Manager Kate Murray had distilled these conversations into a charter for the Long COVID Community Voices Workgroup. Here is the purpose statement from the charter:

> *[The Long COVID Community Voices Workgroup] brings together diverse perspectives to lead and guide the Minnesota Department of Health's (MDH) response to long COVID through a lens of health equity. The lived experience and technical expertise of members will help steer disease surveillance activities (such as design and dissemination of surveys) to understand the burden and impact of long COVID among Minnesotans most impacted by the COVID-19 pandemic. Alongside partners in healthcare, the workgroup will aid in identifying opportunities and strategies toward screening, supporting, and coordinating care for patients with long COVID. MDH will also partner and contract with members for culturally appropriate messaging and resources for a variety of audiences and aid in identifying trusted messengers to effectively communicate information and findings about long COVID to all Minnesotans (MDH 2022, p. 1).*

Envisioning the role of community partners

As part of these early conversations, we determined that the workgroup's orientation would ideally sit somewhere between "community involved" and "community directed" according to Wilder Research's Community Engaged Research Framework (Figure 1). While the framework was useful in this regard, the workgroup and its role is not fully situated in it. As Jay noted, "We had this idea to do a Community Based Participatory Action Research approach, but we're not just doing research—it's practice. … [We asked] how can we modify this CBPAR approach to support our long COVID work?" (co-theming meeting notes, 1/17/202). Beyond Wilder Research's framework, we also discussed MDH's Principles of Authentic Community Engagement, Sherry Arnstein's Ladder of Citizen Participation, and Nexus Community Partners' *Community Engagement Assessment Tool*—each of which helped us to more clearly envision how the workgroup might function within MDH.

2. Community Engaged Research Framework

Project phase	Community informed *Community as advisors*	Community involved *Community as collaborators*	Community directed *Community as leaders*
Project planning/ decision-making	Community members advise on the project (one-time input, limited decision-making control)	Community members (e.g., community advisory committee) give input throughout the project and are involved in decision-making	Community members drive the project, set timelines, define research question
Data collection	Community members review and give input to data collection strategies, tools; facilitate connections	Community members conduct data collection (e.g., as subcontractors); determine most appropriate methods and co-create tools	Community members develop questions, determine approaches, and make staffing decisions; gather information
Data analysis	Community members identify questions that need to be answered using additional analyses	Community members participate in data analysis (e.g., coding, interpretation), ask for additional analyses/raise new questions, interpret meaning	Community members lead analysis, ask for additional analyses/raise new questions, interpret meaning
Reporting/sharing results	Community members review and provide feedback to drafts of reporting materials (of all types)	Community members help identify key findings and develop recommendations, determine best modes for reporting	Community members write reports or develop other materials or approaches for reporting
Dissemination	Community members advise on dissemination strategies and key audiences	Community members co-present findings, help determine key audiences, share information in their networks	Community members determine audience(s), present findings

Beyond these resources and their implications for the workgroup, we talked about ensuring that relationships in the group are intended to be long-term (e.g., not time limited or contract-based), being upfront with partners about the power the workgroup has and does not have within MDH (and the power that MDH staff have or do not have), and recognizing that everyone will come to the group with different interests, resources, and capacities. As Kate summarized: "My feeling is that some organizations, like MDH, are going to have a ton of capacity whereas other organizations may only have one or two staff. That doesn't mean that we should have more weight than the others when it comes to putting ideas forward and arriving at solutions. Everyone has an equal voice, regardless of capacity" (planning meeting notes, 1/14/2022).

These initial scoping and planning efforts aligned with recommendations from the field about effective community-institution partnerships, such as the following advice from the Quality Improvement and Innovation Partnership (2009): "It is important right at the start to come to a basic understanding about the purpose of coming together.

Whether there is a need to cooperate across services only to share information or there is an opportunity to develop more formal relationships across stakeholders, the time taken to forge a common purpose determines the process and structure" (p. 13). Further, the literature review guided these early workgroup efforts in multiple ways—by offering examples for thinking through different partnership types, presenting potential governance approaches for the workgroup, and describing various roles that partners might fulfill (Adebayo et al., 2018; Division of Tuberculosis Elimination, 2007; Giachello, 2007; Health Research & Educational Trust, 2017b; Health Research & Educational Trust, 2016; JSI, 2012; National Business Coalition on Health, 2013; Safon et al., 2022).

Starting relationships with workgroup members

With a solid enough understanding of the purpose of the workgroup and how it might be situated within MDH, we began figuring out what kind of community representation might be most useful in helping MDH accomplish its long COVID health equity goals. As Jay said, "We know that COVID disproportionately affects BIPOC communities and tribal communities," naming that communities disproportionately affected by COVID should be prioritized for representation in the workgroup (planning meeting notes, 11/9/2022). Disability was at the forefront of our conversations around community representation as well, with Jay likewise noting that "10-30% of people who are infected [with COVID] experience persistent symptoms … ranging from mild to debilitating" (planning meeting notes, 11/9/2022). These priority communities, rooted in data about who is most affected by COVID-19, directed MDH's recruitment approach for the workgroup.

Making first contact with potential partners

Kate led efforts to connect with and invite community organizations to join the workgroup. To jumpstart this process, we created a list of organizations we had relationships with or that we knew of and thought might be a good addition to the workgroup. Many of these organizations had worked with MDH before—for example, by serving as COVID Community Coordinators (CCCs), which are community-based organizations MDH contracts with to help connect Minnesota's communities to COVID-19 testing and vaccination resources, and to provide access and support for health recovery. This recruiting approach aligned with recommendations from the literature, with multiple articles noting the importance of first establishing a high-level understanding of which organizations and communities a partnership may want to engage with, such as through asset mapping or taking stock of relationships that are already in place (Giachello, 2007; Health Research & Educational Trust, 2017a; Health Research & Educational Trust, 2017b; Quality Improvement and Innovation Partnership, 2009).

Kate gave multiple presentations to the CCCs about long COVID and invited them to connect one-on-one to learn more about the Long COVID Community Voices Workgroup. She also invited one-on-one conversations with representatives from organizations on our recruiting list who were not CCCs. In these conversations, Kate provided information about MDH's plans regarding the Long COVID Program and used the workgroup's charter as a way to succinctly describe MDH's goals for the workgroup, which the Health and Educational Research Trust (2016) noted as a best practice for orienting potential partners. Then she focused the conversation on the potential partner's goals regarding what their community needed or wanted in a long COVID response—and how these goals aligned, if at all, with MDH's hopes for the workgroup and the Long COVID Program. The Division of Tuberculosis Elimination (2007) affirmed Kate's conversational and relationship-centered approach to connecting with potential partners, offering, "The success of the [recruiting] process is founded on establishing trust with potential partners through

an open and honest exchange of information. The partnership recruiter communicates an interest in, and respect for, the health priorities and concerns of the potential partner" (pg. 9). Shakesprere et al. (2021) offered similar advice for beginning relationships with potential partners, saying that it can be useful to first address how a partnership can be mutually beneficial by discussing the following questions with potential partners: "How can [the partnership] provide value to this community partner? How will [the partnership] benefit the community?" (pg. 12).

Navigating capacities and partner experiences with MDH

Prior to the first workgroup meeting, it took about six months to build relationships and understanding with potential partners about the Long COVID Community Voices Workgroup. As Kate mentioned, "We talked with HACER [Hispanic Advocacy and Community Empowerment through Research], CAPI [Centre for Asian and Pacific Islanders, formerly], the CILs [Metropolitan Center for Independent Living, Southeastern Minnesota Center for Independent Living] months before we actually met as a group" (co-theming meeting notes, 1/17/2024). Multiple potential partners shared that they did not have the capacity to join another group. Jay reflected on this part of the process: "It was a struggle. We were asking people to sign on to something new and more. … It was the throes of COVID. It was hard finding people [with] the bandwidth" (co-theming meeting notes, 1/17/2024).

Beyond these capacity concerns, Jay and Kate noted the complexities of building reciprocal partnerships as representatives of a state agency. Jay underlined the importance of not relying solely on previous or ongoing efforts at MDH, such as the CCCs, to forge the connections necessary to build up the workgroup: "A lot of this stuff is about relationships—and not necessarily about relationships that other people have. … You need a warm hand-off if you are leveraging someone else's relationship, or you need to take the time to develop the relationship before moving into something with a bigger scope" (co-theming meeting notes, 1/17/2024). Kate shared a similar sentiment, noting that potential partners' experiences with just one MDH staff person could determine their openness to partnering with MDH, especially if their experiences were negative. She said, "Some organizations straight up said to me, 'You're all MDH. What this person from MDH did matters with how I am going to interact with you.' That will vary even within individual organizations. There is a lot of history that can impact those relationships before you're in the room together. … We want to be respectful of how many asks we're making of communities, and you'll never know all the projects going on in the agency. It's important to do some internal investigation to understand what relationships are out there" (co-theming meeting notes, 1/17/2024).

Ultimately, the Long COVID Community Voices Workgroup's initial partners came from a variety of relationships. For example, Jay and the executive director of HACER, Rodolfo Gutierrez, have known each other for long time, which offered a good foundation for inviting HACER into the partnership. Partners such as Stairstep Foundation and African Immigrants Community Services (AICS) came to the workgroup through their role as CCCs and through other instances of partnering with MDH. One partner, SEMCIL, joined the workgroup as they were in the process of ending their involvement as a CCC, noting that the workgroup was better aligned with their goals for supporting their community around long COVID. Jay summed up how this diversity of relationships contributed to some early successes in the workgroup: "We've been fortunate with this group. We had some existing relationships. Kate worked hard to start new relationships. … When that mix came together, it built on each other. If there's trust from a couple of organizations, newer organizations will see that trust. Hopefully over time you start having trust with the newer organizations, too" (co-theming meeting notes, 1/17/2024).

Setting directions together as a workgroup

The Long COVID Community Voices Workgroup convened for the first time in June 2022, with representatives from Hispanic Advocacy and Community Empowerment through Research (HACER), the Metropolitan Center for Independent Living (MCIL), the Southeast Minnesota Center for Independent Living (SEMCIL), and the Stairstep Foundation. Members introduced ourselves, our roles at our organizations, and what we felt was pertinent to share with the workgroup about our experiences with long COVID. Jay framed the group's goals, such as the short-term need for trusted messaging about long COVID and the longer-term vision of helping to build community capacity around long COVID care and resources. Then he invited input from members about their motivations for joining the group.

Prioritizing community capacity and intersectional perspectives

From the outset, there was consensus among workgroup members around building community capacity, particularly among communities that were marginalized by MDH's COVID response. Alfred Babington, Executive Director at Stairstep Foundation, offered, "Whatever we do, at the end of the day, will it end up with greater capacity in our communities?" (workgroup meeting notes, 6/28/2022). Rosalie Eisenreich, Strategic Initiatives Director at SEMCIL, underlined this sentiment as she referenced MDH's early efforts to address COVID-related needs in Minnesota's disability communities: "I think that community capacity is huge. One of the things we struggled with as a CCC is that disability CCCs were brought in six months after the others. It wasn't built with us in mind" (workgroup meeting notes, 6/28/2022). Rodolfo Gutiérrez, Executive Director at HACER, likewise observed how HACER's community was marginalized by MDH's initial COVID response: "I've been thinking about community capacity building as well. It is very important. … When COVID was the issue and the solution was the vaccines, the distribution plan was assigned with the Minnesota majority in mind: White people. The focus was also on elderly people—for scientific reasons, but not cultural reasons. … In southern Minnesota, we had a lot of cases in the meat packing industry—they were young, many of them died, and there wasn't anything to help them at the beginning of the pandemic" (workgroup meeting notes, 6/28/2022).

These motivations from workgroup members demonstrate the importance of intersectionality in public health work. In addition to shared experiences of marginalization during MDH's COVID response, members voiced a desire to improve their own work via an intersectional view of their constituents. As Babington said, "When have I, in the African American community, thought specifically about serving people with disabilities even in my community? … I'm guilty! This is a great opportunity to have this cross-fertilization" (workgroup meeting notes, 6/28/2022). Jenni Schwartz, former Assistant Director of Independent Living at MCIL, noted similar concerns about who MCIL is and is not connected to: "When we started our CCC work, our default was people who were already receiving services from us. There is this population of people who may have a disability who are not connected to services. How do we find them? How do we get them the information they need?" (workgroup meeting notes, 6/28/2022).

In the first workgroup meeting, Jay and Kate asked those present about people, communities, or perspectives that should be included in the workgroup moving forward. Members noted the absence of representation of Indigenous, Asian, and African immigrant community perspectives—as well as the risk of tokenizing workgroup members as the sole representative of a particular community's perspectives. The first five meeting agendas included recruitment and representation as standing discussion items. In this way, the group established a practice of revisiting

the question of community representation by explicitly acknowledging perspectives that were not present and encouraging members to look to their networks to help fill these gaps, which is noted as a best practice by the Health Research & Educational Trust (2016).

Over time, Mayly Xiong, Sarah Xiong, Keo Phomsoukha, and Gisselle Ramirez from CAPI (February 2023) and Abdirizak Diis and Mohamed Ahmed from AICS (August 2023) joined the workgroup. Notably, Indigenous perspectives and lived experiences have not been represented in the workgroup to date, despite efforts to invite Indigenous-led organizations into the workgroup. Reflecting on these initial and continuing gaps in community representation, Jay commented, "We had visions of more and different kinds of representation. We couldn't do it. At some point we had to say, 'This is what we have, let's work with this'" (co-theming meeting notes, 1/17/2024). Kate furthered this idea: "[We learned] we can't have a checklist of 'Here's the communities we need represented'— asking one person to represent a whole community. We don't want to be that checklist. We want a variety of organizations—different objectives, different sizes—approaching the work in a lot of different ways. … Having that be the goal instead of a rigid checklist is important, too" (co-theming meeting notes, 1/17/2024).

Building out the workgroup's focus areas

In subsequent meetings, members discussed how the workgroup could improve MDH's long COVID response from a health equity standpoint. Kate presented three areas of focus for the workgroup: 1) messaging and communicating about long COVID, 2) gathering data about the prevalence and experiences of long COVID, and 3) contributing community-based perspectives to clinical guidance around long COVID. With a spirit of co-creation, she then opened up discussion: In what ways did workgroup members think MDH should address these areas?

While this approach is aligned with recommendations from the field about collaboratively setting a vision and the ways that a partnership may work towards that vision (Health Research and Educational Trust, 2017b; and Division of Tuberculosis Elimination, 2007), workgroup members wanted more direction from Jay and Kate around the group's goals and activities, especially as they reach out to others to potentially join the workgroup. They wanted more clarity around the group's direction because of the emergent nature of long COVID and because, similar to their own organizations, other potential partners were likely short on time, resources, and capacity. As Babington explained, "As much clarity as you can put on the table immediately about this committee, it would be better. … How firmly does MDH have a grip on what long COVID is? Maybe there isn't clarity on that—but it would be good to have clarity" (workgroup meeting notes, 7/22/2022 and 8/23/2022). This desire was echoed by Rodolfo, "What are we going to say to potential partners in regard to what we will be doing in the group? … We need more certainty about their role when asking them to join this group. Is it that MDH wants information about how long COVID is affecting people? … Is it how is MDH going to help us provide resources to long COVID patients?" (workgroup meeting notes, 8/23/2022).

In response to members' desire for more direction from MDH, Jay and Kate offered some potential activities in each focus area. Regarding messaging and communications, workgroup members could help to ensure that communications materials are meaningful for their communities as well as disseminating the materials in ways that would reach their community members. Regarding gathering data, workgroup members could help with survey design to provide meaningful information about their community's experiences with long COVID as well as co-analyze the data to help determine MDH's next steps for addressing long COVID. Regarding clinical guidance, workgroup

members could provide community-based feedback on draft guidance or protocols created by MDH and its clinical partners around diagnosing and treating long COVID.

Lastly, goals of system transformation from an intersectional perspective underpinned early ideating around the workgroup's activities—particularly the intersection of health, culture, and disability. Because long COVID is a potentially disabling condition, a holistic response would likely demand collaboration between MDH and other state agencies like the Department of Human Services and the Department of Employment and Economic Development. As Rosalie summarized, "This is about disability rights. Long COVID is not always recognized as a disability. … This is an opportunity where we can set the record straight ahead of time" (workgroup meeting notes, 7/22/2022).

Guiding MDH's long COVID strategy

Communicating with Minnesotans about long COVID

As early as November 2022, the workgroup made plans to pursue community-based communications regarding long COVID, such as MDH providing standardized language and messaging that workgroup members could adapt for their community context and disseminate throughout their networks. However, in the background of the workgroup are the structures of the State, such as workflow coordination, funding mechanisms, and contract processes. Paired with the unknowns of long COVID, these structures stalled most of the workgroup's communications efforts. The emergent nature of long COVID meant that communications materials didn't get approved before new information made it necessary to update them—which started the approvals process over again. As Kate explained, "We had stops and starts with a few pieces. … MDH is really sensitive about anything related to COVID— understandably. We want to make sure we don't overstate what we know and be consistent in our messaging. … The facts were changing; the messaging was always evolving" (co-theming meeting notes, 3/11/2024).

Beyond ensuring the accuracy of information, Kate raised important concerns about what people would actually do with information about long COVID: "We don't have a good call to action for long COVID, so we default to telling them to talk to a healthcare provider—which is problematic for a lot of reasons. Some people, especially among those most likely to have long COVID, don't have a primary care provider or don't trust healthcare systems. Some providers don't believe in long COVID or say that it's all psychosomatic. We don't have good guidance on how to identify long COVID, so we didn't want to throw people into the lion's den for all this testing that comes back 'normal' because we're not running the right tests—and then they get a big bill" (co-theming meeting notes, 3/11/2024).

Further, workgroup members underlined the complexities of translating medical language about an evolving condition like long COVID. As Rodolfo offered, "Today we had a talk with two medical doctors about long COVID. They did it in Spanish. They are not using the term 'long COVID' in Spanish. They are talking about the prevalence of COVID—a totally different idea. … We are going to get lost in translation as we talk about long COVID and its complications in languages outside of English" (workgroup meeting notes, 4/13/2023). Mayly raised similar concerns, particularly around language like "long-term care" and the need for guidance and clear definitions when creating materials for communities that CAPI partners with (workgroup meeting notes, 2/9/2023).

Ultimately, MDH communications staff produced a number of communications materials without input from workgroup members, such as a visual one-pager that presented long COVID symptoms and short summary videos

for social media in multiple languages. Kate shared these materials with workgroup members to share with their networks, noting the number of social media shares as an indicator that Minnesotans are interested in long COVID: "It got 228 shares—for MDH this is big. … It shows that people are wanting information about this" (workgroup meeting notes, 3/9/2023).

Surveying Minnesotans about long COVID

Similar to the communications efforts, nuances around language and the emergent nature of long COVID impacted MDH's Post-COVID Survey. As Rodolfo suggested when Jay and Kate asked for feedback on survey questions, "Around things like tiredness and other symptoms [in the survey], we need to find the right word for the translations. Otherwise it can be really confusing. Some people may feel depressed but not express this in the way that the survey wants" (workgroup meeting notes, 2/9/2023). Similarly, Mayly noted the importance of translators and incentives for surveys with CAPI's constituents: "From our experience with long surveys, participants are more likely to finish the survey if there is an incentive and if there is a translator available to help" (workgroup meeting notes, 2/9/2023). Jay iterated that MDH's surveying team is "set for doing the survey in languages other than English" and also invited workgroup members to help pilot the survey via their staff and constituents. Rodolfo and Mayly both agreed to help pilot the survey via their networks (workgroup meeting notes, 2/9/2023).

It felt natural to shift the workgroup's attention from communications to surveying, in part because MDH had time-sensitive resources to conduct the survey. As Jay explained, "We were leveraging other COVID funds in the department. The COVID-19 epidemiology team had staff who would be available through the end of June 2023. Then their staff would decrease; their contracts were going to come to an end" (co-theming meeting notes, 3/11/2024). Even though Jay, Kate, and the COVID-19 epidemiology team successfully fielded the post-COVID survey within this deadline, the quality of survey data arguably suffered for the tight timeline. As Jay told workgroup members, "Our response rates are not good. It's really hard to get people who want to participate in the survey. … I was hoping we would get 700 surveys from each of the key groups that we wanted. Our estimate is that maybe 20% [of those surveyed] are reporting long COVID symptoms, so then we'd have 100-150 people of each group … and can dig into long COVID. We planned on 3,000-4,000 responses, but we just need to make do with the numbers that we have" (workgroup meeting notes, 4/13/2023).

All told, nearly 1,600 Minnesotans completed the survey for a response rate of about 6%, meaning that it would be difficult to use the data to generalize about racial subgroups—let alone disaggregate beyond race, such as focusing on the experiences of African American, Ethiopian, or Somali respondents within the Black racial category. While MDH was unable to achieve the number of completed surveys needed for in-depth subgroup analysis, the process of engaging workgroup members around the survey was beneficial for MDH's long COVID efforts. As Jay explained, "We had two main things we wanted to accomplish bringing the survey to the workgroup: 1) Better understand what information our community members might want to know about COVID and long COVID so we could make sure to include them as potential measures in the survey itself. … 2) The COVID response itself didn't take into account these underserved communities upfront—we didn't want to repeat that mistake. We wanted to make sure we had that input upfront via our Community Voices group" (co-theming meeting notes, 3/11/2024).

Providing guidance about long COVID to Minnesota healthcare professionals

In addition to survey and communications work, Jay and Kate initiated a long COVID clinical guidance group with assistance from Stratis Health. Jay described it as "a group of providers with expertise in seeing patients with long COVID as well as people who represent different healthcare systems throughout the state, such as people from federally qualified clinics and those who live rural areas" (workgroup meeting notes, 3/9/2023). Kate offered that the clinical guidance group was focused on similar questions about identifying and treating long COVID as well as doing so in an equitable way: "This group has a little bit more of a concrete idea about what long COVID is, but right now there are different clinical definitions. Even with this group, there is not consensus. … There is a big equity lens applied to this in that group. Some representatives are at Mayo or the University of Minnesota and have access to different specialists and resources. Then these small clinics and primary care folks are saying even if they did want to refer someone to a six-week occupational therapy program, that's not realistic for their patients. They want to make sure we're not just perpetuating some of these inequities and only designing care for folks who have access or resources already" (workgroup meeting notes, 3/9/2023). While there has been extended discussion at Community Voices meetings about how these two groups might mutually support one another, there has been no collaborative effort between them to date.

Accessing legislative funding for long COVID efforts

In the midst of trying to finalize long COVID communications, helping to field a statewide post-COVID survey, and starting the clinical guidance group, Jay and Kate also prepared a proposed budget to the legislature for ongoing funding to support MDH's long COVID work. As Kate summarized to the workgroup, "The governor has recommended funding for long COVID work through MDH, but we're still waiting for the budget bill to be introduced. … We think the state funding is going to be really important" (workgroup meeting notes, 3/9/2023). Here is the recommendation from Governor Walz:

> *The Governor recommends an investment from the general fund to understand the impacts of long COVID in Minnesota and to support those most affected by partnering with long COVID survivors and communities disproportionately harmed by the COVID-19 pandemic. Of the total investment, $900,000 annually is for grants. Of the proposal total, over 64% of funds will return to communities, local and tribal public health, and partners in health care (State of Minnesota, 2023, p. 182).*

At the June 2023 Community Voices meeting, Kate and Jay announced that the legislature approved ongoing funding to support MDH's long COVID efforts for the next two biennia—through June 2027. Jay summarized what the funding means for MDH's approach to long COVID: "There's a lot of autonomy here. We don't have our pre-planned deliverables, like with the CDC funding. Because long COVID is intersectional and complex, we can justifiably address other areas and conditions" (workgroup meeting notes, 6/8/2023). Further, Kate reiterated the community-oriented nature of the funding, saying, "Two-thirds of the ongoing funding is intended to go out to communities in contracts and grants. It could mean more specific community assessments, and better and more culturally appropriate messaging—which would increase our understanding of long COVID and how it's impacting communities as well as get the message out" (workgroup meeting notes, 6/8/2023).

This was welcome news to workgroup members, who had been discussing for months the connections between long COVID and other life circumstances, like getting older or living with a disability. As Babington commented, "Take '[brain] fog,' for example. I happen to be older than the rest of the people on this call. … I nap more now! Is it that your life changed because of COVID, or is it normal?" (workgroup meeting notes, 11/14/2022). Babington also summarized the workgroup's goal of helping MDH best serve the communities most affected by COVID. He said, "I don't think there's anything about the melanin of our skin that affects if we get COVID. … There are also some communities—our communities—who have been disproportionately affected, disparately impacted. How we can mitigate that impact?" (workgroup meeting notes, 4/13/2023).

Clarifying the goals of long COVID grants and contracts

Energized by the promise of ongoing funding, the workgroup met in-person for the first time in September 2023 at the Wilder Center. The purpose of this meeting was to deepen connections among workgroup members and to use the survey data to generate overall goals for how MDH could use grants and contracts to support community-driven long COVID responses. Jay, Kate, and Julie Hoffer from the COVID-19 epidemiology team prepared data tables that highlighted key findings from the survey along with discussion questions regarding how grant and contract opportunities could best serve communities most impacted by long COVID.

Internally, the team talked at length about how to meaningfully include workgroup members in this conversation while also making sure to avoid conflicts of interest—since member organizations may want to apply for grants through MDH's Long COVID Program. Jay framed the tension: "If you want an advisory group that has credibility, they may be in a position where they could apply—and if they're involved directly in designing the request for proposals (RFP), then they can't play. This is a best practice [referring to co-creating state initiatives with community members], but if you do it, it can exclude some key partners" (planning meeting notes, 8/23/2023). After further discussion with grant and contract specialists within MDH and other state agencies, the team decided to keep any discussion about long COVID community-based funding opportunities at a high level. For example, at the in-person meeting, workgroup members did not discuss specific strategies or approaches to addressing long COVID that could be supported by MDH grants. Rather they talked about overall goals for how grantee efforts could be guided by the survey results as well as how grantee learnings and successes might be broadened beyond the particular communities with whom grantees work.

Overall, workgroup members prioritized supporting the growth of community capacity for whole-person wellness via long COVID grant and contract opportunities. According to workgroup members, a focus on growing community capacity around long COVID could include many facets, such as expanding focus beyond long COVID to include its numerous associated conditions, an intersectional lens regarding the experiences and identities that people bring to their lives and communities, and efforts toward systems transformation that help to proactively address social determinants of health and a person's likelihood to get COVID to begin with. As Babington summarized partners' input, "How do we use long COVID—this opportunity, this mechanism—to push for holistic and intersectional community health? Addressing long COVID is an opportunity for systems change" (workgroup meeting notes, 9/14/2023).

Workgroup members also prioritized networking and sharing resources among grantees and others interested in addressing long COVID, with Rodolfo saying, "We need opportunities that are not competitive with other communities or small organizations. No more 'you took the money from us.' Put us to work together" (workgroup

meeting notes, 9/14/2023). Further, partners mentioned the importance of bringing together lived experiences and medical expertise to inform clinical guidance around long COVID and crafting a shared vision of wellbeing that honors community perspectives. As Rosalie asked, "Is there a way to create something with MDH that combines medical and community perspectives, since there is a clinical group? Let's figure out our common goals and how we network with ourselves across the state" (workgroup meeting notes, 9/14/2023).

Procedural barriers to state-community partnerships

The September 2023 in-person meeting with workgroup members was vital for helping to clarify how community grants and contracts might contribute to MDH's long COVID efforts—but in the months and weeks leading up to the meeting, Wilder and our MDH partners experienced procedural barriers that could have resulted in the meeting being canceled.

The barriers we experienced came from contract issues. Some background: in addition to serving as the workgroup's coordinator and note-taker, Wilder also provided partners with a modest stipend for their participation. Wilder fulfilled this role since MDH could not use CDC funds to issue partner stipends directly. The CDC clarified that Wilder could administer them and we amended our contract with the Minnesota Department of Management and Budget (MMB) to do so. As part of this contract, Wilder assisted with other components of MDH's CDC grant beyond the workgroup, such as the Regional Health Equity Networks and MDH's tribal health response. Wilder amended the contract a few times to reflect work changes in these areas as well.

In May 2023 Health Equity Evaluator Lovel Trahan sought a contract extension so that Wilder could continue supporting MDH's CDC-funded activities, including the workgroup. He learned that the contract had surpassed an amendment threshold which limited the number of times a contract can be changed, and MMB's contracting procedures required earlier notice to amend it again. This requirement was a surprise to Lovel, others at MDH, and to Wilder. Lovel sought more information about how to amend the contract, until Wilder received an email from MMB staff saying they were terminating the contract.

In total, Wilder was off-contract for four months, including in September 2023 when we hosted the in-person workgroup meeting. Without a contract, we couldn't bill MDH for the space reservation fee. Jay and Kate attempted to set up a separate purchase order to pay the reservation fee, but were told by different state staff people that the purchase order came too late and couldn't be processed in time for the meeting. Wilder decided to host the meeting anyway and absorb the space costs so the workgroup wouldn't be disrupted at a pivotal time in our efforts.

All this being said, Wilder should have ensured that we fully understood the details of our contract. At the same time, we urge appropriate staff across state agencies to review relevant policies with the goal of encouraging community partnerships—which can be emergent and fast-moving—as a strategy for improving health equity in Minnesota. We expect that a policy review like this would be particularly important for future state-community partnerships, especially with organizations that are not as well-resourced as Wilder and for whom it may be more difficult to absorb unexpected costs.

Envisioning what's next and how the workgroup can continue to contribute to MDH's long COVID efforts

In early 2024, MDH issued a request for proposals (RFP) titled *2024 Long COVID Network & Capacity Building*. The priorities in the RFP echoed workgroup conversations around intersectionality, community self-determination, and serving communities disproportionately affected by COVID:

> *This RFP will give priority to applications that demonstrate an ability to work effectively in partnership with, and/or to organizations that serve, communities disproportionately impacted by the COVID-19 pandemic, long COVID, or related conditions. These include but are not limited to rural and low-income areas, Black and African Americans, immigrants, American Indians, Asian-Pacific Islanders, Hispanic and Latino(a) communities, LGBTQ+ people, and people living with disabilities. Addressing intersectionality within these groups is encouraged. … The Long COVID Program values community-led solutions, person-centered approaches to care and support, cultural and lived knowledge and wisdom, and organizations that reflect the populations they serve. (Minnesota Department of Health, 2024, p. 8).*

Further, the RFP listed the following expected outcomes for the grant program, suggesting a diversity of ways in which grantees might contribute to MDH's long COVID efforts, including and beyond the workgroup's stated goals around data, communications, and clinical guidance:

- **Improved understanding** of the impact of long COVID and related conditions in communities across Minnesota, particularly those that have faced historical health inequities and/or disproportionate impacts from the COVID-19 pandemic.
- **Increased public awareness** of long COVID and related conditions and their potential effects on health and wellbeing, employment, education, and quality of life.
- **Reduced stigma** around long COVID and related conditions and associated disability.
- **Increased access** to sector-specific and culturally appropriate materials about long COVID in response to the needs of the priority populations served.
- **Enhanced capacity, training, and education** for local organizations to serve and support people with long COVID and related conditions.
- **Promotion of coordinated, person-centered, evidence-informed practices** around the prevention, diagnosis, and management of long COVID, including during the clinical encounter and beyond to wrap-around services and local support networks.
- **A grantee network of entities that provide information, care, and support** for people with long COVID and related conditions across communities and systems. This network will share best practices and community-led solutions and enhance coordination of efforts and strategies where applicable.

At the time of writing this case study, MDH has not announced the 2024 Long COVID Network & Capacity Building grantees, though some workgroup members shared that their organizations had applied. Over a few meetings, partners discussed the purpose of the workgroup moving forward, with Kate asking, "How might this group look when we have a grantee cohort? What is the longer term vision for this group and how it might interact with the

grantees?" (workgroup meeting notes, 3/14/2024). Workgroup members initially expressed concern about real or perceived conflicts of interest if their organization is a grantee and part of the workgroup. Kate responded by noting the carefulness with which they approached this question for the in-person meeting: "We didn't review the grant itself with this group—not the grant criteria, not the scoring. Nothing. We went to our Office of Grant Administration to talk about that. They are very concerned with crossing those lines and we have not crossed any of those lines in this group. We are confident in that" (workgroup meeting notes, 3/14/2024).

Encouraged by this reminder, Babington offered a potential role for the workgroup in guiding MDH's Long COVID Program overall: "The ability to walk together, talk together—that seems invaluable. You're going to have grantees in these areas, but the ability to continue the broader dialogue is what this group offers" (workgroup meeting notes, 3/14/2024). Further, Rodolfo noted persistent issues with MDH's COVID response, suggesting a need for community perspectives that the workgroup can provide, "We've been working as a CCC for a long time. We've been doing as much as we can to shift the script coming from providers and MDH—but things don't really change. We are using the same communications, the same formats. There is no consideration of a culturally appropriate approach from the beginning. … We are always having that gap in this process" (workgroup meeting notes, 3/14/2024). Lastly, Jay reiterated the importance of the workgroup for the Long COVID Program's goals around networking and capacity building: "The value of this group too is how we can grow and maintain all of these relationships as a network" (workgroup meeting notes, 5/14/2024).

Around the time MDH issued the RFP, Mayly let us know that CAPI was leaving the workgroup, saying that their vaccine clinics had been slow and their constituents were interested in resources about overall wellness rather than just COVID. Upon hearing this news, we scheduled a meeting with CAPI to learn more about their organizational priorities and how they might stay connected with the workgroup moving forward. Mayly communicated that CAPI would like to receive information about long COVID via newsletters or emails and that they would reach out if they had questions or renewed interest from their community members. About CAPI's wellness efforts, she shared, "With post-COVID work, our efforts are focusing more on alleviating stress—holistic activities like yoga or healing circles, diet and nutrition, and resources for staying active" (CAPI exit meeting notes, 4/15/2024). Mayly ended the conversation by underscoring the benefits that CAPI experienced by participating in the workgroup, such as hearing perspectives from other community-based organizations and learning about long COVID.

CAPI's exit and the issuing of the RFP signaled a transition for the workgroup. Not only did these events foretell changes in the workgroup's role, but also in the makeup of the group and who will carry its goals forward. With this case study, we hope to preserve some of the insights the workgroup has catalyzed so far and set a precedent of documenting and sharing progress at key inflection points for the workgroup. To date, the Long COVID Community Voices Workgroup has offered numerous lessons for how MDH should approach community partnerships as a strategy for health equity. These include how to begin and build relationships, the nuances of prompting and facilitating co-creation, the importance of intersectionality and recognizing multiple perspectives, the complexities of navigating conflicts of interest, and how contracting and business procedures can impede emergent or time-sensitive partnership opportunities. Looking forward, Wilder is excited by the promise of supporting the workgroup's next phase and continuing to share important lessons for how state agencies can effectively partner with the communities they serve.

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Appendix

The following table provides information from Figure 1 about the phases that MDH went through to start and maintain the Long COVID Community Voices Workgroup. It includes the phase order (that is, Phase 1, Phase 2, etc.), the name Wilder gave to each phase for the case study (e.g., Phase 1 is named "Framing the workgroup"), and the goals or activities accomplished in each phase (e.g., a goal for Phase 1 was that the workgroup would be informed by MDH's COVID Community Coordinators approach).

A1. Phases of the Long COVID Community Voices Workgroup

Phase order	Phase name	Goals or activities for each phase
1	Framing the workgroup	• Informed by MDH's COVID Community Coordinators approach • Situated between "community involved" and "community directed
2	Starting relationships	• Representation from communities most impacted • Intentionally built mutually beneficial relationships for MDH and partners • Comprised of existing MDH relationships and new connections
3	Setting directions together	• Provide guidance around long COVID • data, awareness, and care • Use an intersectional and whole-person understanding of wellness • Build capacity for community self-direction
4	Guiding long COVID strategy	• Long COVID survey design and data interpretation • Clarifying the purpose of grants: Effect systems change by centering community, fostering partnerships, and sharing information and resources
5	Envisioning what's next	• Share knowledge and expand impact of community-directed approaches • Technical support and networking opportunities for grantees

The following table provides information from Figure 1 about key moments in MDH's efforts to start and maintain the Long COVID Community Voices Workgroup. Moments include: the workgroup's first meeting (June 2022), when the long COVID survey entered the field (March 2023), when legislative funding was allocated for long COVID efforts (May 2023), when the workgroup began helping interpret long COVID survey data (June 2023), when Wilder had a contract gap with the state (June-September 2023), and when the workgroup had its in-person planning meeting (September 2023).

A2. Timeline of key moments for the Long COVID Community Voices Workgroup

Year	Month	Timeline point description
2022	June	First workgroup meeting
2023	March	Long COVID survey in the field
2023	May	Legislative funding allocated for long COVID
2023	June	Workgroup began helping interpret survey data
2023	June through September	Contract gap
2023	September	In-person planning meeting