CARHE Guidelines for Research and Project Support*
Center for Advancing Rural Health Equity Endorsement Process
Finalized Statement
September 28, 2024

Introduction

Over the past several years, there have been increasing numbers of initiatives to engage community members and local communities in support of research, clinical improvement efforts, and education. Increasingly, external funding for health services research requires demonstration of community engagement. In addition, health professional students are progressively focused on finding community-based learning projects in their quest to address health disparities and social justice.

The goal of engaging communities in research, education, and clinical redesign is admirable but there are unintended consequences.   Through the flood of multiple requests, we risk burdening our community partners as they evaluate opportunities and negotiate terms of engagement. Engagement requests from researchers and educators are uncoordinated, often forcing the community organization to serve as coordinators. The lack of standard, high-quality engagement practices raise the risk that the community members will have a poor experience, experience harm, and decreased willingness for future engagements. Risks for unintended damages are greater in rural communities where resources are severely constrained.

Over the past two years, multiple researchers have approached the Center for Advancing Rural Health Equity seeking letters of support for research grants.   Co-designed and guided by principles of equity, CARHE is uniquely positioned to support members of the academic and broader community in coming together to work on research or implementation projects. However, CARHE does not have an established process for evaluating requests for support.

In 2024, members of the CARHE leadership council and representatives from research and medical education, came together to develop the process, roles, and expectations for CARHE support. The CARHE Research Support Task Force provides the following guidelines as a "first edition," intending to continuously learn from our experiences to improve this work.

CARHE Research Task Force

The Research Task Force (the Task Force) was established with support from CARHE Leadership Council. Task Force objectives included:

1. Define CARHE expectations of researchers and student groups engaging communities to improve rural health/health equity
2. Define what communities should expect if they are working with a CARHE-endorsed researcher/student group
3. Determine the process for researchers who seek CARHE support

*Throughout this document, the term 'research' refers to a range of activities including traditional research, implementation research, student projects, or clinical—community care redesign initiatives.

Task Force members include:
- Andrew Loehrer
- Terri Lewinson
- Emily Zanleoni
- Angela Zhang
- Anna Tosteson
- Ruth Berggren
- Sally Kraft

Members of the Task Force initially met in March 2024 and again on May 21 and June 17, 2024. Task Force members reviewed and edited this Guideline document.

The importance of this work

The Task Force discussed the importance of creating a high-value process for supporting research. If CARHE provides a letter of support, this is an endorsement of the proposed project or research activity and signals our "seal of approval" to our communities.   CARHE's credibility with our community is our strength; if we break community's trust by supporting researchers or project leaders who do not uphold equity-based practices, we lose CARHE's most important asset.

However, an endorsement from CARHE cannot guarantee a project's outcome. Task Force members acknowledge that endorsement indicates that the researchers credibly plan to uphold equity values and practice high-quality engagement strategies.

Critical to success is transparency. Researchers and project leaders must understand expectations and CARHE "conditions" for support.   CARHE's role is to promote community-engaged work, not to play the role of a 'regulator' or 'enforcer.'   CARHE is accountable for clearly articulating roles and expectations and supporting ongoing learning and engagement skill building.

The Task Force also discussed that CARHE endorsement is not a "one and done." Researchers who are not endorsed initially may re-apply and earn endorsement after adjusting their proposal or working to engage the community to strengthen their approach. This dynamic offers an opportunity for CARHE to provide guiding support, helping the researcher find community partners with whom to collaborate in project co-design.

Overall, CARHE seeks to catalyze, nurture, and expand high-quality partnerships for research, improvement, and implementation projects.   Opportunities to nurture this work include: :

- "Brokering" relationships, helping partners find each other;
- Providing access to community-engagement training and education resources;
- Developing standard guidelines (compensation for community experts, roles and responsibilities templates, practices for sharing power, etc.).

Pre-existing review process
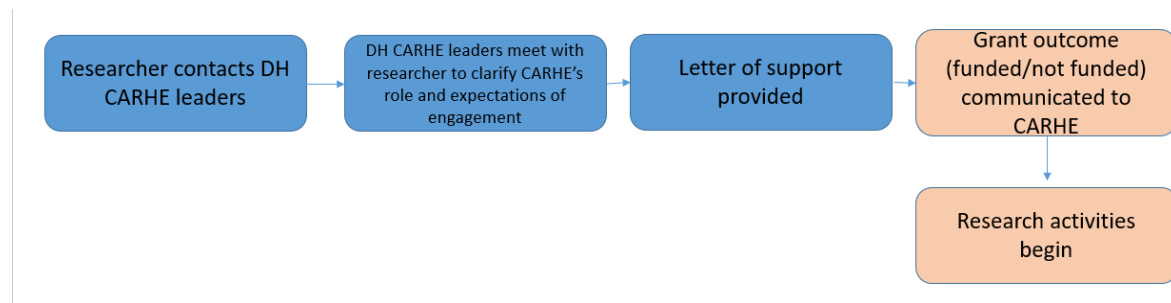
At the time the Task Force met in March 2024, CARHE had received requests for 7 letters of support for research and educational programs. These initial requests were handled on a case-by-case status (above process) and highlighted the need to better define CARHE's approach.

What will CARHE support?

The Task Force recommends supporting proposals that:

1. Are aligned with CARHE mission and vision
2. Seek meaningful engagement
3. Are designed to ensure academic teams collaborate equitably with community partners, learn from the intervention, and share findings in ways that benefit the community
   - An NIH proposal would be expected to have a more robust research design than a student service-learning proposal but both projects should be conducted so that results are informative and relevant to the project.
4. Have an explicit connection between the research proposal and health equity
   - Anticipate variation in methods for demonstrating this connection. For example, an NIH researcher should use an evidence-based conceptual framework to link her intervention to improvement in health equity, while a student-led project may use a generalized, common framework.
5. Engage the community from conception through dissemination
   - The Task Force acknowledged this may not always be feasible. It is required that the researcher transparently identify the level of engagement and partners have a shared understanding of the expectations for that level of engagement.
6. Address a high-priority community-identified concern.

Ideally, all of these criteria would be fulfilled but there may be variation in how robustly the proposal aligns with the criteria.   The Task Force recommended a scoring rubric that ranks the 'level' of CARHE's endorsement, e.g. a 1-3 scale.

CARHE is not resourced to provide technical support for research (statistical analysis, study design, etc.). Proposals requesting only this type of support will not be endorsed.

CARHE expectations of research and project teams

CARHE is accountable for clearly communicating our expectations of researchers and project teams. CARHE cannot be accountable for how activities are conducted. However, researchers and project teams requesting CARHE endorsement will be required to acknowledge a set of CARHE expectations. CARHE will actively support research and community teams seeking knowledge and skill development in engagement practices.

CARHE expectations of the researcher and/or project team include:

1. Collaboration. Commitment to integrate community constituents at the earliest and highest possible level of collaboration throughout the span of the project. Ideally, researchers should have established relationships in the community that would inform the subject of their research proposal and would include community input on all aspects of the project from study design to intervention to data analysis and interpretation to dissemination of findings. CARHE Research Support Task Force members acknowledge that this is not always feasible given the reality of funding opportunities. The following suggestions were made to support deeper collaboration:
   - CARHE will facilitate "building bridges" and create opportunities for researchers and project leaders to connect. Examples include hosting in-person gatherings or asking CARHE staff and leaders to help make connections to existing community networks, serving as "brokers" of future partnerships.
   - Researchers and project leaders should transparently identify the level of collaboration they wish to achieve during the project period. All partners should have a shared understanding of the collaboration's roles and responsibilities.
   - Researchers and project leaders should identify a specific person(s) who serves as a representative of the partner population. While no single individual can represent an entire community, CARHE is seeking evidence that the researcher has a real relationship with the partnering group, not just naming a 'generic' group of persons.
   - CARHE should work with researchers and funders to advocate for greater community input. This may include funding and time for researchers to meet with community members, to build the project team, and to identify the research question collaboratively.
2. Compensation. Community experts working with research/projects teams should be fairly compensated for their time and work.
3. Stewardship. Researchers need to minimize the burden on community partners. This includes practices such as having the researcher travel to the community, using existing community meetings rather than creating separate meetings, and running meetings efficiently.
4. Clarity. Teams need to define clear roles and responsibilities for all partners.
5. Define timelines. Community and research leads have clear, agreed timeline for the project.
6. Transparency. Project results will be shared with the community.
7. Shared power. The academic team should prioritize the community's needs. If, through the course of the project, the research project creates harm to the community (or fails to provide value to the participants), the community members must have "veto" power; researchers need to be willing to "pause" or 'terminate" activities based on community input. Decision- making processes should be transparently defined and agreed upon by both partners.

8. Evaluation. CARHE expects the researcher to establish a method to evaluate the experience of the community partners through the project.
9. Ethics. CARHE should establish the expectation that researchers and student teams have completed an appropriate course of community-engagement ethics training and provide links to vetted resources.

CARHE commitment to community members working with CARHE-endorsed projects

The broader community will benefit from knowing that a researcher or project team has received CARHE endorsement.   An endorsement from CARHE signals the project purpose is aligned with CARHE mission and vision and project leaders understand CARHE expectations. This is not a guarantee that the project will go well.   An endorsement from CARHE acknowledges that the researcher has agreed to use high-quality community engagement practices.

The Task Force spent much time discussing CARHE's accountability to the community. The Task Force grappled with CARHE's role in determining if an endorsed research project caused harm.   CARHE is not a quality assurance agency and cannot monitor the quality of engagements.   CARHE <u>can</u> direct communities to academic resources for assistance e.g. IRB or Geisel faculty and administrative leaders. With ongoing experience, CARHE's governance structure will facilitate iterative learning between researchers, educators, clinicians and community members, identifying areas where additional skill building and better practices can be developed.