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Holding Space for All of Us

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Abstract

Negative experiences and misunderstanding are common in tribal-academic research partnerships. The Holding Space: A Guide for Partners in Tribal Research draws on the concepts of *governance*, *trust*, and *culture* to strengthen relationships, honor tribal sovereignty, counter histories of opportunistic research, and recognize all ways of knowing. We apply the Holding Space toolkit concepts to the All of Us Research Program and call on all research studies funded by the federal government to honor governance, trust, and culture in research partnerships with tribal nations.

Need for Tribal-Academic Partnerships

While social and health research has addressed some health challenges in American Indian and Alaska Native (AI/AN) communities,^{1,2} health disparities persist³ and are not easily resolved.^{2,4} For example, diabetes prevention and control require strategy implementation at the individual, family, and community level.⁵ Additionally, many AI/ANs and tribal nations have long-standing mistrust of research and research policies shaped by interactions with opportunistic academic researchers doing federally funded work without tribal input or benefit sharing.^{4,6,7}

Participatory or **community-engaged research** is one approach to reducing mistrust and ensuring tribal communities' equal partnership in research.^{8,9} Strong **tribal-academic research partnerships** that adhere to principles of participatory research can play a key role in developing the multilevel and contextualized solutions required to achieve health equity for AI/ANs.^{9,10} The National Institutes of Health (NIH) and Patient-Centered Outcomes Research Institute acknowledge the scientific value of inclusive, partnered research,^{11,12} and the Common Rule requires federally funded researchers to comply with state, local, and tribal laws.¹³ However, theory-practice gaps—manifest in discounting tribal sovereignty, paying little attention to cultural protocols, or minimizing community concerns raised by research—can cause or reintroduce mistrust and exacerbate disparities. For example, one recent research incident with the Havasupai Tribe demonstrates the need for meaningful tribal-academic partnerships in genetics research.¹⁴

Researchers and federal agencies interested in partnering with tribal nations often lack not only knowledge of tribal sovereignty and tribal nations' past negative experiences with research but also skills for building successful research partnerships.^{8,10,14} To respond to these knowledge and skill gaps, the National Congress of American Indians (NCAI) and the University of Nevada, Reno developed the Holding Space: A Guide for Partners in Tribal Research¹⁵ (Holding Space toolkit) to provide education to tribal and academic research partners on the importance of applying the concepts of governance, trust, and culture in their research partnerships.⁹ This article examines how these Holding Space toolkit concepts can be applied to the NIH All of Us Research Program's tribal outreach efforts and data collection plans.

NIH All of Us Research Program

The NIH All of Us Research Program was developed as part of the Precision Medicine Initiative announced by President Obama in 2015.¹⁶ Its aims are to enroll a large number of participants reflective of the diverse US adult population, collect biospecimens (ie, blood, saliva) and health data (ie, from a survey, medical records, physical measurements, and digital tracking), deidentify individual responses and publicly share the data (via cloud-based storage), and enable research on health conditions and development of targeted therapies. NIH funding, released in 2016, enabled creation of the All of Us recruitment network, which, in 2018, began enrolling participants who are diverse in terms of race, ethnicity, age, sex, ability, and health conditions.¹⁶ However, active recruitment of AI/ANs is currently on hold pending meaningful consultation and partnership with tribal nations. Tribal nations have expressed significant concerns about initial plans for the NIH All of Us Research Program's planned research and data sharing activities. These initial concerns include lack of tribal consultation prior to program initiation, questions about how AI/AN participants' data (including their tribal affiliation information) will be shared and used, and lack of information about tribal roles in research review and partnership.^{17,18} The main concepts from the Holding Space toolkit could help address these concerns and questions.

Holding Space Concepts

Governance. The NIH All of Us Research Program appeared to have misunderstood requirements to consult with tribal nations. In 2017, it formed a Tribal Collaboration Working Group and described the group's formation as one of its "engagement activities."¹⁹ But tribal consultation is not community engagement. Tribal consultation must be treated formally, according to established federal-tribal policies. Tribal sovereignty must be understood and respected during any partnership with tribal nations, which are responsible for stewarding tribal resources and promoting well-being among tribal members, citizens, and lands. Many tribal laws govern human subjects research beyond federal institutional review board (IRB) **requirements for human subjects research**. Tribal nations have a right to government-to-government relationships with the federal government and may invoke their own processes of research review and apply their own guiding principles to making decisions about initiatives that affect them.^{20,21} For 2 years, important partnership decisions, meaningful recruitment activities, and opportunities for AI/ANs were postponed until the NIH initiated a formal tribal consultation on the All of Us Research Program in 2019 after considerable input from tribal nations and advocates.^{17,19} Some outstanding concerns remain, particularly about data access, ownership, and the rights of tribal nations. The tribal consultation process is ongoing.

Trust. Trust is foundational to partnership success. Given the federal trust responsibility to provide health services in exchange for lands that were taken, tribal-federal partnerships are more likely to be successful when based on functional trust, or trust characterized by agreed-upon and clearly articulated roles and responsibilities.^{9,22} Despite efforts to build functional trust, mistrust or suspicion can still be present. Although tribal nations understand precision health's benefits for individuals, due to a history of negative experiences with and suspicion of population research, tribal nations see citizen protection as a primary function.⁶ AI/AN inclusion in the All of Us Research Program—a population research program—requires tribal belief that the research's potential benefits outweigh its potential harms.⁷

In 2015, the All of Us Research Program conducted a survey to gauge attitudes toward and potential concerns about precision medicine research and to measure support for such a study.²³ Unfortunately, the published report did not include AI/AN responses. It is not clear whether AI/AN individuals did not participate or if their responses were combined with those of other groups, a common practice. What is known, however, is that distrust and conflict between tribal nations and the federal government persisted for 2 years until the All of Us Research Program heard the calls for tribal consultation and initiated it in 2019.²⁴ A lesson from the Holding Space toolkit is that developing meaningful partnerships in order to conduct investigations that are useful for all stakeholders requires that researchers work with tribes early in the research process and recognize the types of trust and strategies that can help reduce conflict.

Culture. Human subjects research is not culturally neutral and neither are its topics, questions, and processes.^{9,15,25} Both research institutions and tribal nations have their own cultures and traditions, which sometimes result in unnecessary struggle over whose culture will prevail. For example, ethical and regulatory guidelines applied by IRBs tend to focus on reducing an *individual* subject's risk of harm. For tribal nations, however, risk is assessed most often in terms of *community* impact, and individualistic ethical frameworks might inadvertently exacerbate community risk.²⁶ This difference between tribal communities' and academic researchers' assessment of risk can cause delays in the research process. For example, focus on speed and efficiency is yet another value in individualistic ethical frameworks. By contrast, in community-based approaches, time is regarded more as a requirement for careful, deliberate tribal stewardship. The Holding Space toolkit promotes cultural humility as a virtue and value in weighing potential benefits against risks of harm. Understanding the differing cultures present in tribal-academic research partnerships can lead to a better path forward for the research.

Conclusion

The Holding Space toolkit concepts^{9,15} can be applied to strengthen tribal-federal research partnerships, including those needed to fund and support meaningful consultation and common research goals for the All of Us Research Program. Consulting with tribal nations and understanding the critical role of tribal governance, trust, and culture in research can facilitate improved individual and community health outcomes. We all have much to contribute, and we all have much to learn and gain by holding space for each other.

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