

PCORI Project Summit 2021: A Participatory and Inclusive Research Agenda for Medical Respite Care

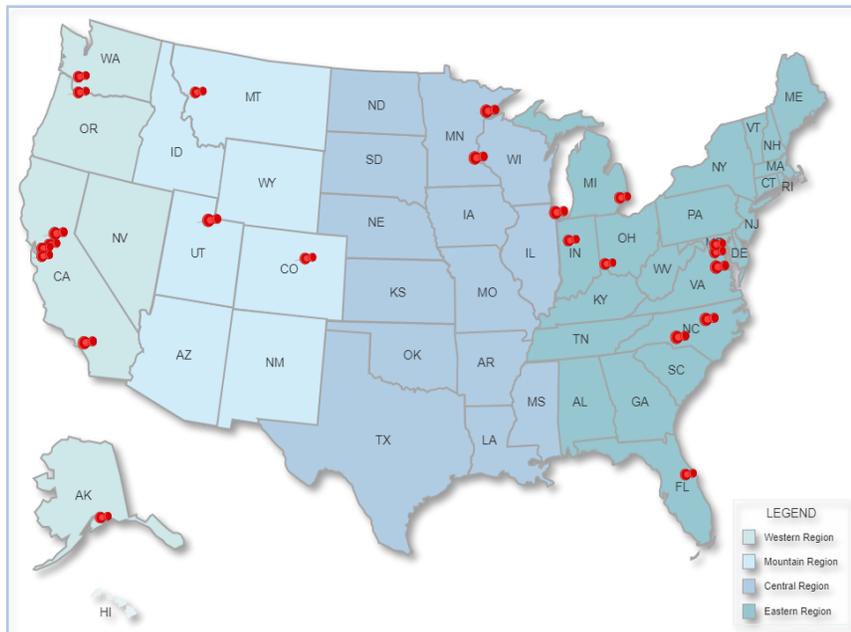
Background

Medical respite care (MRC)* is acute and post-acute care for people experiencing homelessness (PEH) who are too ill or frail to recover from an illness or injury on the streets or in shelter, but who do not require hospital level care. MRC programs offer short-term residential care that allows individuals experiencing homelessness the opportunity to rest, recover, and heal in a safe environment while accessing medical care and other supportive services. While there is evidence that MRC programs improve health outcomes and reduce unnecessary costs to health care systems and communities¹, this essential service remains widely under-researched, and the perspectives of people with lived experience of homelessness (PLE) are under-represented in the existing literature.

The National Institute for Medical Respite Care (NIMRC), a special initiative of the National Health Care for the Homeless Council (the Council), has begun to address this need by convening MRC programs from across the country to implement a stakeholder engagement project funded by the **Patient-Centered Outcomes Research Institute (PCORI)****. The primary goal of the project was to collaboratively develop a robust research agenda that (1) identifies high-priority research topics for MRC and (2) ensures that the voices of people with PLE are at the center of future research efforts.

Summit Overview

In August of 2021, NIMRC hosted **63** stakeholders (30% of whom were PLE) representing **22** geographically and structurally diverse MRC programs for a two-day, virtual project summit.

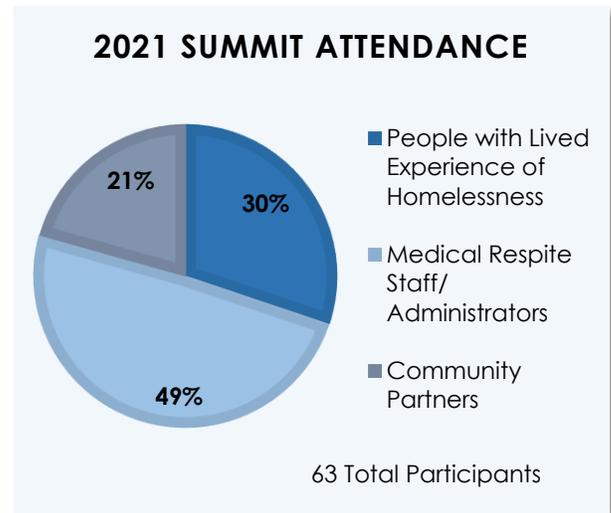


Map of MRC programs represented at the summit.

Participating stakeholders, including two clinicians, one MRC program administrator, and three PLE, actively shaped and guided the summit content by giving presentations and participating in a panel Q&A. The majority of the event was spent engaging in small, focus-group discussion sessions facilitated by subject matter experts. The discussion agendas were developed based on previous stakeholder input and focused primarily on

understanding and overcoming barriers to engaging PLE in research, the health and systems-level benefits of MRC, and opportunities to implement and disseminate MRC research. All sessions were recorded, and an analysis of the summit conversations informed the development of specific research priorities for MRC and recommendations for successfully engaging PLE in the research process. The results of a participant evaluation survey administered at the conclusion of the summit showed that:

- **88%** of respondents felt better equipped to participate in research and engage with other stakeholders.
- **91%** of respondents were “very” or “extremely” interested in participating in similar engagement projects in the future.



Key Findings & Future Opportunities

Five distinct but interrelated **research aims (goals/priorities)**, and **12 engagement strategies** tailored to address barriers faced by PLE emerged from a careful review of stakeholders’ discussions. The importance of cultivating trusting and empowering environments in which the voices of PLE are heard and valued was a central theme. Additionally, opportunities to enhance community partnerships, leverage existing data sources, and increase standardization in MRC should be further explored. As the project results are disseminated through the Council’s networks of MRC providers, researchers, health care and social service organizations, and people with lived experience of homelessness, we are confident that they will galvanize support for high-quality and patient-centered research that demonstrates the value and impact of MRC. The full report can be accessed [here](#).

Research Aims for the field of MRC:

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|  <p>Aim 1: Engage and support PLE as researchers.</p> |  <p>Aim 2: Develop and test standardized MRC models and measures.</p> |  <p>Aim 3: Connect with and use existing data sources.</p> |
|  <p>Aim 4: Study MRC from pre intake to discharge and follow-up.</p> |  <p>Aim 5: Study social relationships in MRC.</p> | |

| Strategies for effectively engaging PLE in MRC research: | |
|--|---|
| <ul style="list-style-type: none"> • Emphasize shared decision making. • Utilize peers with lived experience of homelessness. • Educate researchers and other stakeholders about homelessness to mitigate biases and stigma. • Clearly explain the methods and purpose of the research. • Address logistical barriers: transportation, cell phones, etc. • Value lived expertise by compensating fairly. | <ul style="list-style-type: none"> • Leverage partnerships with trusted community agencies. • Form advisory boards of PLE to guide and review research. • Build trust and rapport over time. • Explore creative methods for data collection and dissemination: photo/video, poetry, storytelling, etc. • Support educational opportunities for PLE. • Host aftercare events post-MRC (e.g., community meals). |

* “Medical respite care” may also be known as “recuperative care.” These terms are synonymous.
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 1. NIMRC (2021). [Medical respite literature review: An update on the evidence for medical respite care.](#)
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