Building the Evidence Base for Medical Respite Care: A Participatory and Inclusive Research Agenda

November 2021

NATIONAL
INSTITUTE
—*for*—
MEDICAL
RESPITE
CARE

Acknowledgement

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INTRODUCTION

Medical Respite Care

Medical respite care (MRC) fills an important gap in healthcare when patients are not sick enough to remain in an inpatient hospital setting but are too sick to be returned to the streets or traditional shelter settings (Zerger et al., 2008; Zlotnick et al., 2013). Medical respite

> **Terminology**:
> "Medical respite care" may also be known as "recuperative care." These terms are synonymous.

care was introduced in the mid-1980s and has grown from 73 facilities in 2013 to 117 facilities at present (NIMRC, 2021a; NIMRC, 2021b). Although there is considerable variation in size and scope of MRC programs, a systematic review (Doran et al., 2013) found that MRC tended to reduce future hospital admissions, inpatient days, and hospital readmissions. MRC has also been associated with improved housing outcomes (Doran et al., 2013). Some research has begun to highlight outcomes from guest perspectives as well, leading to important findings beyond health care use and cost (Biederman et al., 2014; NIMRC, 2021c), but the voices of people with lived experience of homelessness (PLE) remain widely under-represented in the existing literature. As momentum continues to build around MRC, it is increasingly important that the evidence-base for this essential service grows and evolves as well.

Participatory & Patient-Centered Research

Participatory research is "characterized by working with a community, changing the balance of power, involving a different role for the researcher, and active participation of the community at all stages of the research process" (Northway, 2013; p.174). Such orientations to research and evaluation on medical respite care not only fill a research gap but can enhance research in numerous ways. First, these approaches can serve to build trust throughout research processes from study design conception to research implementation and dissemination (Goodkind et al., 2016). They can also improve study recruitment success and follow-up response rates (Row et al., 1995). In addition, participatory research can help inform research questions, improve access to data, and suggest meaningful future directions (Greene, 2021).

Of note, community members may be defined in different ways and play different roles in the research process—depending on the organizations and topics involved (Gong et al., 2009). Specific

to MRC, participatory roles may include (but are not limited to) staff and administrators, clinicians, peer providers, volunteers, guests, or former guests with lived experience of homelessness. PLE are often recruited as research subjects, but in participatory research orientations, PLE are researchers and research participants. To be sure, participatory research and evaluation fall on a continuum of engagement and involvement across stages of the research process (Minkler & Wallerstein, 2008). Accordingly, matching commitments and involvement between formally trained researchers and community members with lived experience can be challenging (Muhammed et al., 2014). However, there is considerable value in starting with limited, feasible objectives and building from there to increase participation and involvement over time as relationships grow and trust develops (Horton & Freire, 1990).

Challenges to participatory research in the context of MRC include systemic barriers and discrimination associated with being unhoused, varying health statuses, histories of trauma, cognitive and literacy limitations, and varying familiarity with and access to technology. In contrast, important advantages related to this type of research include improved engagement, shared learning, more equitable processes, and results that are more relevant and beneficial to communities and service recipients (Jagosh et al., 2012). Table 1 presents barriers and facilitators to participatory research described during the summit.

Participatory research also requires funding to succeed (Plumb et al., 2004). The Patient-Centered Outcomes Research Institute (PCORI) recognizes that researchers and providers alone should not speak for clients and patients (Frank et al., 2014), and PCORI is a foremost supporter of patient-centered research that is inclusive of patients and community stakeholders throughout research processes (Parry et al., 2021). In addition to providing financial support, PCORI, and its awardees, have produced a multitude of resources to advance this work. Examples include the PCORI Engagement Rubric[1] which outlines foundational principles of research engagement and the Patient Engagement Toolkit[2] which provides specific guidance on recruiting patients as partners, training

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[1] The PCORI Engagement Rubric can be found here: https://www.pcori.org/sites/default/files/Engagement-Rubric.pdf
[2] The Patient Engagement Toolkit can be found here: https://research.kpchr.org/Patient-Engagement-Toolkit

patients, offering patient-engagement services, and collecting patient and scientific partner feedback.

Description & Purpose of this Research Agenda

The National Institute for Medical Respite Care (NIMRC), a special initiative of the National Health Care for the Homeless Council, planned and implemented a year-long stakeholder engagement project, *Identifying Strategies to Engage Medical Respite Care Programs and People Experiencing Homelessness,* to explore opportunities for advancing patient-centered outcomes research within the field of MRC. This research agenda is based on the cumulative activities leading to and including a two-day project summit involving various stakeholders (many of whom had lived experience of homelessness) from more than 22 MRC programs and communities nationwide. This entailed a review of notes from summit planning meetings, participation in the summit, and analysis of a qualitative data synthesis produced by Vanderbilt University's Qualitative Research Core (VU-QRC). The data synthesis reported main and sub-group categories for each of four summit sessions (with multiple subgroups participating in each session) in addition to a consumer panel discussion and a final plenary session. Summit participants and the National Consumer Advisory Board (NCAB)[3] were also engaged in revising and finalizing the priorities and recommendations outlined in this research agenda. A full description of the project methodology can be found in **Appendix A: Methods**.

The identified research aims, and proposed research questions, are based on the findings from the project summit (including facilitators and barriers to research) in relation to varying research perspectives. First, this involves looking at research from multiple levels, including national and regional levels of research on MRC (macro-level), community-level questions connecting multiple sites, services, partnerships, and stakeholders (meso-level), and site-specific level questions, analyses, and individual cases (micro-level). Second, this is based on the importance of connecting theory and data. Accordingly, research aims are based on summit data and connected to relevant theoretical perspectives. Research aims are then connected to data sources, methodologies, and

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[3] National Consumer Advisory Board: https://nhchc.org/consumers/ncab/

research questions. Such data sources may be existing or may come from original data collection from multiple methodologies including surveys, interviews, focus groups, or case studies. Third, this agenda is informed by the process of medical respite care and the range of activities conducted before intake to discharge and follow-up. All research aims are in relation to challenges and concerns with trust, competing interests in outcomes and goals, and relationships to administrators, providers, guests, partner organizations, and communities.

The identified research aims are described in more detail below and lead to specific research questions. Importantly, aims (and questions) are not meant to be considered in isolation; there is significant overlap between them. For example, the first aim is meant to connect with aims two-five so that research and evaluation activities can be as inclusive and participatory as possible. In addition, standardized measures can be connected with existing data sources like homelessness management information systems (HMIS) and could be helpful for national, regional, or site-specific research (specific to aim four). Such measures could also be linked to research on social relationships (i.e., aim five). The logic connecting research aims and research questions is presented in Table 1. Table 2 synthesizes and connects summit data to specific aims and research questions. Table 3 displays specific tools for research and dissemination that were recommended during the summit. Specific research aims and questions for each aim are further described, followed by the three tables.

RESEARCH AIMS

The specific identified aims are all intended to include PLE as co-investigators. The first aim specifically explores the process, facilitators, and challenges of engagement alongside benefits associated with participatory research. The subsequent aims address issues that are essential for demonstrating the impact and value of MRC and improving the quality and efficacy of service delivery. Achieving these aims and addressing the corresponding research questions will involve strategies to incorporate multiple theoretical perspectives and mixed methods and necessitates intentional and sustained engagement with PLE.

Research Aims for the field of Medical Respite Care:

Aim 1: Engage and support PLE as researchers.

Aim 2: Develop and test standardized MRC models and measures.

Aim 3: Connect with and use existing data sources.

Aim 4: Study MRC from pre intake to discharge and follow-up.

Aim 5: Study social relationships in MRC.

Specific Research Aims and Questions

Aim 1: Engage and support PLE as researchers

The first aim is based on themes from summit sessions describing the importance of peer providers/peer mentors and including PLE as researchers. Much research has shown the value of peers with lived experience in recovery services (Bassuk et al., 2016), and similar framing could be used in medical respite care. This can be extended through the intentional inclusion of peers as researchers and could be connected with participatory research study designs, outcomes, and measures (Daigneault & Jacob, 2009; Minkler & Wallerstein, 2008). Importantly, training opportunities and professional development may be important for PLE to learn research skills alongside projects and practice. Although participatory research and evaluation are often more exploratory and developmental, such work can be iterative and built upon over time. Furthermore, a participatory orientation can overlay all other study aims as follows. Specific research questions related to participatory research and evaluation activities are below.

1. *How does engagement of PLE as researchers impact retention and follow-up with research study participants in MRC?*

2. *Does engagement of PLE as researchers result in more relevant outcomes and/or more reliable data collection?*

3. *What facilitators and barriers influence engagement with research among PLE?*

4. *How can PLE most effectively build research skills and knowledge?*

5. *What opportunities exist for PLE to pursue research positions in and outside of homelessness services?*

Aim 2: Develop and test standardized MRC models and measures

The second aim is based on summit discussions about the need for research on common elements shared across MRC sites and regions, including national level data. Of importance, differing contexts and program variations will be important to study. Research specifying outcomes may draw from existing program outcomes on hospital admissions, inpatient days, and hospital readmissions, as well as housing-related outcomes. Studying the existing *Standards for Medical Respite/Recuperative Care Programs*[4] and efforts to expand and refine measures and outcomes could particularly benefit from patient centered and participatory approaches. An inclusive Delphi study design with experts and guests and panel members refining measures could be a helpful approach to develop an instrument (or assessment components) that could be standardized and used to demonstrate program effectiveness (Feo et al., 2018; Shoemaker et al., 2020). Results may also help to articulate the need for MRC in additional communities and serve to identify and test evidence-based practices within MRC. Specific research questions are below.

1. *How do key stakeholders perceive existing efforts to standardize MRC, and how should such decisions be made?*

2. *How can existing MRC programs be grouped as model types?*

3. *What outcomes measures can be standardized across models of MRC programming?*

4. *How can standardized measures demonstrate need for MRC?*

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[4] *(See the Standards for Medical Respite/Recuperative Care 2021)*

5. *How can standardized measures demonstrate efficacy of MRC?*

Aim 3: Connect with and use existing data sources

The third aim is based on conversation about collaboration and data sharing as well as integration with existing data sources at the community level. This largely relies on relationships with Continuums of Care via the Homelessness Management Information Systems (HMIS), hospital systems, payers, and community health centers, though other opportunities should also be explored. Additional data linking could take place with community surveys, census data, and other public sources. Although there are challenges to building capacity and setting up the infrastructure to make use of myriad data sources, this aim could facilitate important systems-level decisions and responses (Fowler et al., 2019). Such research would be strongly engaged with literature on data interoperability (Almeida et al., 2020; Daclin et al., 2016; Gaynor et al., 2014) and research on advancing equity through data sharing groups (Sensmeier, 2020). Importantly, the perspectives of PLE should be represented in the planning and oversight of such data sharing initiatives. Corresponding questions for aim three are presented below.

1. *What organizations collaborate with MRC programs?*
2. *What existing data sources could help to demonstrate the impact of medical respite care?*
3. *How can medical respite care measures and outcomes be shared within and across communities?*
4. *How can external data sources be made accessible for data analysis?*
5. *How can shared data sources be used to inform community level policy making decisions?*

Aim 4: Study MRC from pre intake to discharge and follow-up

Aim four focuses on the optimization of various stages of MRC programming and assessing guests' experience throughout the intervention. Such research can focus on program implementation and work with implementation science framing (Nilsen, 2015). Studies examining referral relationships and intake processes, medical and supportive services provided, community-based partnerships, discharge planning and implementation, housing status and health outcomes post-discharge, and more would complement other aims in important ways. This research could

also incorporate story-sharing tools such as those described in Table 2 (e.g., Photovoice, Story Catcher). Photovoice has long been used to help empower participatory researchers, including people affected by homelessness (Cheezum et al., 2019; Nault et al., 2019). Specific research questions for aim four are presented below.

1. *How are successful referral and intake processes developed and maintained?*
2. *What partnerships and referral relationships are most needed to meet MRC guests' needs?*
3. *How can MRC programs help guests transition to housing?*
4. *How can follow-up with guests after discharge work best and what outcomes should be assessed?*
5. *How do cases of successful program completion compare to cases of early or unplanned discharge?*

Aim 5: Study social relationships in MRC

The fifth aim draws on the myriad relationships described by participants in the summit including the importance of interpersonal connections between guests, peers, and providers, and relationships between MRC programs and hospitals, local communities, partnering service providers, and other stakeholders. Study perspectives could focus on the relationships between social tie formation and health (Greene, 2018; Smith & Christakis, 2009), or on the benefits of shared decision making (Joosten et al., 2008; Shay & Lafata, 2014), which was introduced several times during the summit. Research on social relationships overlaps with program level data on performance and outcomes and could be complemented with mixed methods as well (Small, 2011). As described previously, relationships should be considered in micro, meso, and macro contexts, accounting for the perspectives of individuals, organizations, and broader communities. Research questions for aim five are below.

1. *What does shared decision making look like between guests and providers?*
2. *What communication strategies are most effective for MRC providers?*
3. *How can partnering health care, government, and social service organizations best learn about MRC and homelessness?*
4. *How can referral organizations best learn about MRC and homelessness?*

5. *What beneficial relationships are formed during MRC and maintained after discharge?*

SUMMARY

Summit discussions emphasized the enormous need for participatory research approaches in which PLE are actively engaged members of the research team to inform future investigations into MRC. Further, strategically building trust and collaborative relationships (both interpersonal and between organizations) to support engagement were identified as core elements of a meaningful research agenda for MRC. This necessitates intentional and sustained engagement activities throughout each stage of MRC from pre-intake to discharge and follow-up. Although MRC programs vary and contend with unique community level challenges, increased guidance and standardization related to MRC program models and measures are needed to demonstrate need and efficacy. These issues and gaps are addressed in research aims one and two.

Opportunities related to accessing, sharing, and leveraging existing data sources should be explored and could potentially facilitate important systems-level responses and decisions (aim three). Aim four highlights the value of incorporating research into existing MRC activities and services and examining each stage of the MRC process through the lenses of providers, PLE, and other stakeholders. Aim five focuses on social relationships between guests, providers, stakeholders, organizations, and local communities. Although this is possible with all aims, such research could involve multiple data sources and questions from other aims and involve mixed methods, combinations of primary and secondary data, as well as various configurations of survey, interview, focus group, and other observational data sources.

Table 1 highlights both barriers and facilitators to effectively engaging PLE in research activities that emerged during stakeholder discussions. Specific research aims and questions are connected in Table 2. Table 2 includes organizing concepts to help guide research in relation to specific data from the MRC Summit. The table presents potential methodologies and data sources, connects this to research questions, and includes contextual examples. Based on summit synthesis data, tools and approaches for research data collection and dissemination of results are further described in Table 3.

Table 1: Barriers and facilitators to engagement

Barriers to engagement:	Facilitators to engagement:
• Past traumatic and stigmatizing experiences leading to mistrust of health care and social service systems. • Inadequate access to reliable transportation. • Limited access to necessary technology as well as the ability to charge devices and connect to the internet. • Unmet medical, social, and behavioral health needs. • Fatigue from having to recount difficult experiences repeatedly to multiple organizations/providers in order to access services and resources. • Jargon and overly technical communication and research methods/delivery. • Concerns about confidentiality and/or negative perceptions and the impact on the quality of care received.	• Create opportunities for shared decision-making wherever possible. • Form advisory boards made up of PLE to guide efforts and provide feedback. • Utilize peers with lived experience of homelessness. • Mitigate biases through enhanced training/education about homelessness for multiple stakeholder groups involved in research (e.g., researchers, students, providers, administrators, etc.). • Clearly and respectfully communicate roles, expectations, methods (including confidentiality), and especially the purpose of the data collection and ultimate aims of the research. • Host aftercare events for those who have completed the program (e.g., a community meal) in order to maintain connection. • Build trust and rapport over time through researchers embedding themselves in the community. • Address logistical barriers by providing tangible resources such as transportation assistance, pre-paid cell phones, etc. • Leverage partnerships with established community partners (e.g. health centers, shelters, housing providers, etc.) to maintain connection over time. • Explore creative and accessible methods of both collecting data and disseminating results (e.g., video, imagery, storytelling, etc.). • Provide fair compensation that acknowledges the value of lived expertise. • Support educational opportunities for PLE.

Table 2: Connecting specific aims to research questions

Research Aim 1: Engage and Support PLE as researchers (Researchers with Lived Experience)				
Key concepts and supporting data from Summit discussions	**Data Sources and Approaches**	**Challenges**	**Research questions**	**Examples for Reference** (Examples are for additional context and are not intended to be prescriptive)
Key Concepts 1. Participatory research 2. Participatory evaluation **Supporting data** • Involve guests • Go beyond readmission rates • Help PLE tell their stories – explore creative ways • Bring people to the table – strength's focus • Sensitivity to the skills of clients • Form partnerships with academic institutions	• Individual MRC program or groups of programs • Case study • Mixed method designs (in combination with aims 2-5)	• Participation less defined at onset • Trust • Health • Time • Funding	*1. How does engagement of PLE as researchers impact retention and follow-up with research study participants in MRC?*	Evaluating PLE's comfort-level and participation in surveys administered by peers with lived experience versus academic researchers.
			2. Does engagement of PLE as researchers result in more relevant outcomes and/or more reliable data collection?	Comparing stakeholders' perceptions of the utility of participatory study results with those from the existing literature.
			3. What facilitators and barriers influence engagement with research among PLE?	Studying trends in reasons for participation (or reasons for not participating) in research activities.
			4. How can PLE most effectively build research skills and knowledge?	Case study analyses on learning processes within participatory research and associated future opportunities.
			5. What opportunities exist for PLE to pursue research positions in and outside of homelessness services	Initiating and evaluating a partnership between a research institution and an advisory board of PLE who contribute to studies related to homelessness.

Research Aim 2: Develop and test standardized MRC models and measures (Standardization)				
Key concepts and supporting data from Summit discussions	**Data Sources and Approaches**	**Challenges**	**Research questions**	**Examples for Reference** (Examples are for additional context and are not intended to be prescriptive)
Key concepts 1. Standardization 2. Evidence based practices **Supporting data** • Test existing standards • Supplement existing standards and metrics for implementation and outcomes • Consider timelines for readmission data, (e.g., 6-9 months) • Work with hospital systems • Build evidence to support MRC as a covered Medicaid benefit • Study staffing and capacity	• Participatory research • Registry and networks of MRC programs • Expert interviews • Surveys • Delphi study (consensus study) design	• Need for flexibility and adaptability • Agreement on models and measures	1. *How do key stakeholders perceive existing efforts to standardize MRC, and how should such decisions be made?*	Surveying key stakeholders, including PLE, regarding their satisfaction with the existing Standards for MRC[5] and the perceived usefulness of these standards.
			2. *How can existing MRC programs be grouped as model types?*	Examining factors such as the facility type, scope of clinical services offered, and staffing models and using these factors to define MRC program models.
			3. *What outcomes measures can be standardized across models of MRC programming?*	Convening a workgroup to identify fundamental elements of MRC that should be measured across sites/contexts.
			4. *How can standardized measures demonstrate need for MRC?*	Implement and study universal housing-status screening within a health system to determine the number of unhoused patients.
			5. *How can standardized measures demonstrate efficacy of MRC?*	Tracking a selected outcome such as rates of successful connections to ongoing primary care across many MRC sites to generalize results.

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[5] *(See the Standards for Medical Respite/Recuperative Care 2021)*

Research Aim 3: Connect with and use existing data sources (Leveraging Data)				
Key concepts and supporting data from Summit discussions	**Data Sources and Approaches**	**Challenges**	**Research questions**	**Examples for Reference** (Examples are for additional context and are not intended to be prescriptive)
Key Concepts 1. Data interoperability 2. Complex systems responses **Supporting data** • Referral data • Regional data networks • Track resources services and outcomes • Share data and findings with creativity (e.g., poetry and social media) • Contact databases and updates to data • Integrate with EMR data and other shared databases • Government agencies, hospitals, shelters, housing authorities, primary care, food banks	• Participatory research • Hospital system data • HMIS • American Community Survey data • Census data • Uniform Data System (community health centers) • Payer data • EMS data • Coroner data	• Data sharing • Confidentiality • Infrastructure for data matching, merging, or linking	1. *What organizations collaborate with MRC programs?*	What percentage of MRC programs partner with their local Continuums of Care and can access and edit data in HMIS/Coordinated Entry?
			2. *What existing data sources can help contextualize medical respite care outcomes?*	Utilizing Medicaid/MCO claims data to explore changes in beneficiaries' use of emergency services and outpatient care.
			3. *How can medical respite care measures and outcomes be shared within and across communities?*	Can existing collaboratives/networks of MRC programs be leveraged to refine measurement tools and share outcomes?
			4. *How can external data sources be made accessible for data analysis?*	Examining case studies in communities where a local data sharing collaborative has been successfully implemented.
			5. *How can shared data sources be used to inform community level policy making decisions?*	Assessing how policy makers receive and make use of data and findings.

Research Aim 4: Study MRC from pre intake to discharge and follow-up (Understanding MRC)				
Key concepts & supporting data from Summit discussions	Data Sources and Approaches	Challenges	Research questions	Examples for Reference (Examples are for additional context and are not intended to be prescriptive)
Key Concepts 1. Implementation science 2. Shared decision making **Supporting data** • Screening, enrolling, treating, discharging, and follow up • Account for varying backgrounds medical histories and current needs • Personal and medical history • Trauma-informed care • Strengths-based, client centered • Patient guides or navigators • Transportation and logistics • Make MRC as stress free as possible • Build trust	• Participatory research • Site or program level existing data • Surveys, Interviews, Focus groups	• Avoiding exploitative experiences • Fairly selecting categorizing and representing success and failure for future learning • Balancing unique versus more typical experiences • Limited capacity for research and evaluation beyond program operations	1. *How are successful referral and intake processes developed and maintained?*	Conducting interviews with both MRC program staff/administrators and partnering hospital staff/administrators in multiple communities to identify common elements.
			2. *What partnerships and referral relationships are most needed to meet MRC guests' needs?*	Community asset mapping and needs assessment based on referral options, availability and accessibility of those options, and success rates with referrals.
			3. *How can MRC programs help guests transition to housing?*	Capturing and measuring case management activities that support transitions to housing (eg. obtaining necessary documents, connecting to coordinated entry, increasing income, etc.).
			4. *How can follow-up with guests after discharge work best and what outcomes should be assessed?*	Exploring partnerships with federally qualified health centers to monitor long-term health outcomes and primary care usage post-MRC.
			5. *How do cases of successful program completion compare to cases of early or unplanned discharge?*	Comparing characteristics of planned versus unplanned discharges from MRC in order to identify any patterns/disparities.

Research Aim 5: Study social relationships in MRC (Relationships)				
Key concepts and supporting data from Summit discussions	**Data Sources and Approaches**	**Challenges**	**Research questions**	**Examples for Reference** (Examples are for additional context and are not intended to be prescriptive)
Key Concepts 1. Social networks (individual and organizational) 2. Health communication 3. Racial and experience concordance **Supporting data** • Effective communication between MRC staff and clients • Shared decision making • Relationships between MRC and behavioral health providers • Appointments support • Follow up events (e.g., family and community days, special talks and presentations, and shared meals) • Stigma and discrimination • Representation of experience within MRC staff and advisory boards	• Participatory research • Surveys, Interviews, Focus groups • Observational data	• Requires longer-term study designs (e.g., longitudinal studies) • Funding • Time • Research capacity • Research response rates, retention, an follow-up	1. *What does shared decision making look like between guests and providers?*	Evaluating program-level policies that maximize client choice and their impact on program outcomes (eg. guest-reported satisfaction, retention, meeting care plan goals).
			2. *What communication strategies are most effective for MRC providers?*	Implementing a trauma-informed care and/or empathetic communication training program for MRC staff and evaluating the impact on guests' experience.
			3. *How can partnering health care, government, and social service organizations best learn about MRC and homelessness?*	Studying access to information about MRC and homelessness and assessing for perceptions (and misperceptions).
			4. *How can referral organizations best learn about MRC and homelessness?*	Evaluating the efficacy of periodic educational/outreach events (eg. a "lunch and learn") for discharge planners from the referring organization.
			5. *What beneficial relationships are formed during MRC and maintained after discharge?*	Qualitative investigation of the significance of relationships formed with other guests and providers/staff for wellness and future engagement in services.

Table 3. Tools and approaches for research and dissemination

Storytelling *Sharing stories helps us to connect with and understand each other, even when our life experiences differ drastically. Systematic efforts to collect and share stories in compelling formats can make a profound contribution to accomplishing research aims.*	Story catcher's programs[6] • Applications and/or online services that allow people to record and share their stories. • Offers multiple ways of eliciting, capturing, and sharing stories: video, audio, documentaries, music, etc. Social Storytelling Toolkit[7] • Collection of resources that can help MRC programs and research teams collect data and communicate findings in creative ways. • Includes example projects and presentations, as well as a consumer-produced Storytelling Guide, template release forms, and links for working with mixed mediums (e.g., images, digital recordings, and social media).
Photovoice *Photovoice can empower PLE to tell their own story and provide a foundation for educating stakeholders about experiences of homelessness.*	• Cameras are used by PLE to document aspects of their daily lives. • Photos are collected, and PLE are asked to share and interpret the significance of the images. • Supported in existing research (Budig et al., 2018).
Cell phones & devices *While many PLE do have access to cell phones/devices, these can easily be lost or stolen and can be difficult to keep charged and activated while navigating homelessness.*	• Invaluable in maintaining contact with research participants and co-researchers and notifying them of research activities. • Essential for accessing telehealth and virtual visits with other providers/case managers. • Programs and researchers can provide pre-paid minutes and data plans. • Programs and researchers can provide access to safe and convenient charging locations.
Partnerships with academic institutions *Such partnerships can embody co-learning, providing PLE with valuable information while educating future clinicians and researchers about homelessness.*	• Helping professions departments at universities can develop internship/practicum relationships with MRC programs (e.g., nursing, occupational therapy, medical students, social science researchers). • Facilitating health education and life-skills groups for MRC guests. • Assist in creative activities that are therapeutic and help guests tell their story (e.g., creating videos or art projects).

[6] Story catchers' programs: https://thestorycatchers.com.au/ ; https://www.thestorycatchers.com/ ; https://storycatcher.app/
[7] The Social Storytelling toolkit can be found here: https://nhchc.org/press/storykit/

Collaboratives and networks of MRC programs *Opportunities for programs to connect and share best-practices and lessons-learned were identified as critical activities by summit participants.*	• Building relationships with other MRC providers and learning about innovative approaches in the field in real-time. • Can share outcomes and information between communities that enrich research projects. • Capitalize on existing associations/networks like NIMRC and the Respite Care Providers' Network (RCPN)[8]. • Disseminate research findings in a targeted and effective way.

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[8] Respite Care Providers Network: https://nimrc.org/respite-care-providers-network/

Appendix A: METHODS

Recruitment & Planning

The National Institute for Medical Respite Care (NIMRC) leveraged its network of medical respite care (MRC) programs across the U.S. and initiated a competitive application process to recruit participants in December 2020. Twenty-seven geographically and structurally diverse MRC programs were initially selected to participate in three virtual planning convenings followed by a two-day project summit. Based on feedback from a survey of participating programs, the decision was made to hold the project summit virtually due to logistical and health concerns associated with the COVID-19 pandemic. Programs were asked to bring a minimum of one representative to each planning session and a minimum of three representatives to the final project summit: one MRC program staff member or administrator, one consumer-representative or person with lived experience of homelessness (PLE), and one community partner.

All meetings were held using Zoom® technology. The three planning convenings featured presentations from subject matter experts (SMEs) that grounded the project in the engagement principles of PCOR and examined the existing literature/evidence base for MRC. NIMRC staff facilitated small group discussions during the first two planning sessions around research gaps and priorities, strategies for engaging people experiencing homelessness in PCOR, cultivating community partnerships to support research activities, and more. Detailed notes from each discussion were provided to all participants for review, and participants were given the opportunity to add comments and make revisions on an ongoing basis using a shared online document. During the third planning convening, participants systematically prioritized topics/themes drawn from these initial discussions via a Mentimeter® survey, and the results were used to finalize a discussion agenda for the project summit.

Implementation of the Summit

The two-day, virtual project summit was held in August 2021, and 63 stakeholders representing 22 MRC programs (as well as 8 NIMRC staff members) participated. Forty-nine percent (n= 31) of participants were MRC staff/administrators, 30% (n= 19) were people with lived experience of

homelessness, and 21% (n= 13) were community partners. The summit consisted of four sessions focused on the following issues:

1. Strategies for effectively engaging PLE/MRC consumers in PCOR.
2. Identifying MRC research priorities: benefits to communities and systems.
3. Identifying MRC research priorities: population health benefits.
4. Opportunities to support, implement, and disseminate MRC-focused PCOR.

Six participants (three of whom had lived experience of homelessness) gave brief presentations and/or participated in a panel Q&A relevant to summit content. The majority of each two-hour session consisted of small-group discussions in which participants were divided into four-to-five groups and directed to Zoom® breakout rooms. Each discussion group had two moderators (a SME and a Council staff member) who facilitated the conversations, and each breakout room was recorded. Participants provided additional feedback through an evaluation survey and both written and oral responses during the closing plenary session of the summit.

Data Analysis & Drafting the Research Agenda

Following the summit, recordings of all discussion groups, a panel Q&A with PLE, and the closing plenary session were transferred to Vanderbilt University's Qualitative Research Core (VU-QRC) for analysis. VU-QRC examined the recordings and consolidated the findings from the discussion groups to produce a detailed summary of prominent themes and priorities. Based on this detailed summary and supplemental notes from discussion group moderators, a comprehensive research agenda for MRC was drafted. NIMRC secured the services of an affiliate researcher with relevant expertise (who also attended the summit) to assist in authoring the document.

Stakeholder Feedback & Revisions

In October 2021, two additional, virtual meetings were held with key stakeholder groups including the National Consumer Advisory Board (NCAB), participants from the summit, and additional experts in the field to solicit feedback and recommendations related to the first draft of the research agenda. The input provided by these stakeholders informed the revision process, and a finalized document was completed.

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