# Building Capacity for Productive Indigenous Community–University Partnerships

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# Building Capacity for Productive Indigenous Community-University Partnerships

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## Abstract

This paper describes capacity development as a key aspect of community-based research with indigenous communities. University research engagement with indigenous communities includes extensive, and often negative, historical antecedents. We discuss strategies for developing effective, egalitarian, and balanced indigenous community-university relationships to build research capacity of these communities, and to create sustainable partnerships to improve health and wellness, and to reduce health disparities. We draw on the experience of eight investigators conducting research with indigenous communities to assess effective strategies for building and enhancing partnerships, including (1) supporting indigenous investigator development; (2) developing university policies and practices sensitive and responsive to Indigenous community settings and resources, and training for research; (3) developing community and scientifically acceptable research designs and practices; (4) aligning indigenous community and university review boards to enhance community as well as individual protection (e.g., new human subjects training for Indigenous research, joint research oversight, adaptation of shorter consent forms, appropriate incentives, etc.); (5) determining appropriate forms of dissemination (i.e., Indian Health Services provider presentation, community reports, digital stories, etc.); (6) best practices for sharing credit; and (7) reducing systematic discrimination in promotion and tenure of indigenous investigators and allies working in indigenous communities.

**Keywords** Research capacity · Indigenous · Tribal-academic partnerships · Collaboration

## Introduction

The history of universities' lack of engagement with indigenous communities is complex and includes frequent examples of negative and/or exploitative interactions that have had long-lasting effects, often still remembered when the term "research" is voiced in tribal council meetings and/or community events. Much of the work done by university researchers in indigenous communities has been viewed as extractive (primarily conducted by non-Native researchers with little or no feedback from community members), leading to a mistrust of research, research of limited or no benefit to indigenous communities, and even adverse effects (e.g., stigmatization) in some cases (Kelley et al. 2013; Satter et al. 2014).

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Past work has documented a series of important challenges for partnering university researchers with indigenous communities (Solomon and Randall 2014). These include geographic and logistic barriers, lack of understanding and familiarity of researchers and their institutions with indigenous culture and systems of organization and governance, lack of willingness of academic institutions to accommodate indigenous communities, and lack of understanding and familiarity of indigenous communities with university researchers' requirements and systems of organization.

Working with indigenous community partners takes time and frequently requires rural, in many cases, remote travel (Belone et al. 2016, 2017). Weather conditions can impede travel and internet communications may be unreliable or nonexistent (Jernigan et al. 2012). Lodging and meal options may be far from local study communities. These conditions present challenges to undertaking research in collaboration with Indigenous communities in a manner that permits frequent and ongoing engagement in every stage of research design, implementation, and dissemination.

Universities frequently rely on researchers to independently establish and maintain relationships with indigenous communities, with little guidance, oversight (e.g., value alignment), or support. Work with indigenous communities requires interaction with and understanding of different world views, different cultures and languages, diverse skill levels, priorities, and differing indigenous community infrastructures (including governing and social), including having to work with multiple Institutional Review Boards and multiple levels of indigenous community governing bodies. The latter may require the production of community documents and reports, as well as approval for any research publications or presentations at conferences (Belone et al. 2017; Jernigan et al. 2014). These differences in understanding create a substantial learning curve for researchers new to working with indigenous communities.

Researcher priorities (e.g., exploring hypotheses focused on the individual and not the community) can conflict with Indigenous communities' priorities and urgent need for assistance (e.g., need for direct care). Universities may lack the resources, awareness, or the willingness to be responsive to indigenous communities' needs and forms of engagement (e.g., differing types of contracts, billing and financial requirements, and forms of incentives permissible), which have often been barriers to research implementation. A related challenge is that universities do not permit indigenous community and other indigenous community entities to function as full partners in the research process.

Indigenous communities and entities within those communities frequently have specific research needs, such as expertise in program evaluation, statistical analysis, and report/grant writing. Indigenous communities' need for programmatic funding is based on the fact that staff usually cannot be covered full-time under one grant but must work on several different grants (research/non-research) to stay employed full-time within their community. Conversely, Indigenous communities frequently have limited understanding of the constraints placed on researchers based in academic institutions relating to research approvals, promotion and tenure, difficulties in obtaining sustained grant funding over many years, and the specific requirements for such research funding (e.g., specific data collection requirements or publication milestones).

In recent decades, indigenous community-university research partnerships have improved somewhat, due to a number of initiatives that have attempted to address the history of missteps, misunderstanding, and mistrust that have characterized many relationships between university researchers and indigenous communities in the past. A leading and early example is the Native American Research Centers for Health (NARCH) program, which has been in operation since 2000. This program, a partnership between the National Institutes of Health (NIH) and the Indian Health Service (IHS), provides funding to Native American tribes or tribally based organizations and their academic partners to (a) engage in competitive research of relevance to the indigenous community, (b) increase the collaborative research capacity and partnerships of the indigenous and academic organizations in reducing distrust, and (c) develop the health (including behavioral and mental health) research careers (and to provide a pipeline into these careers) of indigenous individuals. The NARCH program has successfully funded research opportunities, supported scholarly networks, funded graduate, doctoral and postdoctoral research training, and supported faculty development for Indigenous researchers, creating a new generation of indigenous scholars (Belone et al. 2018).

In addition, a variety of relatively recent publications have provided detailed guidance for university-based researchers about conducting health research in respectful partnership with Indigenous communities, in ways that benefit these communities and the health of their members (Belone et al. 2016, 2017; Simonds and Christopher 2013; Jernigan et al. 2015a, b; NCAI 2016; Thomas et al. 2011). These publications, as well as the additional resources suggested within them, provide a much-needed roadmap for researchers interested in working effectively with Indigenous communities. As well, there are excellent roadmaps for participatory research with indigenous populations internationally (e.g., First Nations, Maori, and Aboriginal populations) as well as a copious literature on community-based participatory research (CBPR) (Belone et al. 2017; Cochran et al. 2008 Blackshear et al. 2016) discussed in detail in other papers in this special issue.

At the same time, many indigenous communities have enhanced their role in partnerships with universities through the development of their own research review boards, as well as engaging community members and leaders in identifying the most significant health issues in their communities. These

efforts, which have been attributed in part to efforts such as the NARCH initiative, as well as the growing demand for CBPR as an alternative to traditional research, provide guidance for evaluating the significance and feasibility of research proposed by academics. Additionally, they ensure the ethical conduct of research, the protection of individual members of the community, and of the community as a whole. Successful efforts to develop the research careers of Indigenous scientists (Manson et al. 2006) so that they are competitive for NIH research funding have also enhanced research capacity within Indigenous communities, as well as community-university partnerships.

Despite these advances, and the potential benefits, publications that systemically describe strategies for enhancing research relationships between academic and Indigenous partners remain scarce. One challenge has been that many universities provide little guidance or training for working in indigenous communities, leaving it up to the researchers to forge relationships themselves and learn or share experiences. In other words, institutionally supported policies or initiatives within universities providing learning opportunities for researchers new to working with indigenous communities are rare. It is also true that some university/funding agency requirements (e.g. Collaborative Institutional Training Initiative (CITI) requirements, ownership and sharing of data, passive approval in terms of manuscripts) can sometimes directly contradict indigenous community research requirements (Jernigan et al. 2015a, b). Many of these communities have data ownership requirements that include the return to the community of all data following completion of research and writing of publications, or provision of proof that the data have been destroyed. These requirements can contradict data-sharing arrangements preferred by funders. In addition, manuscript approval processes, if in place, can take considerable time, leading funders to add passive approval clauses as part of the funding agreements (i.e., if approval is not given in a fixed time, approval is assumed). These requirements, which are intended to facilitate the translation of scientific knowledge into practice, may inadvertently increase the possibility of harmful effects, such as the publication of stigmatizing findings that can cause harm to individuals and communities.

The Intervention Research to Improve Native American Health (IRINAH) network of investigators emerged as a result of an NIH funding opportunity (initially released as PAR-11-346 and reissued as PAR-14-260) that actively encouraged the development of a community of scientists to expand the knowledge base regarding intervention science with Indigenous populations as well as to share instruments, strategies, and resources (Crump et al. 2017). To support the building of this community, NIH program officers provided administrative support to assist in organizing monthly phone conferences, disseminating meeting minutes, and coordinating annual meetings. The first year's collaborative calls and in-person meeting resulted in an editorial, co-authored by the majority of the study PIs as well as several community partners, that advocated moving away from a deficits-focused approach, to one that focuses on fostering wellness. The editorial culminated in a series of recommendations to advance the field of intervention science in moving beyond health equity to wellness. It was also an initial indication of how IRINAH network partners could collaborate to leverage greater attention for indigenous health issues nationally (Jernigan et al. 2015a, b).

This effort led to deeper collaborations, the development of working groups based on specific subsets of interest, including the topic of this manuscript, as well as other working groups (e.g., indigenous methodologies, cultural adaptations of evidence-based interventions, policy work within Indigenous communities, etc.). The various ways in which the IRINAH network can be leveraged to use research for action and social change, the purpose of CBPR, continues to evolve. However, key priorities remain the development of an evidence base for intervention science in indigenous communities that considers indigenous methodologies, addresses the social determinants of health, and includes effective interventions at multiple levels so that Indigenous communities may also receive maximum benefit from the NIH's significant investment in health research. This paper presents selected case studies of experienced university researchers, some of whom are indigenous themselves, working in indigenous communities, and seeks to identify lessons learned by, and key strategies employed by IRINAH researchers to address challenges for building strong indigenous community-university health research partnerships.

## Methods

The methodology used for this paper includes both a review of the literature regarding the experiences and lessons learned by partnering university researchers and Indigenous communities, and the direct experiences of selected IRINAH investigators, all of whom are coauthors of this paper. The eight coauthors self-selected to participate in this paper, and share their experiences based on their interest in and experience with the topic. Collectively, the eight authors have worked in indigenous communities for a total of 134 years and have worked with 117 communities, which includes sovereign tribal nations as well as indigenous communities in rural and urban areas, with some likely overlap. Of the eight authors, five are indigenous, though not only working with their own indigenous communities (Supplemental Table 1). Their viewpoints

are not intended to represent the entire IRINAH network of investigators.

Based on the comprehensive literature review and a series of in-person as well as online discussions among all of the co-authors, the lead author drafted a series of questions intended to elicit strategies employed by IRINAH projects to address the key challenges we have discussed. The lead author then shared the questions, via e-mail, with each investigator for their specific detailed responses in regard to their specific IRINAH study, and also more generally in relation to their past work with Indigenous communities:

- How are you supporting indigenous investigators in your current IRINAH project? How have you done so in past projects?
- What policies or practices exist at your university that are sensitive to Indigenous community settings (including resources, training)?
- What strategies have you used to develop research designs that are acceptable from both scientific and Indigenous community perspectives?
- In what ways are university and tribal (e.g., IHS) review boards aligned? How have your projects assisted in improving these relationships?
- What forms of collaborative dissemination have you set up, agreed upon for your current IRINAH project? For past projects?
- How are Indigenous (and non-Indigenous researchers working in Indigenous communities) supported in terms of the university promotional process?
- What remaining issues (gaps) need to be addressed?

Questions asked IRINAH investigators to draw upon their extensive experience working with indigenous communities, inclusive of, but extending beyond their specific IRINAH project. For each question, IRINAH coauthors provided a text response, ranging from a few sentences to several paragraphs. The lead author initially reviewed the qualitative responses to each of the above queries made by the eight coauthors and identified important themes and subthemes. These themes and examples were reviewed and refined by coauthors, a form of member checking. The findings presented represent a combination of empirical results from the six ongoing case studies, and the experience base of each of the coauthors, in response to the questions.

## Results

Findings are presented as a series of key strategies/lessons learned for addressing the challenges, identified earlier in this paper, that are drawn from the experiences of the IRINAH investigators.

### Build University Capacity to Work with Indigenous Communities by Identifying Key Competencies Needed, and Offer Formal Trainings/Courses

Most academic institutions lack formal or informal training programs to prepare researchers to work with indigenous communities. In part, this is due to lack of knowledge about desired competencies necessary for researchers to actively and productively collaborate with indigenous communities in a manner that is mutually beneficial, i.e., that will both advance knowledge and address urgent health problems and inequities. Some desired competencies that facilitate and nurture research with indigenous communities include: familiarity with relevant aspects of history, culture, economics, and forms of tribal government (knowledge of processes required in gaining approval at various levels within a Indigenous community infrastructure); identifying appropriate approaches to community engagement and community capacity building; developing and providing training to indigenous partners; planning multiple forms of research dissemination; strategies for co-learning; and building equal partnerships.

Institutions promoting research with Indigenous communities have developed and require short courses and trainings that offer researchers contextual and conceptual knowledge and skills to conduct collaborative research. Many universities have developed their own internal capacity to work in Indigenous communities. Frequently, this is accomplished by establishing a university-based center. Examples include the Center for American Indian Health (Johns Hopkins), Center for Indigenous Health and Center for Participatory Research (University of New Mexico), the Indigenous Wellness Research Institute (University of Washington), Partnerships for Native Health (Washington State University), and the Centers for American Indian and Alaska Native Health (University of Colorado). These centers serve vital functions for connecting university researchers with communities, and often share many common characteristics, such as having a board that consists of mainly Indigenous representatives, emphasizing the hiring and training of community members, establishing sub-contracts with indigenous communities, pushing for the creation of university policies on research with indigenous communities, identifying community PIs or co-PIs, and development of local community research teams (Belone et al. 2017). Many of these centers invest in the professional and scientific development of indigenous PIs.

Several current IRINAH Indigenous investigators have been, or are currently involved, as either mentees or mentors, in programs designed to promote career development of Indigenous scientists. These include the Native Investigator Development Program through the Native Elder Research Center (Washington State University and University of Colorado Anschutz Medical Campus), the Indigenous HIV

AIDS Research Training Program (University of Washington), or the Native Children's Research Exchange Scholars Program (University of Colorado Anschutz Medical Campus). In addition, the Obesity Prevention Research and Evaluation in Native North American communities 2 (OPREVENT2) trial (PI: Gittelsohn) collaborates closely with the Johns Hopkins Center for American Indian Health in training and support of Indigenous doctoral students.

Capacity-building strategies can also be effective without the support of a research center. For example, other approaches include the development of specific courses and academic programs for working with Indigenous communities, including the Masters of Public Health (MPH) degree in American Indian Health, offered at North Dakota State University; courses in Native Hawaiian Health, offered through the University of Hawaii School of Medicine; and online MPH programs for Indigenous community members or tribal college employees at the University of Montana.

As part of the Tribal Health and Resilience in Vulnerable Environments (THRIVE) study (PI: Jernigan), the Institutional Review Boards (IRBs) of the partnering tribal nations formalized an "orientation to research" process for all future tribal-university collaborations based upon the CBPR process utilized as part of the THRIVE study partnership. Specifically, members of the tribal IRBs of both nations worked with the PI to document the CBPR processes employed as part of the study. The process began at the very beginning of the partnership, prior to funding, when the team was conceptualizing the research questions, and continues through publishing research findings and disseminating findings to communities.

## Build Indigenous Community Capacity to Work with Universities, and to Conduct Their Own Research

Workforce diversity is crucial to addressing health disparities and promoting health equity. Unfortunately, there are major inequities in the participation of Indigenous students in science and health careers (Lane-Fall et al. 2017). For example, indigenous students are more likely to enroll in public or tribal 2-year colleges, which offer limited opportunities for science degrees. According to the NIH Working Group on Diversity in the Biomedical Research Workforce, indigenous students are far more likely to exit the multi-stage educational pathway (from kindergarten to professorship) that prepares individuals for a research career than other ethnic groups in the United States.

Training indigenous community members in research can take many different forms, including direct training of tribal college students and faculty, community leadership and liaison funding, and/or partnering on publications or presentations with indigenous partners. The NIH diversity training programs such as Continuing Umbrella of Research Experiences (CURE), Mentored Career Development Awards (K01, K08, K23), and Individual Predoctoral (F31) and Postdoctoral (F32) Fellowship award mechanisms offer research training opportunities for indigenous researchers at various educational stages. Many IRINAH investigators have directly incorporated research career development for indigenous investigators into their studies. For example, OPREVENT2 (Gittelsohn) and THRIVE (Jernigan) directly support the dissertation research of Indigenous doctoral students.

A concern is whether these efforts actually lead to community capacity development, if the indigenous investigators and doctoral students are not based in the community. An exception to this is the Thiwáhe Gluwáš'akapi (PI: Whitesell), which funded an American Indian junior faculty member in residence in her home community. To that end, an area of focus that has been raised by tribal and academic partners from the IRINAH studies funded in Oklahoma, including THRIVE (PI: Jernigan), FRESH (PI: Jernigan), and the Dietary Grant to Prevent Hypertension (PIs: Buchwald/Jernigan) is identifying ways to support the scientific careers of the next generation of indigenous investigators.

Is it realistic to think that Indigenous communities will be competitive for research dollars in terms of their scientific research environments and resources when competing with university environments and their resources? Indigenous investigators who earn doctoral degrees and wish to remain in their own communities to conduct research could undermine their futures to be competitive in receiving research funding if they do not take university faculty positions.

Tribal Colleges and Universities (TCUs), born out of the Tribal College Movement for self-determination, are unique institutions of higher education chartered by their respective tribal governments. More than 75 TCUs operate in 17 states, covering almost all of Indian Country. Generally, they serve American Indian and Alaska Native (AIAN) students on geographically isolated reservations and other areas from more than 230 federally recognized Indian tribes. Recently, the American Indian Higher Education Consortium (AIHEC), representing 36 TCUs, has been successful in obtaining NARCH grants to develop behavioral health research capacity of TCU faculty and staff.

## Employ Formative Research Strategies to Incorporate Indigenous Community Perspectives

Formative research is a proven information gathering strategy that aims to understand community values and perspectives for the purpose of developing culturally acceptable intervention programs (Gittelsohn et al. 1999). Formative research usually combines qualitative and quantitative approaches, conducted in a series of stages, with increasing refinement and focus in later stages (Gittelsohn et al. 2006). A key goal

of formative research is to identify core cultural values that resonate with community members and select appropriate media for communicating those values in a manner that promotes project goals. For example, the OPREVENT2 IRINAH project (PI: Gittelsohn) conducted in-depth interviews with community leaders to assess how decisions are made, as a means of figuring out the best ways to support tribal policymakers, and to develop and refine intervention approaches (Gittelsohn et al. 2017). As part of the THRIVE study (PI: Jernigan), formative research efforts included the incorporation of a health impact assessment and a cost-benefit analysis—evidence-based policy formulation tools that key stakeholders, including tribal commerce and government leaders, stated were essential to them in considering scale-up and implementation. Other IRINAH projects have conducted formative research for program planning, including focus groups and in-depth interviews as methods to design the study, develop intervention materials and strategies and evaluation instruments (EldersAIR, PI: Belcourt; MIWÉ project, MPIs: Booth-LaForce, Buchwald, Oxford; Enhancing Prevention Pathways Toward Tribal Colorectal Health, MPIs: Mishra and English; TCU Be Well BASICS, PI: Duran).

## Utilize Indigenous Research Methods to Build Indigenous Community Engagement

Indigenous research methodologies have been successfully used to enhance community engagement and research quality in indigenous communities. This includes the use of talking circles or community workshops to engage groups of community members and decision-makers. Talking circles are a traditional indigenous method of information sharing and decision making used by a group to discuss a topic in an egalitarian and non-confrontational manner (Fleischhacker et al. 2011; Brandenburger et al. 2016). All participants are empowered to express their point of view through very clearly understood and enacted turn-taking. Creating space for frank sharing of concerns and ideas with investigators and community leadership has been used by multiple IRINAH studies, including THRIVE, Creating Campus Change, MIWÉ, TCU-BeWell BASICS, Enhancing Prevention Pathways Toward Tribal Colorectal Health, and OPREVENT2.

The use of community workshops is a more recent approach and may be considered a variation on talking circles (Gittelsohn et al. 2010). In community workshops, heterogeneous groups of community members, leaders, and other key stakeholders participate in a day-long (or even longer) workshop which uses a series of brainstorming and prioritization exercises to identify the focus of the intervention. The specific foci can include identifying foods or physical activity behaviors for promotion, wording of messages, selection of appropriate communication channels, and determining appropriate incentives. Both talking circles and community workshops are used for community co-development/creation of prevention programs, and co-adaptation of data collection instruments. For example, the IRINAH OPREVENT2 trial conducted a series of workshops with community members, tribal leaders, and school staff in three indigenous communities to determine best strategies and materials for reducing obesity in adults. Two-day-long workshops were aimed at generating revisions/modifications of materials used in other indigenous communities, as well as developing new materials and approaches. The materials are being used as part of a multicomponent intervention in schools, worksites, food stores and via community/social media. The TCU-BeWell BASICS university team brought together more than 15 TCU staff from seven participating TCUs in Seattle to adapt the intervention materials and implementation processes appropriate to tribal college settings and resources.

As part of efforts to refine healthy retail strategies for implementation in the THRIVE study, community members participated in focus groups in which they were shown various healthy eating promotional materials, including signage with various messages in their Indigenous language and English. As well, they were offered samples of healthy foods. They were surveyed using interactive audience response systems allowing them to respond to different scenarios in real time, such as purchasing specific healthier options compared with less healthy options, in response to different store placements, price, and promotion options. This approach allowed community members and researchers to identify not only what would sell but also the "tipping point" whereby community members would choose a healthier item based on taste, quality, price, and promotional messaging.

## Establish Community Advisory Boards Comprised Fully or Mostly of Indigenous Peoples

University engagement with indigenous communities can take diverse forms, with shared leadership and planning as foundational aspects. Many researchers seek to establish community advisory boards early in the research process. These boards ideally have community representation from a cross section of key stakeholders with expertise in a variety of essential domains related to the research project. Ideally, these groups should be convened prior to the drafting of a grant application to ensure that the research priorities and questions align with the local needs, methods, and requirements of both tribal review and the objectives of the funding mechanism.

Some research projects implement boards or steering committees that adopt voting procedures to ensure that consensus decisions are made. This approach was used in the Tribal Colorectal Health IRINAH study (MPIs: Mishra and English). The EldersAIR project used a Community Advisory Board to review the data collection methods, instruments, and to develop culturally appropriate intervention

methods. Contact between the research team and the community advisory board can help ensure that new research applications are informed by local needs, and include sub awards whenever possible made directly to the indigenous community to support research activities in the community.

A variation of this approach is being used as part of the OPREVENT2 trial, where Community Advisory Committees are being created to determine the best ways to sustain OPREVENT2 community activities and to formulate new policies at the tribal and institutional levels (Gittelsohn et al. 2017). Similar approaches have been used for other large trials in Indigenous communities (Jernigan et al. 2017; Lee et al. 1990). The TCU-BeWell BASICS project convenes its annual Community and Scientific Advisory Board meetings, comprised of both TCU Presidents and University researchers.

## Transition from Community Advisory Boards to Indigenous Research Teams (IRTs)

Some researchers have naturally transitioned from decision-making community advisory boards to IRTs to honor Indigenous community partners' shared status as co-researchers in a truly collaborative partnership. In these cases, the IRT has worked with the university team for over a decade in the culturally centered co-creation, piloting, and implementation of prevention program(s) in their own tribal communities (Belone et al. 2017), with the next research steps to be tribally driven, culturally centered dissemination. The Centers for American Indian and Alaska Native Health at the University of Colorado Anschutz Medical Campus has funded field offices in three different reservation communities; one of these has been in continuous operation for more than 25 years. Field offices such as these hire and train local research staff and provide the foundation for sustained community-based research. The IRINAH Thiwáhe Gluwáš'akapi project (PI: Whitesell) emerged from and is being conducted out of one of these field offices, with intervention implementation and data collection led by local research staff. As well, the IRINAH MIWÉ project (PIs: Booth-LaForce, Buchwald, Oxford) to strengthen child attachment in an indigenous community trains and employs local research staff to deliver the intervention and collect research data, which holds promise for program sustainability. Fluctuation in funding cycles, however, pose significant challenges to this model and, specifically, to the retention of local research staff.

It is possible that CABs and IRTs may play different and complementary roles within the power structure of community and research. CABs may be viewed as advisory only, while IRTs may have more power. However, a CAB may naturally play a "checks-and-balances" role for the research team. The appropriate advisory structure will differ from study to study and between communities.

## Learn the Indigenous IRB Approval and Reporting, Process and Follow It Carefully

Thirteen tribes or consortiums of tribes have a Federal Wide Assurance (FWA) as fully functioning IRBs to control the conduct of research in their communities (Morton et al. 2013). Numerous other tribes and tribal consortiums have research review boards/human studies committees. This has not been cataloged exhaustively, which requires an investigator new to a setting to carefully research and learn local protocols and committees reviewing research. For all remaining tribes, the IHS provides IRB support. Compliance with requirements of tribal IRBs indicates that the researcher honors tribal sovereignty; the specific requirements usually vary from university IRBs. University IRBs are focused primarily on individual safety and confidentiality, and secondarily with scientific value. Most tribal research review or tribal institutional review boards require that research should demonstrate clear benefits to the tribal community; they are concerned with community risk, safety and stigmatization, as well as with risks at the individual level. Researchers must consider carefully how to maximize the benefits of their research for Indigenous communities, and communicate this information to community and/or IHS IRBs. Formal agreements between university and tribal/IHS IRBs are rare, but have occurred. For example, the University of Montana's IRB works directly with tribal IRBs to establish reliance agreements, which make the tribal IRB the review board of record. Different processes may apply when doing research with other Indigenous groups such as urban Indian organizations or tribal consortia.

These tribal approval requirements usually are overlaid on top of additional requirements in indigenous communities. Approval by smaller government units may be required (e.g., Navajo chapter approval, Navajo agency approval), as well as institutions that are the focus of the proposed research (e.g., school boards, health boards, worksite management, food store owners, etc.).

## Develop a Plan for Dissemination, Credit Sharing, and Publication

Indigenous community IRBs and most funding agencies require some sort of dissemination plan at the initiation of research, although the purpose and form may differ. Researchers frequently have a limited perspective (or time) for dissemination, and focus mainly on scientific publication. However, indigenous communities are often intensely interested in what has happened and the results of the studies that have taken place; therefore, local dissemination is critical. Feedback to community agencies, especially those with a stake in the research, is often a required part of the dissemination plan. For example, the TCU-BeWell BASICS study utilizes technology such as Zoom video conferencing to conduct quarterly

webinars and annual partnership meetings. The UNM-Tribal FLCP study with three tribal partners holds three large partnership meetings annually, monthly visits to each tribal partner, annual reports tailored for each tribal partner, and the development of digital stories by each tribal partner to share with leadership and their community.

In terms of publication, inclusion of at least one indigenous coauthor (or the entire local research team) on every publication may be required by Indigenous community IRBs, and opportunities should be provided for lead authorship. First-time lead authors may require considerable support with writing, which needs to be part of the dissemination plan. To aid in the development of manuscript(s), the UNM-Tribal FLCP has found that co-presenting at research conferences prepares the tribal partner for the opportunity for direct dissemination. At each UNM-Tribal partnership meeting, time is allotted on the agenda to focus on presentations and publications.

For THRIVE, the RE-AIM model was used as a dissemination and implementation framework, and key stakeholders were invited from both nations to identify data needed to not only to conduct the study but also to implement the intervention strategies, were they to be effective, as policy. Some data collection that was not originally planned, but was added based upon key stakeholders needs, included cost and health impact data. In terms of disseminating findings to community members, quarterly reports are shared with stakeholders, and the PI presents annually at tribal leadership meetings.

## Discussion

This paper has presented the results of interviews with IRINAH investigators, who collectively possess many decades of experience working with indigenous communities. We identified a series of strategies/lessons learned that will serve to enhance collaboration and capacity-building between indigenous communities and university researchers. Importantly, some of these strategies would need to be implemented at the university level, such as the provision of courses for investigators who strive to work with Indigenous communities, and formal community-based training for indigenous peoples themselves. On the other hand, most of the strategies identified are implementable by researchers, including the use of formative research and Indigenous research methods, establishing Indigenous advisory boards and research teams, and developing inclusive plans for dissemination and publication of findings. Use of these strategies has the potential to build community, institutional and researcher capacity, but also will lead to more effective and culturally adapted interventions which are appropriately evaluated and disseminated in accepted ways.

Although these proven strategies represent positive advancement, many key gaps remain. One complex domain is the issue of peer-reviewed publications. These publications remain a primary priority for researchers, to advance scientific knowledge and build academic careers. However, these publications may have limited benefits for indigenous communities, or the possible benefits may be perceived as low. Publications may be beneficial when an Indigenous community or an individual (PI) from the community is seeking additional research, regional, or foundation funding to address a health concern, but scientific findings need to be more accessible and impactful for these communities. Improving translation of public health research and creating innovative strategies for disseminating information within an indigenous community could improve the applied significance of scientific outcomes (Belone et al. 2016). Engaging local media or social media to help disseminate materials that are free from scientific jargon and accessible to people with diverse reading abilities could advance communication strategies in ways that would provide more meaningful opportunities for indigenous communities to benefit from research findings (Jernigan et al. 2014). Study findings presented on local community radio stations could be one form of disseminating published findings. Social media use has shown dramatic increases in most indigenous communities, and would be another potential venue for sharing appropriately translated peer-reviewed publication results.

The Navajo Nation's IRB conducts an annual research conference where investigators are heavily encouraged and/or required to present their work at the conference, held in Window Rock, AZ, the capital of the Navajo Nation. The OPREVENT2 and ElderAIR team trials make multiple presentations each year at this conference. Other Indigenous communities are beginning to host annual research conferences and requiring investigators to share their findings in culturally appropriate ways. In addition, many indigenous advocacy and policy organizations seek to follow and share research findings with AIAN communities through annual conferences, newsletters, and through websites (i.e., National Congress of American Indians, National Council of Urban Indian Health, National Indian Health Board, and regional health boards or epidemiological centers). Partnering with such entities to share knowledge and scientific findings holds significant promise for bridging the gap between intervention science and community knowledge.

A second remaining gap lies in enhancing opportunities for promotion and tenure among researchers working with Indigenous communities. Working in Indigenous communities requires considerable investment in relationship building and maintenance of those relationships over time. Approvals for research, reports, and publications may take time to receive and can act as a deterrent for researchers, especially those who are more junior and/or are on a tenure "clock." These challenges, and the time and steps along the way to meet these challenges are not well-recognized or well-understood by university appointments and promotions committees. One

potential way to address this issue is to increase the diversity of university faculty and administration by development and investment in indigenous faculty members. Additionally, strategic efforts to educate universities regarding the unique challenges to successfully conducting research within Indigenous communities could help inform the promotion and tenure process in meaningful ways. A key strategy we recommend is to create an enhanced NARCH mechanism to support TCU-based investigators for NIH-funded support. The National Institute on Minority Health and Health Disparities (NIMHD) new mechanism—Research Centers in Minority Institutions Programs (RCMI)—to enhance institutional research capacity of institutions such as TCUs, is a promising strategy that falls short, as the majority of TCUs do not offer doctoral degrees in health professions or in a health-related science.

As a third gap, indigenous investigators may face considerable personal challenges, as value systems within academia and research may differ greatly from those in their communities. Indigenous researchers are expected to bridge these two perspectives and carry the additional burden of being viewed as role models to young people from the communities in which they work. On the other hand, indigenous researchers have the potential to be transformative, and to serve as advocates and change agents for their communities. These challenges and opportunities have not been well-explored in the literature. However, a successful example of basing Indigenous investigators in the community has been employed by the Black Hills Center for American Indian Health.

A fourth gap is sustainability. In order to see health outcomes improve over time, sustained interventions and evaluation systems are essential but are typically beyond the scope of specific grant cycles (Belone et al. 2017). Cessation of intervention activities upon termination of funding is the norm, rather than the exception, and can lead to considerable burn-out on the part of indigenous communities. University commitment and resources are needed to help maintain relationships and activities between researchers and indigenous communities while funding is sought, perhaps in the form of bridge funds. In addition, universities should find ways to develop the overall capacity of indigenous communities by sharing intellectual or content knowledge through grant workshops, financial management education, or strategic partnerships between indigenous communities and academic units with expertise matching community needs.

Fifth, collaborating with Indigenous communities effectively can conflict with funding policies. One concrete example of honoring cultural protocol in the context of federally funded research is the issue of serving food at meetings with indigenous community and community partners. This is both essential to working with communities and a significant challenge for research, due to funding restrictions. Another example relates to compensating research participants. University systems for tracking participant payments often result in preferences for gift cards, but in remote rural reservation communities, these cards may be impractical to use (i.e., extensive travel required to redeem gift cards). A more recent example is the NIH's "single IRB" policy which has led to significant negative feedback. Flexibility in these systems in relation to the unique contexts of indigenous communities is important to promote community engagement and to overcome historical mistrust of research. At the institutional level, universities or associations of schools of public health should advocate to improve NIH policies that are misaligned with indigenous culture and autonomy.

A final large question or gap relates to the issue of autonomous research. Is it the ultimate goal for indigenous communities to conduct their own research without university partners? Should it be goal for university-based researchers to merely build indigenous community research capacity, or to support full research autonomy? Presenting these examples may be viewed as a step toward this ideal future. On the other hand, from a practical/experience-based standpoint, this may not be the future outcome. In our experience, most indigenous communities do not want to compete against universities and re-create university environments focused on research; they prefer to partner. They often lack research staff or the desire to hire full teams of research staff due in part to the potential burden of finding ways to support that staff.

## Limitations

The work presented in this paper has several key limitations. We have emphasized our collective work as IRINAH investigators, which is focused on the USA, but we have not included the considerable international literature on indigenous peoples. The study participants in this paper are also the coauthors, and it is possible that certain experiences were reported/emphasized over others. For example, potentially negative experiences in past projects in indigenous communities may be underreported. In addition, it may be argued that this paper represents the viewpoints of a sample of university researchers, and does not represent community stakeholder viewpoints. This limitation is ameliorated to some degree in that five of eight authors are indigenous. Data were not analyzed using formal qualitative methods, which could have led to a deeper analysis and potential opportunities for additional data collection. On the other hand, multiple rounds of review of findings by all coauthors constitutes a form of peer debriefing, which enhances the credibility of our findings.

## Conclusions

Much progress has been made in recent years in establishing research partnerships between universities and indigenous

communities, and the work of the IRINAH program has built on this foundation. Some of the key lessons learned include the following: the importance of building university capacity to work with indigenous communities, including the establishment of dedicated centers and learning Indigenous community approval and reporting processes; building the capacity of Indigenous communities to work with universities, and to conduct their own research; utilization of formative research and culturally relevant information gathering methods to incorporate indigenous perspectives; establishment of indigenous community advisory boards with a movement toward creating sustainable indigenous research teams; and development of culturally centered dissemination plans in partnership with Indigenous communities.

Nevertheless, many gaps still remain. We recommend that university academic promotion and tenure committees consider expanding their criteria to include a wide variety of community engagement and capacity-building activities, including training, grant-writing, analysis, and initial stages of community participatory research (including extensive travel for meetings, study planning and implementation, navigating Indigenous community approval processes, etc.). Dissemination and sharing of findings with indigenous communities through local research conferences, community presentations and other methods should be recognized and valued. Finally, every effort should be made to identify, recruit, and train indigenous investigators in research methods, grant-writing and publication, preparing them as leaders of the next generation of research in partnership with indigenous communities.

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## Compliance with Ethical Standards

**Conflict of Interest** The authors declare that they have no conflicts of interest.

**Ethical Approval** All studies received Indigenous community, tribal colleges and universities, Indian Health Services, and university approvals, and their funding NIH institute's Certificate of Confidentiality as appropriate.

**Informed Consent** All studies collected informed consent on participants as designated by their respective IRBs.

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