Promoting Ethical Research With American Indian and Alaska Native People Living in Urban Areas

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Most health research with American Indian and Alaska Native (AI/AN) people has focused on tribal communities on reservation lands. Few studies have been conducted with AI/AN people living in urban settings despite their documented health disparities compared with other urban populations. There are unique considerations for working with this population. Engaging key stakeholders, including urban Indian health organization leaders, tribal leaders, research scientists and administrators, and policymakers, is critical to promoting ethical research and enhancing capacity of urban AI/AN communities. Recommendations for their involvement may facilitate an open dialogue and promote the development of implementation strategies. Future collaborations are also necessary for establishing research policies aimed at improving the health of the urban AI/AN population. (*Am J Public Health.* 2014;104:2085–2091. doi:10.2105/AJPH.2014.302027)

In 2010, 5.2 million people reported being American Indian or Alaska Native (AI/AN), either alone or in combination with 1 or more races.[1] The majority lived in urban areas, with the proportion increasing from 38% in 1970 to 61% in 2000[2] to 71% in 2010.[3] Despite this trend, the urban AI/AN population is sometimes referred to as an "invisible minority" because their needs are generally overlooked compared with those of other ethnic minority populations.[4]

The federal government is one audience that fails to fully recognize urban AI/AN people, as is evident by a history of racial misclassification. Some data sources use "AI/AN only" for identification and exclude individuals who report multiple races, reducing the accuracy and usefulness of urban AI/AN health assessments.[5] Funding agencies also contribute to experiences of invisibility. The Indian Health Service (IHS) funds urban Indian health organizations (UIHOs) that provide primary medical care and public health case management services for approximately 51 000 urban AI/AN people who do not have access to resources supported by IHS and tribally operated health care facilities.[6] There are, however, only 34 UIHOs in 41 US sites[7] and they have a history of being underfunded. In fiscal year 2012, the 34 UIHOs received a total of $42 984 000 or about 1% of the total IHS budget of 4.3 billion.[6]

In addition, the scientific community has failed to adequately involve urban AI/AN people in research. A PubMed literature review revealed that less than 3% of published AI/AN articles contained empirical data with the urban population (J. Bartgis, PhD, unpublished data, April 2013), which was striking when one considers the proportion of AI/AN people living in urban settings.

The need for more research is also based on documented socioeconomic and health disparities. In 2009, AI/AN people who lived in UIHO service areas were more likely not to have obtained a high-school diploma or general equivalency diploma compared with the general population (23.9% vs 16.2%).[8] More than 23% of urban AI/AN people lived below the federal poverty level, compared with 13.6% of the general population.[8] Between 2005 and 2009, AI/AN people living in UIHO service areas were more likely to report being diagnosed with diabetes, smoking cigarettes, and binge drinking, and experienced higher rates of alcohol-induced death compared with the general population living in the same areas.[8] To address these problems, we need more comprehensive and accurate data,[9] innovative approaches to small population research, and funding opportunities.[10]

We seek to promote ethical research and enhance the research capacity of urban AI/AN communities. We have identified unique considerations for working with this population, including differences from other urban populations and reservation-based communities. We provide recommendations for key stakeholders, including UIHO leaders, tribal leaders, research scientists and administrators, and policymakers. Because of the complex issues raised, we do not provide step-by-step guidelines for implementing each recommendation. Instead, we seek to increase awareness, elicit feedback, and facilitate open dialogue among all partners who are committed to improving the lives of urban AI/AN people. Strong collaborations are needed for future development of research policies and implementation strategies at local and national levels that will have lasting benefits for urban AI/AN communities.

UNIQUE RESEARCH CONSIDERATIONS

To meet the needs of urban AI/AN communities, research methods and policies must take into account some of the unique contexts of working with this population. Some characteristics are different from other underserved urban communities, whereas other characteristics distinguish them from reservation-based communities.

Differences From Other Underserved Urban Communities

Unlike other underserved urban communities in the United States, the AI/AN population has experienced a history of eradication and relocation to urban areas. Migration of AI/AN people began after World War II when the American government sought to end its relationships with tribes.[11] Termination and

relocation policies were created to end the special status of reservations and move reservation-based people to urban areas.[12] A significant number of families was transported to preselected cities and provided limited assistance with housing and employment. Few individuals benefited from relocation, and instead many experienced poverty, loneliness, and physical and cultural isolation.[13,14] Since that time, AI/AN people have voluntarily migrated to urban areas seeking better opportunities, including improved access to health services.[10] However, many have experienced disparities in socioeconomic status, education, and employment compared with the urban general population.[9]

Federal events and policies of genocide and forced acculturation have resulted in distrust of the US government among AI/AN people.[15] The distrust extends to educational systems because of the history of unethical behavior and abuses in educational, research, and health settings.[16] One example is the 2004 lawsuit won by the Havasupai Tribe against the Arizona Board of Regents and Arizona State University researchers for misuse of DNA samples.[17] The blood samples were collected for a diabetes study, but were later analyzed for unrelated investigations on schizophrenia, migration, and inbreeding that were not approved by the tribe. American Indian and Alaska Native communities are reluctant to participate in traditional research because of lack of access to study results, few tangible benefits for communities, disrespect for cultural practices, and distrust of the "Western medical model."[18] Little is known about the research attitudes and experiences of urban AI/AN people. A vignette study conducted in an urban Indian health care facility showed that the odds of hypothetical research participation increased among AI/AN patients when the hypothetical study was conducted by a health care provider rather than a state university or federal government.[19] Participation decreased when the federal government led the study, confidentiality was at risk, and compensation was not provided. More research is needed to understand the factors that affect study participation among urban AI/AN people and research processes that increase the likelihood of successful outcomes.

Other unique considerations are the place of residence and residential mobility of AI/AN people. American Indian and Alaska Native people rarely live in localized urban neighborhoods, often residing beyond the city limits and into broader urban areas.[20] As a result, they frequently lack visible community support unlike other underserved urban populations in the United States.[21] The urban AI/AN population is also very mobile with a tendency to move both within the same county and between different counties more frequently than non-AI/AN people.[22] They also have a history of circular migration, consisting of travel between reservations and urban areas.[11] One study found that 34% of AI/AN adults reported traveling to reservations for up to 30 days and 14% had spent more than 30 days on a reservation in the past year.[22] Greater amount of travel to reservations was associated with closer identification with native culture and dissatisfaction with health care, but not consistently related to self-reported health outcomes.[23] Patterns of mobility and relationships with health status and health care utilization need to be investigated further with input from community members on strategies to increase study recruitment and reduce attrition.

Differences From Reservation-Based AI/AN Communities

Many believe that urban AI/AN identity is distinct from the identities of other AI/AN people. Some suggest that individuals living in urban areas have less understanding of tribal-specific traditions and practices because urbanization has deemphasized tribal identities.[24] Others describe generalized pan-Indian identities that combine beliefs, values, and practices from a broad range of tribal groups.[25] Some characterize generations of urban AI/AN people as having aspatial identity, which is not formed in the context of an Indian reservation or other specific place.[26] Research is needed to test theories of urban cultural identity and apply them to interventions that are culturally appropriate for a multitribal population.

Another difference from tribal communities is the absence of sovereign governing bodies with whom to build research partnerships. American Indian and Alaska Native entities play a critical role in the protection of individual, community, and tribal rights. In urban settings, partnerships may be established with UIHOs; however, as previously mentioned, there are only 34 of them in the United States[7] and they are significantly underfunded.[6] In addition, they are underutilized by some AI/AN people who feel alienated or out of place at UIHOs.[27] Little is known about availability and feasibility of collaborating with AI/AN leaders and organizations that are not affiliated with UIHOs.

There is also the risk that urban communities may be misperceived as "samples of convenience" by scientists who want to avoid the lengthy review process required by tribal governments. Tribes currently do not exert authority over research participation of their citizens living off tribal lands. The IHS institutional review board exerts authority only for research conducted in IHS facilities or with IHS staff or resources. Thus, the responsibility for protecting individual and tribal rights in urban research may fall upon UIHOs and other urban AI/AN organizations. This burden needs to be recognized by multiple stakeholder groups and minimized by building capacity of all urban AI/AN organizations with an indigenous framework. Models applied to tribal communities may be adapted for urban communities, such as one that focuses on building relationships, building skills, working together, and promoting commitment.[28]

RECOMMENDATIONS FOR STAKEHOLDERS

Our recommendations, summarized in the box on page e3 target 4 stakeholder groups: UIHO leaders, tribal leaders, research scientists and administrators, and policymakers. We also acknowledge the important role of other urban AI/AN leaders and believe some recommendations apply to them as well. Our major points were informed by reviews of the scientific literature, consultations with stakeholders, participation in national meetings, and experiences as a faculty member at a Southwestern state university and research director of a national urban Indian organization. The meetings we attended included "Reaching Out to Urban Indians: Best Practices in Communications and Partnerships" in Rockville, Maryland (November 2011), "Research With Urban Indians Meeting" in Seattle, Washington

Recommendations for Promoting Urban American Indian and Alaska Native Research by Stakeholder Groups.

Urban Indian Health Organization (UIHO) leaders
- Monitor and protect the rights of AI/AN people and their tribal cultures through engagement and partnership with tribes served by UIHOs.
- Build organizational capacity and infrastructure for conducting research.
- Utilize national resources for research and technical assistance.
- Establish partnerships with academic institutions and culturally competent researchers.

Tribal leaders
- Recognize the impact of migration on the health and social status of urban-residing citizens, and effects on the sustainability of tribal nations.
- Strengthen relationships with urban-residing citizens by providing education and resources.
- Establish partnerships with urban AI/AN organizations.

Research scientists and administrators
- Implement diverse and innovative research methods that are culturally appropriate and highlight local issues.
- Apply participatory research methods, including community-based participatory research, to studies with the urban AI/AN population.
- Revise promotion and tenure criteria to recognize excellence in community-engaged scholarship and practice.
- Develop culturally appropriate university contract and institutional review board policies.

Policymakers
- Strengthen relationships with urban AI/AN leaders, tribal leaders, and research scientists and administrators.
- Advocate increased funding and resources to support urban AI/AN research.
- Demand culturally appropriate scientific peer-review processes.
- Require more AI/AN grant reviewers and culturally appropriate training of all scientists who may review proposals focused on the urban AI/AN population.
- Increase the workforce of AI/AN scientists by developing education and research training programs and scholarships.

Note. AI/AN = American Indian and Alaska Native.

(June 2012), and "Substance Use Disorders Among American Indian/Alaska Natives in Urban Settings" in Bethesda, Maryland (January 2013).

Urban Indian Health Organization Leaders

Urban Indian health organizations are 501(c)(3) nonprofit organizations that are funded by IHS under Title V of the 1976 Indian Health Care Improvement Act.[5] Title V specifically targets funding for the development of programs for AI/AN people residing in urban areas. Most AI/AN people who live in cities where UIHOs exist seek health care from UIHOs rather than from non-Indian clinics.[29] Services vary by site and may include ambulatory care, health assessment, health promotion, disease education, child abuse prevention, immunizations, and behavioral health services.[6] Community members also view UIHOs as places to interact with other AI/AN people and to cultivate AI/AN identity and culture.[27] Therefore, UIHOs play an important role in monitoring and protecting the rights of AI/AN people and their tribal cultures, which is enhanced by engagement and partnerships with tribes served by the UIHOs. We recommend that UIHO leaders dedicate time to building organizational research capacity, utilizing national resources, and establishing partnerships with academic institutions and tribes (the latter is discussed in the next section). Strengthening capacity and infrastructure are particularly beneficial as UIHOs implement health care reform, which will require improved monitoring of health status and sustainability of best practices.

Building the research infrastructure of UIHOs is challenging because of financial constraints. Funding from IHS urban grant and contract programs cannot be used for that purpose. In addition, because they typically receive less than 1% of the annual IHS budget,[6] UIHOs are often in a perpetual cycle of submitting new proposals to provide quality care, reducing the amount of time dedicated to research activities. Additional barriers are related to proposal restrictions, such as the requirement by the Substance Abuse and Mental Health Services Administration to submit all proposals through a government entity or tribe. The requirement increases the complexity of proposals and disempowers UIHOs from being able to act autonomously. We recommend that UIHO leaders openly discuss the potential benefits, challenges, and solutions for dedicating internal human resources to research protocols and processes to be successful in a reformed health system. UIHO staff may help increase community buy-in and participation in research studies. In return, staff may receive training in research and evaluation that may be used for local data-driven activities and increase leverage for obtaining additional funding and resources.

During periods of financial hardship, we suggest that UIHO leaders increase use of existing resources. The National Council of Urban Indian Health Technical Assistance and Research Center, in Washington, DC, offers research and evaluation training and consultation to urban Indian health programs and communities. The Urban Indian Health Institute, which is part of the Seattle Indian Health Board and is the epidemiology center for all UIHOs, responds to data requests and produces data reports and publications on major health topics. Both organizations are important assets to urban AI/AN organizations and the population in general. However, they have limited capacity to address all

the research needs that exist among urban communities in the United States.

The UIHOs should expand their partnerships to include academic institutions that may offer other resources to address the needs of urban AI/AN communities. They may include scholars with successful records of external funding, research staff and student assistants, institutional review boards (IRBs), grants management, financial services, and library resources. Several successful partnerships have been documented, including a partnership between the Indian Health Care Resource Center of Tulsa Inc and the University of Oklahoma–Tulsa to conduct a community health and needs assessment.[30] A partnership between a Midwestern UIHO and the University of Michigan resulted in studies on the integration of traditional healing in mainstream treatment service[31] and community members' involvement in and views of Indian health.[27] To help the formation of new partnerships, we encourage members of successful UIHO–academic collaborations to disseminate lessons learned about research processes from the viewpoints of all partners.

Tribal Leaders

The number of tribal leaders is large, with 566 federally recognized tribes in the United States[32]; thus, they create a formidable body to advocate the rights of their citizens living in urban settings. Tribal leaders need to recognize the impacts of migration on the social and health status of citizens living in urban areas, and minimize them to sustain tribal nations for future generations. We recommend that tribal leaders promote research by strengthening relationships with their citizens living off-reservation and establishing collaborations with urban AI/AN organizations. The relationships between tribes and their members living in urban areas are largely understudied. One study found that 17.7% of urban AI/AN adults reported feeling not at all connected with their tribe.[30] We encourage tribal leaders to support all their citizens, regardless of place of residence.

Some leaders host town hall meetings or other gatherings in cities where there are large numbers of tribal citizens to learn about local needs and disseminate cultural resources and education. Some tribes disseminate newsletters electronically to citizens living off-reservation. Those approaches may be used to educate urban citizens about research opportunities and ethical practices in collaboration with tribal IRB and research offices, academic institutions, and national organizations dedicated to AI/AN research. Knowledge about participant rights, risks, and benefits may inform good decision-making and increase study enrollment to obtain sample sizes necessary for advanced statistical analyses.

Tribal leaders may also promote research by establishing partnerships with local and national urban AI/AN organizations. Open dialogue is particularly critical with regard to the controversial issue of tribal authority over research conducted with citizens living in urban areas. There are no identified cases of tribes exerting such authority, but the possibility exists in the future. In addition, university IRBs may consider policies that require tribal approvals for studies conducted in urban settings on the basis of assumptions that tribes have authority. If policies are created requiring tribal permissions, barriers to research with the urban population may be substantial, particularly for UIHOs that serve members from hundreds of different federally recognized tribes.[33] Research with those communities would not be feasible, resulting in them being left out of data collection activities. The development of future tribal–UIHO research partnerships may be informed by successful collaborations for best practices in health services. Examples include funding provided by the Navajo Nation to the Friendship House Association of American Indians Inc of San Francisco to support Navajo people receiving culturally grounded residential treatment services.[34] Another partnership exists between the Cherokee Nation and the Indian Health Care Resource Center of Tulsa Inc to provide Special Supplementary Nutrition Program for Women, Infants, and Children services to the community.[35]

Research Scientists and Administrators

Research scientists and administrators of academic and funding institutions have a commitment to conducting scientifically rigorous and ethical investigations and training the next generation of scholars. However, to promote urban AI/AN research, we believe that the scientific community must broaden its activities beyond individual investigations. We recommend that scientists and administrators implement diverse and innovative research methodologies, revise promotion and tenure criteria to include community-engaged scholarship, and develop culturally appropriate university contract and IRB policies.

We recommend that researchers use participatory methods, including community-based participatory research (CBPR), to examine local issues and support social structures and social processes to improve the ability of community members to work together for identified goals.[36] Community-based participatory research is a partnership approach that involves community members, organizational representatives, researchers, and others in all aspects of the research process with all partners contributing expertise and sharing decision-making and ownership.[36] Compared with wide adoption with tribal communities,[37–40] there are few documented applications with urban AI/AN communities. We recommend that scientists and administrators promote CBPR studies and address partnership-related issues that may be unique to the urban AI/AN population. For example, one challenge is to identify who represents the community and how the community is defined.[36] Unlike with reservation-based communities, partnerships are not developed with sovereign nations. Some areas have UIHOs, but others do not, and it cannot be assumed that UIHOs are the best representatives of all members of an urban community.

Another potential challenge is conflicts resulting from differences in perspectives, priorities, assumptions, values, beliefs, and language between members of the same organization as well as across organizations.[36] The diversity of multitribal urban communities increases the risk of potential conflicts. We recommend that successful academic–community partnerships disseminate lessons learned and guidelines for conducting CBPR with urban AI/AN communities. The resources may serve as training tools for scholars and community members and enhance the likelihood of beneficial outcomes for urban AI/AN people.

To fully promote participatory research, we believe that the scientific community must address risks associated with achieving promotion and tenure in academic settings.[36,41]

Promotion and tenure is primarily based on the quantity of publications, reputation of the journals, and successful funding from federal granting agencies within a time-specific period.[36] Participatory research may result in delays in scholarly productivity because of extensive time required for establishing community partnerships, implementing interventions collaboratively, and publishing jointly with community members.[42] Faculty and academic administrators need to advocate updating promotion and tenure criteria to recognize excellence in community-engaged scholarship and practice, as implemented by a number of universities.[43] For example, the University of Arizona revised its promotion and tenure criteria in 2013 to include scholarship of engagement, defined as "integrative and applied forms of scholarship that involve cross-cutting collaborations with business and community partners."[43] The Community–Campus Partnerships for Health at the University of Washington has also created a model for community-engaged scholarship review, promotion, and tenure package.[44]

Scientists and administrators should also revise university contract and IRB policies to encourage participatory research studies with urban AI/AN communities. Some policies still embody traditional research frameworks, values, and beliefs, including that "knowledge production" is the sole right of the academic researchers.[45] We recommend that key issues, such as data control, confidentiality, ownership, publication, and dissemination of results, be addressed with culturally appropriate university contract and IRB policies that are tailored for urban and reservation-based settings. For universities that require special reviews of AI/AN investigations, we recommend careful consideration of how community engagement and approval are defined and assessed. We suggest that all affected parties be involved in the development of culturally appropriate university contract and IRB policies. Emphasis should be placed on polices that promote ethical and timely research with diverse AI/AN communities with fair distribution of benefits and burdens across the entire population.

Policymakers

Promoting urban AI/AN research has limited impact if there are insufficient resources for new investigations and the results do not inform policies that effectively improve the health status of the population. Therefore, we identify policymakers as an important stakeholder group, consisting of legislators, government officials, representatives of leading interest groups, and policy advisers. Our recommendations for policymakers include strengthening relationships with AI/AN and scientific communities, advocating increased funding, demanding culturally appropriate grant review processes, and increasing the AI/AN research workforce.

The underutilization of health research in policymaking was documented in a review of 107 model public health laws.[46] Researchers found that sponsors documented scientific evidence in only 6.5% of the laws. Reasons for poor use of research include lack of personal contact, mutual mistrust, power and financial struggles, and lack of timeliness or relevance of research.[47] We suggest that policymakers promote research by engaging in frequent interactions with urban AI/AN leaders, tribal leaders, and research scientists and administrators. Consistent with the interactive model of research utilization in policy development,[48] we advocate interactions for setting priorities, commissioning research, and communicating findings.

Policymakers should also be involved in the justification and accountability for funding at the national level.[49] We specifically recommend developing policy initiatives that support participatory research because of the costs associated with establishing and maintaining community relationships, such as providing transportation, offering technical assistance, and attending community events.[36] Several agencies support CBPR, including the Centers for Disease Control and Prevention, National Institutes of Health, and Agency for Healthcare Research and Quality.[50] However, the amount of funding for AI/AN research remains inadequate, and even more so for urban AI/AN communities. Aside from IHS support to the Urban Indian Health Institute for epidemiology research, there are no national initiatives to support urban AI/AN health research, in contrast to those that exist for tribal communities (i.e., Native American Research Center for Health). Policymakers need to advocate separate resources for research with urban AI/AN people without threatening support dedicated to reservation-based research.

Policymakers also need to advocate improvements in the scientific peer-review process. The unique considerations identified in this article may not be well understood by scientists serving on review committees. Recent reviewer comments from an unfunded research proposal revealed the possibility of unethical and discriminatory grant reviews by federal agencies (Liz Hunt, written communication, 2013). The Indian Health Center of Santa Clara Valley in partnership with Stanford University received culturally insensitive scientific review comments from the National Institutes of Health (NIH). The feedback included criticism of local community cultural practices and the use of the derogatory term, "half-breeds," when questioning assimilation within urban AI/AN communities. We are unaware of other case examples but believe 1 is sufficient to recommend that policymakers advocate more AI/AN grant reviewers and culturally appropriate training of all reviewers, regardless of ethnic background. American Indian and Alaska Native scholars who work primarily with tribal communities may be less familiar with urban issues, affecting their abilities to assess the quality and feasibility of proposed projects.

The shortage of AI/AN scientists should also be addressed by policymakers by developing education and research training programs and scholarships. In a testimony presented to NIH about the NIH loan repayment program, Chairman Chester Antone of the Tohono O'odham Nation stated,

> in the last 10 years, NIH has supported an average of 7 Native scientists a year to meet the research needs of 565 federally recognized Tribes, more than 220 Alaska Native villages and well over 2 million AI/AN people living in cities across the U.S.[51]

Gaps in the workforce include a limited number of minority senior investigators who may support research applications by junior faculty.[52] American Indian and Alaska Native scholars may offer several advantages including knowledge of language and culture and relationships with tribal communities that may improve recruitment and cultural relevance of findings and interventions.

FUTURE DIRECTIONS AND CONCLUSIONS

This article is a call to action to engage diverse stakeholders in promoting ethical research and enhancing research capacity of urban AI/AN communities. We believe our recommendations are comprehensive enough to elicit thought-provoking responses from the targeted groups and others committed to improving the lives of urban AI/AN people. We seek commentary with editorials, newsletters, blogs, conferences, meetings, correspondence to the authors, and other outlets. We also encourage use of this article to establish collaborations to develop research policies and implementation strategies at local and national levels.

Future research should examine stakeholders' attitudes and behaviors regarding the promotion of ethical research with urban AI/AN communities, as well as evaluate outcomes of tailored research policies. Failure to promote urban AI/AN research may contribute to increased health disparities in the population. Additional negative consequences may include loss of AI/AN rights, misuse of or exploited data, lack of cultural relevance of interventions, reduced benefits to communities, promotion of negative stereotypes, and greater disempowerment of AI/AN people.[38] As a society, we have a responsibility to prevent further injustices. Participatory research may produce solutions critical to improving the lives of future generations of AI/AN people living in urban areas. ■

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Contributors

N. P. Yuan led the writing of the original submission and revisions, developed recommendations, and incorporated feedback from the co-authors, colleagues, and reviewers. J. Bartgis originated the idea for the article, assisted with the writing, developed recommendations, and provided background information and references. D. Demers conducted literature searches, summarized the findings, and edited multiple versions of the article. All authors read and approved the final version.

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Human Participant Protection

This article did not report data from human participants; therefore, no institutional review board approval was necessary.

References

1. US Census Bureau. 2010 Census redistricting data (Public Law 94-171) summary file, Table P1. Washington, DC: US Bureau of the Census; 2010.

2. 2000 census of the population: general population characteristics—United States. Washington, DC: US Bureau of the Census; 2000.

3. Census 2010 American Indian and Alaska Native summary file. Washington, DC: US Bureau of the Census; 2010.

4. Kramer BJ. Health and aging of urban American Indians. *West J Med.* 1992;157(3):281–285.

5. Urban Indian Health Institute. *Visibility Through Data: Health Information for Urban American Indian and Alaska Native Communities.* Seattle, WA: Urban Indian Health Institute; 2009.

6. Indian Health Service, fiscal year 2013. Justification of estimates for appropriations committees. Washington, DC: Department of Health and Human Services; 2012.

7. Indian Health Service. Office of Urban Indian Health Programs. Available at: http://www.ihs.gov/urban. Accessed June 4, 2013.

8. Health disparities in UIHO service areas. Seattle, WA: Urban Indian Health Institute; 2013.

9. Castor ML, Smyser MS, Taualii MM, Park AN, Lawson SA, Forquera RA. A nationwide population-based study identifying health disparities between American Indians/Alaska Natives and the general populations living in select urban counties. *Am J Public Health.* 2006;96(8):1478–1484.

10. Urban Indian Health Commission. *Invisible Tribes: Urban Indians and Their Health in a Changing World.* Princeton, NJ: Robert Wood Johnson Foundation; 2007.

11. Snipp CM, Castle E, Baldwin B, eds. American Indians today. In: Castle E, Baldwin B, eds. *National Rural Studies Committee: A Proceedings, Fifth Annual Meeting.* Corvallis, OR: Western Rural Development Center, Oregon State University; 1992:16–26.

12. Fixico DL. *Termination and Relocation: Federal Indian Policy, 1945–1960.* Albuquerque, NM: University of New Mexico Press; 1986.

13. Fixico DL. *The Urban Indian Experience in America.* Albuquerque, NM: University of New Mexico Press; 2000.

14. Nebelkopf E, Phillips M. *Healing and Mental Health for Native Americans: Speaking in Red.* Lanham, MD: AltaMira Press; 2004.

15. Duran E, Duran B. *Native American Postcolonial Psychology.* Albany, NY: State University of New York Press; 1995.

16. Walters KL, Simoni JM. Decolonizing strategies for mentoring American Indians and Alaska Natives in HIV and mental health research. *Am J Public Health.* 2009; 99(suppl 1):S71–S76.

17. American Indian and Alaska Native Genetics Resource Center. Havasupai Tribe and the lawsuit settlement aftermath. Available at: http://genetics.ncai.org/case-study/havasupai-Tribe.cfm. Accessed November 5, 2013.

18. Burhansstipanov L. Developing culturally competent community-based interventions. In: Weiner D, ed. *Cancer Research Interventions Among the Medically Underserved.* Westport, CT: Greenwood Publishing; 1999:167–183.

19. Buchwald D, Mendoza-Jenkins V, Croy C, McGough H, Bezdek M, Spicer P. Attitudes of urban American Indians and Alaska Natives regarding participation in research. *J Gen Intern Med.* 2006;21(6):648–651.

20. National Indian Child Welfare Association. American Indian/Alaska Native fact sheet for the state of Illinois. 2011. Available at: http://www.nicwa.org/states/documents/IllinoisFactSheet.pdf. Accessed June 4, 2013.

21. Lobo S, Peters K. *American Indians and the Urban Experience.* Walnut Creek, CA: AltaMira Press; 2001.

22. Harvard Project on American Indian Economic Development. *The State of the Native Nations: Conditions Under US Policies of Self-Determination.* New York, NY: Oxford University Press; 2007.

23. Rhoades DA, Manson SM, Noonan C, Buchwald D. Characteristics associated with reservation travel among urban Native American outpatients. *J Health Care Poor Underserved.* 2005;16(3):464–474.

24. Thornton R. Tribal membership requirements and the demography of "old" and "new" Native Americans. *Popul Res Policy Rev.* 1997;16:33–42.

25. Nagel J. The political mobilization of Native Americans. *Soc Sci J.* 1982;19:37–45.

26. Peroff NC, Wildcat DR. Who is an American Indian? *Soc Sci J.* 2002;39:349–361.

27. Wendt DC, Gone JP. Urban–indigenous therapeutic landscapes: a case study of an urban American Indian health organization. *Health Place.* 2012;18(5):1025–1033.

28. Chino M, DeBruyn L. Building true capacity: indigenous models for indigenous communities. *Am J Public Health.* 2006;96(4):596–599.

29. *Reported Health and Health Influencing Behaviors Among Urban American Indians and Alaska Natives.* Seattle, WA: Urban Indian Health Institute; 2008.

30. Johnson CV, Bartgis J, Worley JA, Hellman CM, Burkhart R. Urban Indian voices: a community-based participatory research health and needs assessment. *Am Indian Alsk Native Ment Health Res.* 2010;17(1):49–70.

31. Hartmann WE, Gone JP. Incorporating traditional healing into an urban American Indian health organization: a case study of community member perspectives. *J Couns Psychol.* 2012;59(4):542–554.

32. US Department of the Interior Indian Affairs. Who we are. Available at: http://www.bia.gov/WhoWe Are/index.htm. Accessed October 15, 2013.

33. Hearing: Indian health oversight. Subcommittee on the Interior, Environment, and Related Agencies of the House of Representatives Committee on Appropriations, 113th Cong, 1st Sess (2013) (testimony of D'Shane Barnett, executive director of National Council of Urban Indian Health).

34. Friendship House Association of American Indians Inc of San Francisco. Navajo Nation community gathering and alumni celebration. Available at: http://www.friendshiphousesf.org/2013/news-events/navajo-nation-community-gathering-alumni-celebration. Accessed November 5, 2013.

35. *Annual Report 2012.* Tulsa, OK: Indian Health Care Resource Center of Tulsa; 2012.

36. Israel BA, Schulz AJ, Parker EA, Becker AB. Review of community-based research: assessing partnership approaches to improve public health. *Annu Rev Public Health.* 1998;19:173–202.

37. Norton IM, Manson SM. Research in American Indian and Alaska Native communities: navigating the cultural universe of values and process. *J Consult Clin Psychol.* 1996;64(5):856–860.

38. Quigley D. A review of improved ethical practices in environmental and public health research: case examples from Native communities. *Health Educ Behav.* 2006;33(2):130–147.

39. Fisher PA, Ball TJ. The Indian Family Wellness Project: an application of the tribal participatory research model. *Prev Sci.* 2002;3(3):235–240.

40. Jernigan VB. Community-based participatory research with Native American communities: the chronic disease self-management program. *Health Promot Pract.* 2010;11(6):888–899.

41. Wallerstein NB, Duran B. Using community-based participatory research to address health disparities. *Health Promot Pract.* 2006;7(3):312–323.

42. Seifer S. Documenting and assessing community based scholarship: resources for faculty. In: Minkler M, Wallerstein N, eds. *Community Based Participatory Research for Health.* San Francisco, CA: Jossey-Bass; 2003:429–443.

43. The University of Arizona Associate Provost for Faculty Affairs. Promoting an inclusive view of scholarship. Available at: http://facultyaffairs.arizona.edu/content/promoting-inclusive-view-scholarship. Accessed June 4, 2013.

44. Community–Campus Partnerships for Health. Community-engaged scholarship review, promotion, and tenure packet. Available at: http://depts.washington.edu/ccph/pdf_files/CES_RPT_Package.pdf. Accessed June 4, 2013.

45. Flicker S, Travers R, Guta A, McDonald S, Meagher A. Ethical dilemmas in community-based participatory research: recommendations for institutional review boards. *J Urban Health.* 2007;84(4):478–493.

46. Hartsfield D, Moulton AD, McKie KL. A review of model public health laws. *Am J Public Health.* 2007;97(suppl 1):S56–S61.

47. Innvaer S, Vist G, Trommald M, Oxman A. Health policy-makers' perceptions of their use of evidence: a systematic review. *J Health Serv Res Policy.* 2002;7(4):239–244.

48. Hanney SR, Gonzales-Block MA, Buxton MJ, Kogan M. *The Utilisation of Health Research in Policy-Making: Concepts, Examples and Methods of Assessment (Health Economics Research Group Research Report No. 28).* Uxbridge, UK: HERG Brunel University; 2002.

49. Hanney SR, Gonzalez-Block MA, Boxton MJ, Kogan M. The utilization of health research in policy-making: concepts, examples and methods of assessment. *Health Res Policy Syst.* 2003;1(1):2.

50. Horowitz CR, Robinson M, Seifer S. Community-based participatory research from the margin to the mainstream: are researchers prepared? *Circulation.* 2009;119(19):2633–2642.

51. US Department of Health and Human Services 13th Annual National HHS Tribal Budget and Policy Consultation Session. (2011) (testimony of Chester Antone, councilman of Tohono O'odham Nation).

52. Shavers VL, Fagan P, Lawrence D, et al. Barriers to racial/ethnic minority application and competition for NIH research funding. *J Natl Med Assoc.* 2005;97(8):1063–1077.