

Prioritizing Connection and Centering on Community: Take Your Shoes Off and Don't Put Your Feet on the Furniture

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Abstract

This column describes what it means to be “in” a community and how to create a leading role for community partners in shaping research. It highlights essential components for conducting clinical and translational research in the community, including: (1) invitation to share history and purpose; (2) community-initiated collaboration and engagement; (3) focus on social and cultural determinants of health; (4) community-driven measures and frameworks; (5) application of Indigenous methods and approaches; and (6) implementation of Indigenous and adaptable interventions. Partnering with a community entails building relationships and positioning research around community interests, using methodologies and interventions right for the community.

Keywords

Community, relationships, knowledge sharing, Indigenous, Hawai'i

Acronyms

CAB = Community Advisory Board

IDeA-CTR = Institutional Development Award Networks of Clinical and Translational Research

PIKO = Center for Pacific Innovations, Knowledge, and Opportunities

In 2021, the Center for Pacific Innovation, Knowledge, and Opportunity (PIKO) was established through funding from the Institutional Development Award Networks of Clinical and Translational Research (IDeA-CTR) to encourage the creation and ease the implementation of clinical and translational research that is both culturally responsive and community-engaged to improve the health and well-being of Native Hawaiians, Pacific Islanders, Filipinos, and other underserved communities. The PIKO Community Advisory Board (CAB) ensures that communities can increase their research capacity to address health issues and concerns and are partners in all facets of clinical and translational research, from conceptualization to dissemination. This is possible because CAB members share the same worldview lenses and values as the communities they represent.

Research on underserved populations has demonstrated the influence of social, economic, and political factors in determining health outcomes.¹⁻⁴ Centering community has emerged as a critical strategy to reduce health disparities and build health equity.⁵⁻⁸ This entails community activation and capacity-building to reduce health disparities and build health equity. By

striving for power balance in developing, implementing, and disseminating research, communities have become more vested in participation in research and the sustainability of programs.

Community members understand the complex interplay between cultural, social, environmental, behavioral, and political settings influencing health and well-being experiences and outcomes. Community members should develop a narrative about who belongs to the health research community, how to improve care, and ways to create meaningful healthcare systems. They have lifetimes of history prioritizing relationships and sharing knowledge and experiences regarding health. Community organizations and programs are informed by and honor the peoples they serve.

While numerous articles have been published about ways to work with the community to produce culturally responsive and community-engaged research,⁹⁻¹⁸ this paper highlights vital centering components based on the CAB's experiences. The members of the CAB, have decades of experience in culturally responsive community-engaged research and program development to improve health and well-being in Native Hawaiian, Pacific Islander groups, Filipinos, and other underserved groups in Hawai'i.

Conversations during the CAB meetings suggest that connection is much deeper than trust. It is built on working and learning in ways that honor ancestors, and protect, care for, and sustain communities for generations. The CAB has identified 6 essential components for conducting clinical and translational research in the community: (1) invitation to share history and purpose; (2) community-initiated collaboration and engagement; (3) focus on social and cultural determinants of health; (4) community-driven measures and frameworks; (5) application of Indigenous methods and approaches; and (6) implementation of Indigenous and adaptable interventions.

Invitation to Share History and Purpose

Community includes family, place, support, and identity.⁸ Native Hawaiians, other Pacific Islanders, and Filipinos are distinct social and cultural groups and subgroups with collective ancestral ties to the lands and shared experiences. Their identities,

cultures, livelihoods, and physical and spiritual well-being are linked to their land and lives. Developing meaningful relationships with community partners takes time to learn about the history of the specific community.

The nurturing of relationships aligns with community values. As one CAB member described, “You can’t come to me within 2 weeks, or even 2 months, of the proposal due date and expect me to vet the project with my community and provide a letter of support for the project.”

When a community offers to meet with a researcher, it is an invitation to the researcher to listen and learn—a way to show respect and honor the community. It is like being invited into someone’s home for the first time. “You take your shoes off before entering, and you don’t put your feet on the furniture,” explained another CAB member. Being open to nurturing that relationship and understanding where that community comes from helps to move ideas forward. For a new researcher, entry into the community has nothing to do with research. Researchers start with building a relationship with community members and must show up to support the community. Researchers can be embedded in community organizations and support their efforts. Community-based researchers have much to offer as engaged partners who simultaneously carry out collaborative research.

Community-initiated Collaboration and Engagement

Community collaborators are the bridge and master navigators of cultures and community, providing valuable perspectives on values and life in Hawai‘i. They also use their name to open doors only available to community members. Before sharing any research ideas, the researcher should know whether they share the same values as the community and if there is alignment. There needs to be a commitment, understanding, or alignment between the research and the community organization’s values. “After 20 years of working with a community, I can see now why the first answer I received to working together on a research project was ‘no thank you.’ I didn’t understand the context in which their work was being done,” stated a PIKO CAB member.

It can be challenging to help researchers see some of the community’s social justice or controversies. If researchers live, work, and/or play in a community, the researcher will have something to give back regarding health or services. The research will be grounded in the community and address community concerns and interests in a way that is appropriate for the community. Serving the community provides an opportunity to look through a community lens to see what is needed and what would be beneficial from that research. The community is protected and safe, the community benefits, and there may be new communities that will embrace research. It is about ensuring those who come after any study also have a place.

Social and Cultural Determinants of Health

Social determinants are societal, political, and economic forces that influence the distribution of resources and opportunities that impact the health and well-being of people.²⁰ Social and cultural determinants of health contribute to illness and community inequities, but they also promote resilience, and support the well-being of individuals, families, and communities. Researchers looking to work within a community must know their specific communities’ social and cultural determinants. They need to understand bias and receive training such as the Community 101 Course for Researchers.¹⁹

Hawai‘i is rich with a history of multiculturalism, with unique social and cultural determinants that have created close-knit communities. Common and significant health needs must be addressed based on community input.²¹ Nevertheless, remember that social and cultural determinants will vary in priority by community and may include other important factors based upon each communities’ needs.^{21,22} Hawaii’s long and challenging political history that discouraged Indigenous cultural norms of language and beliefs lends to current cultural determinants. Communities are often centered on Indigenous definitions of health and preservation of cultural traditions, practices, and places. By acknowledging and understanding social and cultural determinants, research relevant to these determinants can be conducted to benefit community health.

Community-driven Measures and Frameworks

Applying Indigenous frameworks and developing community-driven measures requires understanding the Indigenous worldview. Commonalities among Native Hawaiians, Pacific Islander groups, and Filipinos include a holistic view of well-being encompassing the individual, family, community, and place. This shared view emerged over generation upon generation of experiences and existence. It typically includes interconnected relationships to land, spirituality, family, and community. As shared by community members, “‘*āina* (land) is the land, the ocean, the sea, all the elements, plants, people, and their interconnection.”²³ Among existing frameworks,^{21,24-26} Kōkua Kalihi Valley uses the *Pilinahā* framework^{14,25} to shape and establish relationships aligned with their values, including connection to self, others, and land. Given these frameworks, it is unsurprising that a recent review article on the Indigenous context of research found that the most commonly utilized cultural-based measures sought to assess cultural identity, social connectedness, and spirituality.²⁶

Other measures are needed to capture the essence of interventions and their impact using such frameworks and the core elements of well-being. “From a community perspective, we have experts. I want to create jobs and learning opportunities so that we can apply Hawaiian prevention and traditional prac-

tices. Our organization knows how to collect meaningful data, and we know how to use data to justify our programming and evaluation. It is from this space that we can connect people to academic or research opportunities,” shared a CAB member. Some research may need to be put on hold until measures can be developed because the study might not capture the impact of the intervention, and findings could be misleading or detrimental.

Application of Indigenous Methods and Approaches

Native Hawaiian, Pacific Islander groups, and Filipinos’ world-views can voice place-based ways of knowing and learning through stories, ancestral wisdom, and metaphors. As quoted in Oliveira and Wright, Indigenous methods and approaches are “research by and for Indigenous Peoples, using techniques and methods drawing from the traditions and knowledges of those people.”²⁷ Often thought of as “talk-story” approaches, Indigenous approaches are much deeper and more varied to include, but are not limited to, stories, narratives, histories, images, and symbols woven to create understanding through a process often referred to as a journey.^{27,28}

The research design should reflect community needs, protocols, and acceptable approaches. Protocols will vary from community to community. Protocols outline who can receive the knowledge, how long data collection will take, and how learning will be shared. There are some things a researcher should not do, and there are ways a researcher should behave. A CAB member conveyed, “As gatekeepers, we have to be really aware of impact, because when *kūpuna* (elders) get involved, and they have a challenge or an issue, they let us know.” Access to community is a gift of high value for advancing meaningful research and respecting that and lifting that is valued by communities. Moreover, research can empower communities if it reflects an understanding of community strengths and challenges—wherever they are—and brings that lens forward.

Implementation of Indigenous and Adaptable Interventions

Culturally responsive interventions are aligned with cultural values, perspectives, and lifestyles²⁹ and lay on a spectrum from culturally adapted to culturally grounded programs.³⁰ Culturally-adapted interventions seek to modify programs shown to be effective in other groups for local application. Culturally-grounded interventions look beyond Western preventive measures and treatment to embrace different forms of healing, whether traditional, integrated, or developed by a community group from the ground up to design other forms of healing reflecting community interest. A CAB member described, “One of the things that came up for us was the no-

tion of looking beyond Western preventive measures, Western treatment, and embracing other forms of healing, whether that’s traditional or complementary, and including that as part of the research proposals... We acknowledge that both exist and that it’s OK to do both in a collaborative fashion. We are willing to work with another community with cultural practitioners that wants to do something similar... As researchers, think about how each community is different, and each has its traditional healers.” The integrity of the intervention, environment safety, and relationships are critical factors for practitioners’ willingness to participate.

Conclusion

The CAB recognizes that Native Hawaiian, Pacific Islander, and Filipino community members value relationships and knowledge-sharing among community members and with others that engage them. This column explored 6 essential components for conducting clinical and translational research in the community: (1) invitation to share history and purpose; (2) community-initiated collaboration and engagement; (3) focus on social and cultural determinants of health; (4) community-driven measures and frameworks; (5) application of Indigenous methods and approaches; and (6) implementation of Indigenous and adaptable interventions. By developing strategies that involve both the community and researchers, there are clear opportunities to establish, maintain and enhance relationships between both, thus improving outcomes and long-term success.

Conflict of Interest

None of the authors identify a conflict of interest.

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