



Implications for COVID-Related Long-Term Care Research:

A Summary from an International Stakeholder Summit

The International Stakeholder Summit on COVID-Related Long-Term Care Research was convened on March 15, 2023, by the Institute for Patient- and Family-Centered Care through a project entitled, *Building Capacity for Long-Term Care Stakeholders in COVID-Related Patient-Centered Outcomes Research*. This project was funded by a Patient-Centered Outcomes Research Institute® (PCORI®) Eugene Washington PCORI Engagement Award.¹

The virtual Summit brought together 67 participants including long-term care community residents, families, leaders and staff, and researchers, advocacy organizations, and funders from the United States and Canada. The Summit included interactive sessions that built on project findings and recommendations related to the root causes of social isolation and loneliness experienced by long-term care residents and families during the COVID-19 pandemic and how these could be addressed through future research. Research topics and themes identified were divided into six categories including government/policy, partnership, communication, physical space, risk, and staffing. Resident and family participation and their perspectives and insights were foundational to every aspect of the project.

Overall project findings, new resources, and powerful video clips of resident and family perspectives were shared during the Summit. Eight breakout groups, with 9-11 participants in each group, discussed specific research topics and themes within one of the six categories and

¹ This Summit and report were funded by a Patient-Centered Outcomes Research Institute® Eugene Washington PCORI Engagement Award, EASC-COVID-00310. The views presented in this resource are solely the responsibility of the authors and do not necessarily represent the views of PCORI®.

made recommendations. Each breakout group was led by a facilitator and pre-assigned notetaker. This document summarizes recommendations developed during the Summit related to research that might prevent or reduce future harm to health and well-being similar to that experienced by residents, families, and staff during the COVID-19 pandemic. It also includes highlights of a conversation about funding opportunities with two funders who support relevant research and the collaboration with stakeholders in all phases of research.

Research Topics and Themes Discussed by Breakout Groups

Government/Policy

Examples were provided by participants that could be models for future work.

During the pandemic, the U.S. Agency for Healthcare Research and Quality (AHRQ) developed learning communities with nursing homes for infection control and vaccination (<https://www.ahrq.gov/nursing-home/about/index.html>). This presents an opportunity to figure out the most effective way to improve practices in different communities, as well as understand the best and most effective strategies for dissemination and adaptation in a changing environment.

Another example was the provincial-wide endeavor in Canada, the Saskatchewan Long-Term Care Research Network, that was created during the pandemic. It included family care partners, students, researchers, and people working in long-term care. The Network used research to inform or try to inform policy. They examined the importance of family presence, its impact on residents, and then disseminated the research papers that were developed, including sending them to policymakers to try to inform their actions.

A key topic of discussion was that further research is needed about essential care partners, including what should be the required training and how willing families would be to take the training, as well as further research on the actual impact that families are having in the provision of care.

A researcher noted that most nursing homes use their own survey tools to obtain consumer or family, input but there is a nationally validated tool (<https://www.ahrq.gov/cahps/surveys-guidance/nh/index.html/>). If there was some way to insist that the family and consumer experience tools be combined with other quality measures, this would provide useful information to policymakers who take these ratings seriously. Use of these quality metrics could support the stories and voices of residents and families.

In the U.S., the early intervention in child health legislation could be a model. In the 1990's, this legislation mandated that the interdisciplinary team include partnerships with families in all settings. It created opportunities for collaboration at local, state, and national levels, and supported learning for families and other members of the interdisciplinary team on how to collaborate effectively. Consideration might be given to opportunities for this type of

legislatively mandated and supported partnership among residents, families, staff, and leaders in long-term care, public health authorities and government officials. Research and evaluation would be an essential part of this legislation.

Partnership

Strategies were shared for disseminating the research topics and themes related to partnerships with residents and families to different audiences—researchers, funders, government agencies, and long-term care leadership.

A qualitative researcher commented that the videos shared during the Summit were very compelling. An excellent way to reach the research community is through presentations and the academic literature. One approach would be to connect with editors of selected research journals.

Strategies for reaching long-term care advocacy organizations and long-term care communities should be tailored to the targeted group. For long-term care advocacy organizations, such as Consumer Voice, Leading Age, and the American Health Care Association, we could share information about this project and its resources for their conferences, ongoing training initiatives, webinars, and podcasts.

In disseminating information within long-term care communities about the project's research topics and themes developed in partnership with residents and families as well as the information about promising practices for engagement, the following recommendations were made:

- Share information with boards of directors and CEOs to obtain senior leadership buy-in to developing and sustaining meaningful partnerships with residents and families for safety, quality improvement, quality of life, and research projects to improve responses to future pandemics and other public health crises.
- Reach out to Town Hall and Resident Council Meetings.

Another recommendation was to increase resident and family participation on long-term care communities' safety and quality improvement committees and enhance involvement in Resident Council meetings. Then, for the next pandemic, there will be experience in partnering with residents and families. Reaching out to state chapters of resident groups of the National Continuing Care Residents Association (NaCCRA), for example, PARCR in Pennsylvania, would be another strategy.

Communication

Two breakout groups discussed the topic of "Communication" and identified some successful strategies and important considerations for future research.

The Saskatchewan Long-Term Care Research Network, a community of practice, was described as a model for advancing research on this topic. The Network was formed at the onset of the pandemic to support an evidenced informed way to ensure the continuation of family caregivers' presence in long-term care. This included a mix of rapid evidence reviews with the local health authority, as well as participation in an expert panel that listened to the voices of residents and families about how to actually proceed with caregivers being present in long-term care for the well-being of residents and caregivers. The Network continues to meet to support research, advocacy, and community work.

A researcher in the U.S. commented that there was little opportunity for a "bidirectional flow of communication." Interviews revealed that it was very much "one way communication" by regulators or the long-term care leaders to residents and families. For example, the message that was shared by a resident in the video about the significant impact of isolation, was a message that was often heard, but it did not flow back up to regulators.

In the future, research needs to look at innovative models that worked, developing a better understanding of what was underlying nursing homes' willingness to communicate more openly and completely with families and, ultimately, the public. The culture of long-term care communities shapes the interpretation of regulations. As one participant stated: *"If decisions are made and actions taken that don't have the residents at the heart of them, it's not going to go well and won't be implemented in a way that has residents' well-being and interests in mind."* These observations present opportunities for research and education of long-term care leaders.

Physical Spaces

Collectively, this small breakout group thought it would be helpful to gather more COVID-19 and infection control related information about long-term care facilities, specifically about ventilation, access to outdoor spaces, and safe indoor spaces. Identifying promising practices that could guide future facility planning would be useful. Further information is needed about aspects of the environment and specific spaces that were associated with higher versus lower risks. This could build on a 2022 article about French nursing homes. This article highlighted organizational risk factors and showed that dining alone, early ban on visits, and daily access to outdoor spaces were protective in reducing the risk of COVID with no association with mortality; but there were no benefits from room lockdowns and stopping group activities.

Interviewing residents and families about their experiences during the pandemic, both locally and nationally, using qualitative research methods would be a contribution that could inform the work to improve the physical environment.

Risk

Two breakout groups discussed the topic of “Risk.” Families are an invaluable resource in long-term care. There was interest in quantifying a risk profile, that is creating a useful scale as a metric to assess that risk. This would allow family and friends to be assessed and people who are low risk be allowed to continue to “visit” and help with care. One suggestion was that the insurance industry working with medical actuaries might be able to create a risk assessment protocol.

The groups considered whether an integrative option could be used to explore if research could examine the possibility of cohorting by risk tolerance, risk profile, or both. There are two potentially different tools—a risk assessment tool, which determines the risk of a person entering a community and the other is a risk tolerance tool, measuring the preferences of residents, families, and staff. After obtaining this information, the challenge would be to arrange living spaces and social interactions that are the right level for each person.

In quantifying risk and tolerance, a participant asked, *“Will residents and families have a say or will the government just take over?”* Research about various options might help regulators be prepared and have procedures established that then can be adjusted for the situation.

Two participants shared the impact of the ongoing staffing crisis in their long-term care communities. *“It’s absolutely massive in our community, with huge numbers of nursing homes and long-term care communities closing. Fifty percent are closing whole floors of their buildings, because they just can’t find staff to work.”* This is an important consideration for research; leaders and staff in nursing homes are overwhelmed now due to this lack of staff. Thus, they might not have the capacity to participate in research if the requirements are too burdensome and/or if the research does not offer some short-term benefit.

Staffing

Research should focus on new solutions to implement and sustain support for staff, focusing on the essential changes that need to be made. Outreach to government research agencies, university, and community groups should be considered. Relevant journals might issue calls for papers on topics related to these priorities.

There was significant interest in legalizing the essential caregiver role. *“If we could legalize a caregiver who could be in there helping with residents, that would be the support that staff lost when everything got shut down.”* Following the same safety protocols as staff would need to be non-negotiable. Getting the essential caregiver regulation passed, as it has been done by several states, could cover families as well as students. Students from nursing, medical, and social work schools could then come into long-term care for internships or clinical experience, following the same safety protocols as staff. Research can provide information about what worked well in different states which then could be implemented more broadly in the future.

Dissemination

Participants shared recommendations during the Summit for disseminating two new resources, ***Research Topics & Themes for Long-Term Care Developed in Partnership with Residents and Families*** and ***Guide for Promising Practices in Engaging Long-term Care Communities in Planning for Future Research***. The breakout groups offered many recommendations to advance the research agenda. The following are recommendations specifically relevant to reaching the research community.

- In targeting dissemination, it would be advisable to develop a clear understanding of the priorities of long-term care advocacy organizations and researchers. While they may all be interested in finding better answers and offer novel perspectives, their priorities may not be the same.
- In Canada, it may be important to focus dissemination on foundations because they may be funding more person- and family-centered care oriented long-term care research than health care agencies. The Ontario Association of Resident Councils (OARC) in Canada serves as a conduit for resident voices across the province and with the government. OARC has built relationships with local colleges and universities where they are part of the curriculum, having residents teaching about resident rights and how residents are impacted by those themes identified through research. OARC may be in an important position to build on these relationships to connect with researchers about COVID-19 research.
- A suggestion was made to reach out to healthcare and university-based Research Ethics Boards (REBs) and Institutional Review Board (IRBs) and ask them to post these new publications on their websites as a resource for people conducting research in long-term care.
- Social media, including LinkedIn, Twitter, TikTok, Facebook, and YouTube videos, could be another way to reach the research community.

An Exploration of Future Opportunities for Funding Long-Term Care Research (PCOR/CER): Building on Resident and Family Priorities Evolving from Their COVID-19 Pandemic Experience—Panel Discussion

Panelist: Fatou Ceesay, MPH, is a Program Officer for the PCORI Engagement Awards Program. She is the program officer for IPFCC's Long-term Care Engagement Award. We are very grateful for her support. Fatou brings skills in research coordination in a large African program and experience with long-term care, health disparities, and human rights in U. S. programs.

Panelist: Arlene S. Bierman, MD, MS, is Chief Strategy Officer at the Agency for Healthcare Research and Quality (AHRQ) where she is tasked with expanding AHRQ's portfolio on improving health, functional status and well-being, and the prevention and management of

multiple chronic conditions in the aging US population. Arlene is a general internist, geriatrician, and health services researcher.

Panel Moderator: Jeff Schlaudecker MD, MEd is the Endowed Chair of Geriatric Medical Education at the University of Cincinnati. He is a family physician and geriatrician and in recent years, Jeff has been the medical director of a long-term care community in Cincinnati.

Facilitator Question: How do we position the research topics and themes that were discussed today to align with the priorities of funders?

Dr. Bierman - AHRQ's mission is to improve quality, access, outcomes, and equity of healthcare delivery with and across multiple settings. The agenda at this Summit fits well with AHRQ's priorities. AHRQ supports research about what works to improve care, the experience of care, and what works for implementation. There is a science of implementation, which includes how to scale and spread innovations so they become widespread and part of routine practice. In terms of improving care, there are a couple of ways we can approach the research. Clearly, we need to co-design research and co-produce the evidence with the people who are affected, as well as co-create the evidence for what works to improve care and implement changes. The work you've done with this project can inform a lot of very important work for this sector.

Ms. Ceesay - We recognize that residents, their families, clinicians and caregivers face a wide range of complex and often-confusing choices when it comes to health and healthcare concerns. They need trustworthy information to decide which treatment or other care option is best for them. PCORI helps people make those informed healthcare decisions – and improve healthcare delivery and outcomes - by producing and promoting high-integrity, evidence-based information that comes from research guided by patients, caregivers, and the broader healthcare community. These topics should be positioned to support research that will provide reliable, useful information to help people make informed healthcare decisions and improve patient care and outcomes. It should be noted that PCORI primarily funds comparative clinical effectiveness research, or CER. To align with our priorities, questions must compare the effectiveness of two or more strategies for prevention, treatment, screening, diagnosis, or management; compare alternative system-level approaches; or compare factors that may differentially affect patients' adherence to the alternatives (such as out-of-pocket costs).

Facilitator Question: How do we make partnering with residents and families an integral component of research and its dissemination?

Ms. Ceesay - Engagement is one of the key pillars guiding the work of PCORI and integral to the work of those whom we support. We believe that focusing on engagement means that residents, families, and stakeholders from across the healthcare enterprise should be actively and meaningfully involved in the entire research process. The work here today is an example of engagement—developing the research priorities and their dissemination to a range of different stakeholders. While we recognize that partnerships and engagement can take many shapes; it varies with the nature of the research. We believe that effective engagement with a project's

key stakeholders in research requires a well thought out plan. PCORI has an engagement strategy, available on our website, that we encourage everyone to use: www.pcori.org/engagement/engagement-resources.

PCORI's engagement strategy ensures that all partners and researchers are working together to define roles; the roles are clear about who's doing what; and it ensures that everyone is learning together. Residents, patients, and stakeholders are compensated for contributing their time and knowledge, and open and honest communication occurs among all parties. From the beginning to the end of the project, establishing trusting partnerships ensures that personal perspectives, priorities, or experience informs the work as well as offers guidance to improve research processes and materials. We look at engagement in terms of what is being studied? What are the recruitment strategies? Are there partnerships with local organizations that have relationships with the target populations? And then what avenues or platforms are best to disseminate the research? And will the people most affected by the research receive this information?

Participant - A participant shared a comment that it is also important to involve long-term care staff, both front-line and others, in planning and carrying out research so they realize that this is not just an academic exercise but an effort to create "real world evidence."

Dr. Bierman - Dissemination needs to be considered throughout the entire continuum of research. It begins in planning, and should not be an afterthought at the end. Scalability and sustainability of interventions are important—what can we do that actually changes practice so that these interventions and approaches become integral to routine practice? Often people design wonderful and effective interventions, but they're dependent on the additional resources from research funding, so they're not scalable in the real world. We ask about meaningful engagement—are the people using the research or impacted by it involved in the research process? We really need meaningful engagement of those who are going to use and be affected by the research. How do we best get this information to them? There is opportunity here and a lot of this is culture change.

AHRQ is funded, like PCORI, under the Patient Centered Outcomes Research Trust Fund, and is tasked with disseminating evidence for practice. AHRQ has integrated quality improvement with implementation science. While we're trying to improve care, we're also learning what works to improve it at the same time.

Facilitator Question: How can we help researchers and LTC stakeholders recognize current funding streams as relevant and applicable to their work/ideas?

Dr. Bierman - You should use a broad lens in responding to funding announcements. Announcements may not mention long-term care or another specific focus. Think broadly about funding announcements from both PCORI and AHRQ and how they might apply. For example, AHRQ has a large portfolio on patient safety and digital health. Consider these topics and their relevance for your research proposal. For example, would the digital solutions funding

announcement be relevant in enhancing connections in long-term care? You do not need to just rely on specific targeted calls for long-term care research.

Ms. Ceesay - There are two funding streams to keep an eye on. The first is the Investigator-Initiated Approach. Through this approach, investigators submit proposals in response to PCORI Funding Announcements (PFAs), broad calls for research proposals. We believe research meaningfully informed by input from patients and other stakeholders is more likely to be used for making patient-centered health and healthcare decisions and, ultimately, to improve patient outcomes. Therefore, we require that the proposals we fund under these broad PFAs include patients and other stakeholders in each step of the research process. Patients and other stakeholders also participate in our application review process.

This second path, designed to produce targeted PFAs, follows a systematic topic generation and research prioritization process. This process begins with potential research questions solicited directly from patients and other stakeholders through our website, engagement initiatives, and similar efforts undertaken by other healthcare experts and organizations. To date, we have collected more than 1,000 questions through this process.

Participant - In thinking about the scale of research, some research is national and at a very large scale. Perhaps local smaller projects could be funded by the civil monetary penalty funds, putting these funds to good use for pilot projects. An idea that emerged from my resident support group is to find better ways to support staff who are exhausted after the pandemic experience. This type of funding might be able to jumpstart projects like this. There is a window of opportunity now to address some of these issues but this window will close. It is so fresh now; it's been so painful. And people are very motivated. We need learn the lessons from this pandemic so that we can address them more effectively in the future.

Dr. Bierman - Panelists also discussed how smaller pilot projects can lead to a larger study. AHRQ does have several opportunities to fund smaller projects including R03s. There are also R21s for exploratory or developmental grants. In addition, local foundation funding can support some of the necessary preliminary work to strengthen your application to a federal agency. There are small windows of opportunity now and people need to move quickly while these issues are fresh in people's minds.

A researcher participant - She suggested that advocacy groups could be very helpful. States don't always spend the funds collected from fines. It can be challenging to determine if they have been spent or how to request this funding for specific projects. Perhaps partnering with state advocacy groups could lead to the availability of funding for pilot projects.

Ms. Ceesay - As we seek proposals under broad funding announcements, we are also committed to identifying and funding topic-specific research proposals likely to have a substantial impact on practice and patient outcomes. We recognize that, even with the collaboration of patients and other stakeholders, topics selected through an investigator-initiated process could miss important questions that matter to patients. If patients and other

stakeholders are to have a sense of ownership of the research process, then we need to be open to suggestions from the entire healthcare community, and we must make the origins of the topics transparent and traceable. PCORI sends weekly emails about opportunities to apply for funding, newly funded research studies and engagement projects, results of our funded research, webinars, and other new information posted on our site. You may subscribe by going to PCORI.org and scrolling down to the bottom of the landing page.

For further information about this long-term care project:

The Long-Term Care Partnerships section on the IPFCC website includes many resources listed below related to the project, **Building Capacity for Long-Term Care Stakeholders in COVID-Related Patient-Centered Outcomes Research**. Access the section [here](#).

- *Research Topics & Themes for Long-Term Care Developed in Partnership with Residents and Families*
- *Guide for Promising Practices in Engaging Long-term Care Communities in Planning for Future Research*
- Implications for COVID-Related Long-Term Care Research: A Summary from an International Stakeholder Summit
- Recruitment, Orientation, and Support Materials for Residents and Families
- *Key Themes from the Small Group Conversations with Residents and Families*