
February 2023

MEMORY KEEPERS MEDICAL DISCOVERY TEAM



COMMUNITY-BASED PARTICIPATORY HEALTH RESEARCH WITH OLDER INDIGENOUS ADULTS

A Relational Development Guide




Medical School,
Duluth Campus
UNIVERSITY OF MINNESOTA
Driven to Discover®

Who are Memory Keepers?

The Memory Keepers Medical Discovery Team is focused on collaborative research to improve dementia outcomes in Indigenous and rural communities. The team works to address brain health equity through collaborative, community-based research with rural and Indigenous partners.

At Memory Keepers, we use a strengths-based Two-Eyed Seeing approach that values western, local, and Indigenous Knowledge. Our research strives to understand the biological, social, and cultural construction of disease, illness, and health in order to improve diagnoses, develop community health interventions, and improve education for dementia within the context of geographic and cultural diversity. Find out more at <https://memorykeepersmdt.com>.



Two-Eyed Seeing¹

Two-Eyed Seeing is a methodology in which western and Indigenous perspectives are held equally and used with the goal of improving health and wellbeing for the next generations.

This approach is extremely beneficial as it allows researchers to recognize and acknowledge the strengths of both the Indigenous and western knowledge systems, as well as being mindful of the multiple ways of knowing that can be used in the research process.

An explicit Two-Eyed Seeing approach involves addressing the power imbalance between the two knowledge systems and placing Indigenous Knowledge on equal ground with western knowledge.

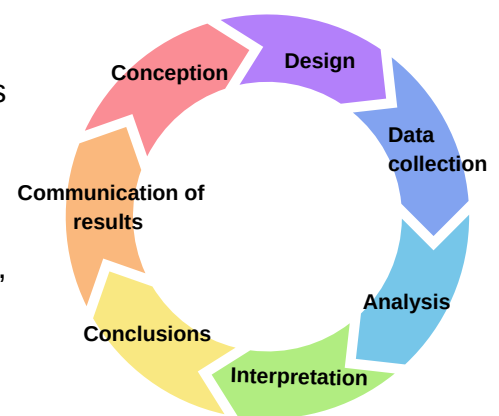
¹ For more information about the Two-Eyed Seeing see Marshall, Marshall & Bartlett (2018) and Martin (2012).

Community-based participatory health research with Indigenous older adults

Community-based participatory research, often referred as CBPR, is an applied collaborative approach to research that enables community members to actively participate in the full spectrum of the research process (see Figure 1). Community members and researchers partner to combine knowledge and action, generating research with the goal of influencing change in community health, systems, programs, or policies. The ultimate goal of this collaborative effort is to improve community health and contribute to the reduction of health disparities.

It is important to consider that initial CBPR outreach requires additional time and costs to support relationship building through travel, compensation for community partners, as well as food served at meetings. Applications for research projects or grant funding should support travel, community-based research staff and any training they may need to fulfill the role, advisory members honorariums, meeting expenses, participant honorariums, as well as communication-related costs, and equipment. Grant planning and applications must build in time and finances to support relationship development and collaborative planning. In our experience, new relationships may require up to 1 year of community engagement time, and established community partnerships pursuing new research projects usually requires 6 months.

Figure 1: Research process



Principles of CBPR²

- **Partnership:** Local involvement and participation in planning, implementation, and evaluation.
- **Empowerment:** Research as a process that enhances community empowerment and supports self-determination and tribal sovereignty.
- **Community control:** Community maintains ownership and control of research process and outcomes.
- **Mutual benefit:** Working in partnership with and for the community for a mutually beneficial outcome.

² The eight principles listed above (and on the next page) were described by Jacklin and Kinoshameg (2008) in their article focused on community-based research methods and Indigenous health research.

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- **Wholism:** Use and production of wholistic knowledge consistent with Indigenous teachings.
 - **Action:** Knowledge produced is used for action.
 - **Communication:** Commitment to community-oriented communication, dissemination, and knowledge translation of research and results.
 - **Respect:** Respect for local Indigenous research philosophy, culture, and ways of knowing. Value of quantitative and qualitative research methods including Indigenous methodologies such as storytelling.

Grounding Indigenous aging and health research in culturally safe approaches

With the increasing aging global population, there is a growing concern from health and social service providers that chronic conditions will threaten the ability of older adults to age in place. Indigenous communities globally experience significantly higher rates of chronic conditions that require health and social services, yet they often lack accessibility to services that support aging in place in rural and remote locations. Indigenous adults and their families often prefer family caregiving models, as they are culturally grounded and more comprehensive than those found in the general population.

The capacity for Indigenous populations to age in place is disproportionately affected by colonial policies and practices and the lack of formal support services in communities, and research involving Indigenous populations must address the lasting effects of colonialism in the researcher-community relationship by working collaboratively and utilizing culturally safe approaches. In other words, solutions should be developed with, rather than for Indigenous communities. Embracing Indigenous Ways of Knowing and Indigenous Knowledge is crucial in developing culturally safe and effective solutions.

Figure 2: Pillars of research responsibility³



³ As pointed out by the NCAI Policy Research Center and MSU Center for Native Health Partnerships (2012, 11), it is critical for researchers to understand and respect these three elements to fully comprehend how they shape the context of the research project.

A guide of how to get started on a culturally safe path

At their core, collaborative and culturally safe research and development approaches are about building and maintaining trust—a continuous process that takes time and effort. There are many important steps to complete and connections to make before conducting research with Indigenous communities. Throughout the process, it is crucial to acknowledge and respect the experiences of the community, listen openly to community members, understand and utilize the expertise of the community partners, and be upfront and sincere about expectations and intentions. Here we detail a pathway of forming these meaningful partnerships to conduct research with communities.

Figure 3: Process of relational development

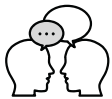


How to develop relationships with communities



1. Community priority identified

The first step of collaborative research is to ask and listen to what the community needs—without assuming you know the answers or solutions. You should be prepared to learn as much as you contribute. Members of a community first identify a need and express interest in forming a partnership to resolve that need. Ideally, the community should reach out to the research partners first, but opportunities for collaboration may be established through meaningful outreach and engagement. For example, researchers can reach out to and build relationships with community champions who can then approach the community to identify needs. Researchers who have specific expertise in a topic or area of research can also ask potential community partners if there is a community interest in their research area and explore ways to collaborate. Networking opportunities can be found by regularly attending events sponsored by Tribal or Indigenous health organizations (e.g., conferences, seminars, and workshops). It can take time to build these meaningful relationships, develop trust, and form a collaboration.



2. Start the conversation early

Start communicating with community members, local champions, partners, and stakeholders early to begin discussing plans. Discuss with your community contacts to determine the appropriate stakeholders and be sure to include Elder groups, senior centers and programs, and caregiver support groups. You should discuss broad goals, funding opportunities, feasibility, community concerns, local priorities and needs, community access and connectivity, and how the mission and values of your organization align with the needs of the community, to name a few topics. Your expectations and intentions should be clear, honest, and sincere. Discuss how a partnership might benefit the participants, community, and society as a whole.

Keep in mind: When engaging in discussions, you should include community voices from all age groups—from youth to Elders—in order to better understand the community and its dynamics.



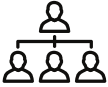
3. Seek appropriate community approvals to support the research and your new partner(s)

Ask about the community approval process, including who you need to be reporting to, and how often. If there is a local research ethics board or committee, find out what you need to do to successfully complete the application. Depending on the specific community and research question, this could be health or social service directors, governance boards or committees, Tribal Council, or some combination of these.



4. Collaboratively establish a governance structure

Discuss how you will all work together and make decisions. Establish contingency plans and communication networks. A research agreement (e.g., Tribal Council Resolution, MOU, and MOA) may be necessary to assist with clarifying roles, responsibilities, reporting structures, and licensing or intellectual property rights.



5. Establish a local community health researcher

In order to equitably involve each side of the partnership in the research process, it is important to ask the community leadership, or the person you will be reporting to, about the process for hiring a local community researcher. The local community researcher (or researchers) will be involved in design, data collection, and interpretation and dissemination of findings. A local community researcher can also provide knowledge of their community and engage with participants who may be distrustful of western research methods. Think outside the academic box when considering who to hire. Place value on local knowledge and lived experience over academic credentials. The community researcher will need to have great organizational skills but equally important is their connection to their community.



6. Work with the community researcher and community partner organization to establish an Advisory Group

Ask the community researcher(s) to identify and suggest members of the community that should be invited to join an Advisory Group. The Advisory Group will be made up of a diverse group of respected community members who will guide the research process. Members may include, but are not limited to youth, Elders, community representatives and leaders, health care staff, formal and informal caregivers and natural helpers, and individuals representing traditional cultural backgrounds and/or language speakers. Members should include a mix of both men and women. Recruit people who can guide the work and ensure Indigenous Ways of Knowing and Knowledge are woven into the project. It may also be desirable to designate a project Elder who can provide guidance on activities and share Indigenous Knowledge outside of the Advisory meeting schedule and agendas. Work with the Advisory Group to determine what model will work best.

Plan to compensate Advisory members and project Elders with an honorarium for their time and expertise, travel expenses, and meals. Advisory members may also wish to travel to conferences and events on behalf of the project.

Keep in mind: Steps 5 and 6 may happen in reverse order depending on community leaders' advice.



7. Collaboratively plan the project and implement the project

Discuss the project goals, methodology, timelines, and dissemination of findings. Monthly meetings may be needed to discuss specific aspects of the project such as development of interview guides, recruitment, data collection and analysis, and reporting findings back to community. Your plans will likely evolve as you communicate with and get feedback from the Advisory Group. Be open to new ideas and feedback.

Keep in Mind: Feedback may include new and unexpected ideas. It is important to actively listen to and ask open-ended questions to allow for a more in-depth conversation. These steps are all a part of the relationship building process and will ultimately add value to the overall project.



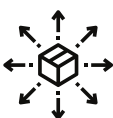
8. Take preliminary findings and any research deliverables back to the Advisory Group for feedback

Present all preliminary findings back to the Advisory Group for feedback and guidance to ensure that local Indigenous Ways of Knowing and Knowledge are included throughout the research. Advisory Group members should be involved in interpreting the results of the research. Data and results should be presented in a way that is accessible to Advisory Group members. When sharing your knowledge be clear about the positive and negative implications of the research findings for the community, Indigenous populations, and society. Be prepared to negotiate and incorporate feedback from the Advisory Group into any additional analysis. You may need to repeat this step a few times as you work with the Advisory Group to develop any reports, manuscripts, or materials that come from the research. The Advisory Group members should have the opportunity to present the research or take an active role in publishing any reports or scientific manuscripts with the research team.



9. Use health literacy best practices for communicating research findings

It is important that any type of dissemination product is vetted through the Advisory Group. The Advisory Group will determine what specific types of dissemination products may need approval from governance. Be sure to share results with all who were involved and/or will benefit from the findings of the research project: participants, community members, Advisory Group members, stakeholders, relevant organizations, and local champions identified by the community, to name a few. Examples of different types of dissemination products may include community newsletters, videos, podcasts, presentations, publications, educational materials, and health promotional materials.



10. Knowledge Translation and Exchange

Work with Advisory Group members and community partners to share findings more broadly, to provide guidance on academic publications and presentations, as well as

the development of interventions. Knowledge Translation and Exchange involves collaborative engagement and mutual learning between the researchers and community partners to produce findings that are relevant and more likely to be used by community partners and the broader research community. Knowledge Exchange may result in the development of additional health promotion materials or additional areas to explore. For more information about Knowledge Translation and Exchange visit: <https://cihr-irsc.gc.ca/e/29418.html>

Remember:

- Relationship building takes time.
- Each community is unique with its own distinct needs and cultural experiences.

Works cited

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Marshall, Murdena, Albert Marshall, and Cheryl Bartlett. "Two-Eyed Seeing in Medicine" in *Determinants of Indigenous Peoples' Health: Beyond the Social*, edited by Margo Greenwood, Sarah de Leeuw, and Nicole M. Lindsay, 44-53. Toronto: Canadian Scholars, 2018.

Martin, Debbie H. "Two-Eyed Seeing: A Framework for Understanding Indigenous and Non-Indigenous Approaches to Indigenous Health Research." *Canadian Journal of Nursing Research Archive* 44, no. 2 (2012): 20-43.

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https://www.ncai.org/resources/ncai_publications/walk-softly-and-listen-carefully-building-research-relationships-with-tribal-communities

Additional resources

Memory Keepers Medical Discovery Team

<https://memorykeepersmdt.com/>

Indigenous Cognition & Aging Awareness Research Exchange (ICAARE)

<https://www.i-caare.ca/>

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