Responsible Research With Urban American Indians and Alaska Natives

American Indian and Alaska Native (AI/AN) communities harbor understandable mistrust of research. Outside researchers have historically controlled processes, promulgating conclusions and recommended policies with virtually no input from the communities studied.

Reservation-based communities can apply sovereignty rights conferred by the federal government to change this research trajectory. Many tribes now require review and approval before allowing research activities to occur, in part through the development of regulatory codes and oversight measures. Tribal oversight ensures that research is directed toward questions of importance to the community and that results are returned in ways that optimize problem solving. Unfortunately, tribal governance protections do not always extend to AI/ANs residing in urban environments.

Although they represent the majority of AI/ANs, urban Indians face an ongoing struggle for visibility and access to health care. It is against this backdrop that urban Indians suffer disproportionate health problems. Improved efforts to ensure responsible research with urban Indian populations requires attention to community engagement, research oversight, and capacity building. We consider strategies to offset these limitations and develop a foundation for responsible research with urban Indians. (*Am J Public Health*. 2018;108:1613–1616. doi:10.2105/AJPH.2018.304708)

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Research missteps in American Indian and Alaska Native (AI/AN) communities have precipitated mistrust.[1] Research has benefited AI/ANs, but outside investigators have historically controlled the process, promulgating conclusions and policy recommendations with virtually no input from the communities studied.[2] Practices sometimes involved deceit and physical harm, such as radiation studies among ANs presented as clinical care.[3] Research reports have stigmatized groups or misrepresented results.[1,4] This history amplified the reactions to recent experiences of the Havasupai and Nuu-Chah-Nulth Nations involving the use of biospecimens for unauthorized purposes.[5]

Tribal communities have sovereignty rights conferred by the federal government to change this trajectory. Most tribes use regulatory codes and oversight measures to require approval before allowing research to occur on a reservation.[6] Tribal oversight ensures that research addresses priority community questions and that results are returned in ways that optimize problem solving.

Unfortunately, tribal protections do not fully extend to AI/ANs who have relocated to urban environments—designated here as "urban Indians" (UIs). Most AI/ANs reside outside reservations, owing in part to the Indian Relocation Act of 1956, a US law that incentivized migration. Today, nearly 70% of tribal members and descendants live in cities.[7] Strauss and Valentino noted, "Urban is not a kind of Indian. It is a kind of experience, one that most Indian people today have had."[8(p104)]

AI/AN-specific research services are available to some UIs. Research conducted in UI Health Service (IHS) facilities requires review by an area institutional review board (IRB) or the National IRB as well as approval from appropriate tribes. UI Health Programs (UIHPs) can use the IRBs of IHS facilities for research undertaken in IHS clinics, and some area committees offer research oversight. However, UI organizations vary widely in their service area population needs, in-house research capacity, and relationships with tribes and IHS health care facilities, all of which affects response to research demands.

Federal regulations require that an accredited IRB—typically affiliated with a researchers' institution—review studies involving UIs, but this review may not incorporate the distinct cultural perspectives that tribal oversight provides, nor does it ensure that community needs are sufficiently prioritized. We consider here strategies to offset these limitations and build a foundation for responsible research with UIs.

NEED FOR RESEARCH WITH URBAN INDIANS

UIs suffer disproportionate health problems, including higher rates of cancer, diabetes, and cardiovascular and infectious diseases,[9–11] and are more likely to smoke than are non-Hispanic Whites.[10] Heterogeneous in tribal membership and racial status, UIs often have ties to multiple tribes, forming a network of individuals who participate in communal cultural and social events. AI/ANs residing away from tribal areas since childhood can feel distanced from kinship and reservation homelands, affecting the degree to which they sense belonging with a particular tribe. The Urban Indian Health Commission says, "What we're finding now is second, third generation. . . . They want to reconnect and

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reclaim some of those vestiges of identity."[12(§3p4)] Urban Indians experience stresses associated with the AI/AN experience, such as generational trauma imposed by boarding school policies that removed children from homes, alienating them from culture and subjecting them to physical and psychological abuse at the hands of educators.[7]

UIs face ongoing struggles for visibility and access to health care. AI/ANs in UIHP service areas are more likely than are individuals of all races to have incomes below the poverty level and higher unemployment rates.[10] Yet, UIs are often omitted or inconsistently recognized in local and national AI/AN health assessments and IHS health reports, where they are lumped into categories of "other" or "statistically insignificant." Such practices result in underreporting of UI health concerns at the population level.

The IHS is charged with executing federal trust obligations for services to AI/ANs, including research oversight, regardless of residential status.[13] Yet, it was not until 1979 that the IHS Improvement Act authorized nonprofit UIHPs in metropolitan locations to serve AI/ANs living outside tribal coverage areas. Today, 40 UIHP service areas include more than 1.2 million AI/ANs in 19 states and receive just over 1% of the IHS budget. This allocation is consistently under scrutiny, including attempts to abolish federal resources for UI health.

Research directed to address these problems, informed by understanding of the UI experience, could analyze factors contributing to adverse outcomes along with the development of strategies to improve UI health and well-being.

SHARED INTEREST IN AI/AN RESEARCH

Research with AI/ANs has implications for both tribal and urban populations, particularly when reporting differences between AI/ANs and other populations can harm nonparticipants who share group identity. How data interpretation and identifiers are included in analysis can influence whether results are misrepresented or stigmatizing—such as suggestions that adverse health outcomes result from irresponsible behaviors rather than social conditions. Considering the social, cultural, and political networks across reservation and nontribal lands, processes are needed that ensure research protections and benefits regardless of tribal enrollment and residential status.

Some data raise particular concern. Genetics is increasingly important in biomedical research but may carry risks connected to identity and shared heritage, including the potential to probe issues such as parentage or consanguinity.[14] Scientific claims can have implications for tribal enrollment, a status typically determined by blood quantum or proof of ancestry. Furthermore, research on population migration patterns may implicate tribal treaties and land rights.[15,16] Sensitivities also apply to investigations of substance abuse, HIV infection, or other potentially stigmatizing conditions. Genetic variation studies associated with substance abuse, for example, could bolster stereotypes despite evidence suggesting that heritability of alcohol misuse is either similar or reduced in AI/ANs compared with other groups.[15]

Community-based participatory research (CBPR) offers strategies to ensure that studies reflect health priorities and community oversight. CBPR promotes equitable inclusion of community partners in all aspects of research and seeks to reorganize power relationships, allowing communities to direct research questions, study design, data interpretation, and dissemination of findings. Although some researchers use CBPR in pursuing studies with UIs, this is by no means the rule.

A successful tribal CBPR project illustrates the need for similar robust partnership approaches in urban settings. Vitamin D deficiency research in Alaska resulted from concerns among tribal leadership about neonatal rickets, a decrease in calcium and phosphorus in bones that is potentially caused by insufficient vitamin D.[17] These findings prompted supplementation in pregnant women and neonates, promotion of a traditional diet of vitamin D–rich foods and fatty fish, and additional research to identify factors contributing to the deficiency.[18] The community reviewed study designs, participated in biannual meetings, and approved presentations and publications. Expansion of this research to UIs living in northern latitudes could identify increased vitamin D deficiency and lead to appropriate interventions, particularly if informed by community knowledge about dietary intake and sun exposure.

An example of successful UI research is the Diabetes Prevention Program, a randomized control trial that decreased type 2 diabetes incidence by 58% through lifestyle intervention.[19] This program engaged several tribes and at least one UI organization in the study.[20] The Diabetes Prevention Program process involved consultation with tribal and UI community leaders and governing boards, and the research team hired AI community members to serve as research assistants. Burrage, Gone, and Momper[21] also conducted a study with a Midwestern UIHP to identify resources, challenges, and cultural aspects affecting AI youth suicide prevention. Researchers attended advisory council meetings that provided project guidance and oversight. Council members participated in funding discussions and assessed measures for questionnaire adaptation to identify resources and support for AI youth suicide prevention. The UIHP director approved the study along with the university partner's IRB. These studies offer a guide for developing broader UI community–based research.

RECOMMENDATIONS

UI organizations seek to strengthen research capacity to direct and control studies undertaken in their communities. Establishing this infrastructure requires the development of research review systems and partnership approaches to health research as well as an increase in the number of AI/AN health professionals participating in and leading federally funded research. Constructing these systems presents an important opportunity for the National Institutes of Health (NIH) and other federal agencies to work in concert with UI organizations to outline expectations and requirements for research involving UIs.

Research Oversight

AI/AN research oversight may include intertribal IRBs or UIHP-directed ethics review panels. Model processes must consider UI organizational needs for technical assistance as they

weigh benefits and harms of participation, negotiate resources with partners, and identify research priorities. The Urban Indian Health Institute is a division of the Seattle Indian Health Board and a tribal epidemiology center that provides public health support to UIHPs. The Urban Indian Health Institute established a review process requiring applicants to describe how the proposal benefits AI/ANs.

Since 2000, the Urban Indian Health Institute has emerged as a national leader in calling attention to UI health needs and developing research engagement processes. Today, the Urban Indian Health Institute Research Review Board includes Seattle Indian Health Board staff, providers, and board members to ensure that studies reflect community priorities, benefit patients or the larger AI/AN population, and minimize risks. The Southcentral Foundation represents another example of support for urban and rural AN research oversight. The Southcentral Foundation includes a tribal review process and, if the research takes place on the Alaska Native Health Campus in Anchorage, additional approvals may be required by the Alaska Native Tribal Health Consortium and the IHS Alaska Area IRB.[22]

Community Engagement and Empowerment

Responsible research with UIs requires attention to community engagement and empowerment. Definitions of best practices for engagement are needed as well as research oversight models, capacity development, and implementation of funding priorities. UI organizations and advocates should lead deliberations to identify approaches and standards, engaging key agencies including the IHS, universities, and foundation and federal research funders such as the Robert Wood Johnson Foundation and the NIH. Strategic discussions should address whether national or regional standards for oversight are ideal for meeting the needs and goals of vastly diverse UI organizations. Potential outcomes include partnership guidelines outlining roles and responsibilities and defined consultation needs for issues such as the appropriate use of demographic data. Model agreements, communication and dissemination plans, and data-sharing parameters could also be considered; these would ideally be developed by AI/AN researchers and organizations and endorsed by participating stakeholders. Engagement processes and partnership agreements should be described in peer-reviewed journals to foster the visibility of UI research needs and broader public discourse of proposed solutions.

Community knowledge and expertise should be consulted to develop health priority questions throughout the research process, including project conceptualization and grant writing. Researchers can also use key informant interviews, focus groups, or community volunteer work with AI/AN youths to better understand the context of health issues and design studies that provide tangible outcomes while expanding career horizons for future generations. Training community members as research assistants and hiring local AI/AN businesses (e.g., artists, curriculum specialists) incorporates cultural values and establishes a sense of ownership of research so that outcomes lead to sustainable change.

A strong basis for engagement guidelines exists in scholarship on indigenous research and CBPR,[23] but there is a need for focus on research in urban settings. For example, researchers need guidance regarding appropriate representative agencies for UI communities. Furthermore, epidemiological research in UI populations should seek advice on the use of tribal and other demographic identifiers to avoid making inappropriate generalizations. Tribal affiliation in data collection can lead to valuable hypothesis development, but precautions should be taken to ensure anonymity and cultural safeguards to minimize group harm.

Policy approaches that support best practices should be addressed. University IRBs represent a leverage point where protocols involving AI/ANs could require UI review procedures to ensure that they meet agreed-upon standards and incorporate appropriate protection and pragmatic considerations. For example, the Arizona State University Board of Regents settlement with the Havasupai tribe included a legal requirement for tribal approval of research involving their community members. Although the law's intention was commendable, tribal approval for every participant represented in diverse urban-based studies is not always feasible and could have the effect of stifling research.[24] There remains a need to define appropriate and realistic standards, which could then be incorporated in both IRB review and UI research-funding requirements.

Capacity Building and Infrastructure

Increased research capacity is needed within UI organizations along with promotion and support of partnership-based approaches in research institutions. Activities could include the creation of a national clearinghouse on UI research, consultation support, and materials on appropriate practices; this would enable outside researchers to familiarize themselves with indigenous research models, CBPR principles, and UI service population needs and research priorities. Investing in training and employment of UIs creates bidirectional learning opportunities across universities and communities and empowers AI/ANs to conduct research independent of outside agencies. Academic partners build trust by promoting community capacity to lead the research, including proposal development, study design and implementation, and analysis and dissemination of findings to inform decisions.

UI organization staff with research experience may seek higher degrees to further skill sets or take on new roles, sometimes nationally, to influence responsible research practices with AI/AN communities. One example is a Centers for Disease Control and Prevention grant recently awarded to the Urban Indian Health Institute to develop public health infrastructure by providing UI organizations with training, resources, and chronic disease information on UI populations. Such capacity-building awards should be made available to UI organizations throughout state and federal agencies, including the NIH and the Environmental Protection Agency, that affect the social and environmental health of UI populations.

Research-Funding Priority

Funding mechanisms should solicit the expertise of organizations that prioritize UI research.

Federal policies typically require UI organizations to partner with a tribe or university when responding to research announcements, particularly through the NIH and the Substance Abuse and Mental Health Services Administration. This represents a failure to recognize the independent abilities of organizations to conduct quality research and diverts funds from studies specifically designed to address UI health needs. Additionally, funding announcements that require institutional matches can be burdensome for organizations strapped by underresourced facilities.

Federal mechanisms are needed specifically for UI organizations that are uniquely positioned to implement research that integrates evidence-based practices with community-driven solutions to health problems. For example, UIHPs are well suited to lead studies on benefits of practice-based evidence such as integrating traditional healing into mental health services for UI adults and youths.[25] Finally, to ensure UI needs and research priorities are recognized in the grant review process, indigenous scholars and others knowledgeable of UI issues should be recruited for relevant study sections. Considering the complexities of UI research environments and agendas, expertise in this area should be recognized as crucial in grant application assessment.

Federal research-funding opportunities for UI organizations with appropriate capacity could increase efficiency and the impact of funds. The relationship-building aspect of CBPR requires resources and time, which should be covered by federal grants. Moreover, academic research institutions should reward faculty on the basis of goals that align with UI disease prevention and social change equally to internal promotion standards such as peer-reviewed publications and grant productivity. Indirect costs associated with academic budgets (often more than 50% for institutional expenses) can also limit the effect of resources when total grant costs are capped. UI organizations can be poised to lead the work, especially in communities that have not been served well by outside researchers. Many UI community–based organizations already have the infrastructure to implement effective interventions resulting from research and, therefore, are ideal leaders to translate research into practice. AJPH

CONTRIBUTORS

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