Accelerating and Strengthening Native American Health Research Through a Collaborative NIH Initiative

Aria Davis Crump¹, Kathy Etz¹, Judith A. Arroyo², Nanci Hemberger³, and Shobha Srinivasan⁴

¹National Institute on Drug Abuse, National Institutes of Health, Bethesda, MD, USA

²National Institute on Alcohol Abuse and Alcoholism, National Institutes of Health, Bethesda, MD, USA

³Scientific Consulting Group, Inc., Gaithersburg, MD, USA

⁴National Cancer Institute, National Institutes of Health, Rockville, MD, USA

Abstract

This paper is intended to provide an overview of the considerations that informed the development of a National Institutes of Health funding opportunity to promote health and prevent disease in Native Americans, including American Indian, Alaska Native, and Native Hawaiian communities. NIH Institute staff thoughtfully considered epidemiologic research findings and feedback from constituents regarding the need for more published research overall and stronger prevention efforts to address persistent health concerns affecting many Native communities. This led to the publication of four funding announcements supported by multiple NIH Institutes and one NIH Office. Through the efforts of researchers, tribal leaders, community collaborators, and NIH leadership and staff, a growing body of knowledge regarding culturally informed approaches to supporting health in Native Americans is emerging. This article describes how staff who developed the funding opportunities envisioned a process to support high impact science through ensuring methodological rigor, responsiveness to prevention needs, and respect for community heritage, values, and history with non-Native peoples. In addition, this article highlights the growth of the researchers and collaborators within a community of scientists expanding the knowledge base further by sharing their research resources, instruments, and strategies for engaging in scientific inquiry that meets the needs of Native communities and those of funding organizations.

Keywords

Native American; Health promotion; Disease prevention; Research ethics

Correspondence to: Aria Davis Crump.

Compliance with Ethical Standards

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

Ethical Approval This article does not contain any studies with human participants performed by any of the authors.

Informed Consent Because this article is not data-based, informed consent is not applicable.

Disclaimer The contents of this publication are solely the responsibility of the authors and do not necessarily represent the official views of NIH.

This supplemental issue of *Prevention Science* includes papers written by investigators who received National Institutes of Health (NIH) research funds under announcements PAR-11-346 and PAR-14-260 to conduct health promotion and disease prevention research among American Indians, Alaska Natives, and Native Hawaiians (referred to in this article as “Native Americans”). This group of investigators comprises the Intervention Research to Improve Native American Health (IRINAH) research network in which members collaborate and support fellow colleagues’ efforts to develop and test sustainable, culturally grounded, and culturally appropriate health promotion and disease prevention interventions that span a range of health conditions. Research projects focus on prevention of disease and improvement in health outcomes related to cancer, cardiovascular disease, diabetes, alcohol/drug disorders, and toxic exposures. More than 20 projects have been funded involving youth and adults in a variety of settings (National Cancer Institute 2016). Investigators typically have an extensive history of working collaboratively with Native populations, and several principal investigators are Native Americans. By design, IRINAH investigators engage in regular meetings and take advantage of opportunities to share their experiences and knowledge with others in the network.

The IRINAH funding announcements were predated by other NIH efforts to support research relevant to surveillance, etiology, prevention, and treatment of health conditions among Native Americans. Several NIH Institutes and Centers (ICs) have funded research in Native communities by issuing IC-led initiatives and by selecting investigator-initiated applications for funding. NIH ICs have funded highly innovative work specific to their missions (e.g., Beauvais et al. 2004; Jobe et al. 2012; Lee et al. 1990; National Cancer Institute 2017), and several NIH ICs have participated in the Native American Research Centers for Health (NARCH) Program, a long-standing research infrastructure and research training development funding opportunity announcement (FOA) specifically for American Indian and Alaska Native communities (National Institute of General Medical Sciences 2017). In 2015, the NIH Tribal Health Research Office was established to ensure that the agency receives input and actively collaborates with Tribal Nations regarding NIH programs and policies (see <https://dpcpsi.nih.gov/thro>), and NIH IC staff and leadership continue to pursue approaches to supporting biomedical and behavioral health research that is responsive to the needs of Native Americans.

Despite ongoing efforts, serious health inequities persist for Native populations (Gone and Trimble 2012; Keppel 2007; Roubideaux 2005). American Indians and Alaska Natives have been identified as having higher rates of morbidity and mortality resulting from preventable causes (Jacobs-Wingo et al. 2016; Keppel 2007). While less well documented in part because of inadequate data (Korngiebel et al. 2015), Native Hawaiians similarly have elevated rates of disease and illness (Keppel 2007; Liu and Alameda 2011). While our understanding of the extent of the disparities across multiple diseases and disorders is limited, it is clear that these disparities are pervasive and affect individuals living in rural and urban areas (Jacobs-Wingo et al. 2016).

To strengthen, enhance, and accelerate the progress of research on health promotion and disease prevention, staff at the National Cancer Institute led the effort to develop the FOAs listed above. Published in 2011 and reissued in 2014, the FOAs were focused on testing

interventions to promote health and prevent disease with consideration given to the interests and concerns expressed by Native American leaders and researchers working in these communities. Eight NIH Institutes and one Office welcomed applications submitted under this announcement. In 2017, the FOA was reissued as PAR 17-496 and renamed “Research to Improve Native American Health,” reflecting an expansion of the scope of allowable research projects beyond health promotion and disease prevention. A companion exploratory and/or developmental research FOA was also issued (PAR-17-464). The goal of issuing these announcements was to support rigorous scientific research leading to culturally-relevant and sustainable interventions to reduce mortality and morbidity in Native American communities. This paper provides highlights of lessons from prior research that has informed the development of the current and ongoing efforts.

Supporting the Research Process in Native American Communities

Several aspects of the FOAs supported the need for high quality, high impact research studies that would be acceptable to communities. In this spirit, and based on recommendations from several sources (Christopher et al. 2008; Fisher and Ball 2003; Institute of Medicine 2013; Israel et al. 1998; Wallerstein and Duran 2010), interventions were expected to be culturally appropriate and investigators were strongly encouraged to employ research approaches involving community partnerships. In fact, the use of Community-Based Participatory Research (CBPR) (Israel et al. 1998; Wallerstein and Duran 2010), in which academic teams work with community members to identify the health issue to be investigated, conceptualize and design the research, develop or adapt measures, collect and analyze data, interpret findings, and disseminate results, was specifically encouraged. The announcements indicated that diverse intervention approaches were acceptable for study including incorporating traditional cultural practices into prevention and health promotion strategies.

A special emphasis panel was convened by NIH’s Center for Scientific Review to assess the scientific merit of the applications submitted for funding consideration. This made it possible to convene reviewers with extensive knowledge of best practices for working in Native communities. In addition, the FOA specified that funded investigators should participate in collaborative activities to advance transdisciplinary science in Native American communities. As of the publication of this article, the investigators involved in these studies meet regularly by phone and annually in person to support this goal.

Recognizing Expectations of Native American Research Participants

A legacy of mistrust between Native American communities and researchers has made it essential for investigators to carefully consider the requirements and expectations of Native American groups involved in health-related research. Scholars have addressed mistrust of research and have outlined important steps to address it (Pacheco et al. 2013; Wallerstein and Duran 2010). When working with tribes, it is critical to respect the concept of tribal sovereignty (Chadwick et al. 2014) and understand that developing formal agreements with tribal governments to conduct research is a necessary part of the process (Harding et al. 2012).

An Institute of Medicine workshop summary addressed the needs of Native American communities participating in research, stating, “Research plans should be developed in conjunction with the communities,” and, “To improve the health of indigenous peoples, research should reflect community needs, priorities, and realities” (Institute of Medicine 2013, p 9). Notably, these recommendations are typically addressed through effective use of the CBPR approach previously described.

Issues surrounding the provision of full informed consent for research participation and data sharing are also of critical importance and missteps and/or communication failure can cause harm to research participants and the research process (Mello and Wolf 2010). Investigators must act upon their obligation to ensure that the purpose of the research is transparent to Native leaders and study participants as a part of the informed consent process (Harding et al. 2012). This includes engaging in a collaborative process to develop and document plans regarding ownership of participant data, research publications and other products, and biological samples. In some cases, tribes or collaborators may seek to retain ownership of data and biological samples and/or may not be willing to participate in open-ended data sharing agreements (Harding et al. 2012).

A publication developed jointly between the National Congress of American Indians Policy Research Center and Montana State University Center for Native Health Partnerships (2012) advanced values for conducting research with tribes. The recommendations described, such as respecting cultural and local knowledge and having shared goals, are consistent with the spirit of the NIH FOAs. In fact, one of the major recommendations in these documents is planning for sustainability, which is an important principle for both Native American communities and the NIH institutes. Planning for sustainability is expected of all intervention projects funded under this initiative as communities should fully benefit from research participation when interventions are proven to be effective.

The IRINAH Network: a Community of Scientists Dedicated to Native Health

IRINAH investigators are very diverse in their disciplines and backgrounds, but have a common interest in the health of Native populations and encounter similar research-related challenges and opportunities. Monthly meetings of IRINAH grantees and an annual grantee forum have provided a platform to ensure that the investigators can collaboratively advance the best possible science despite unique circumstances. For example, several researchers work in areas that are remote or have an underdeveloped research infrastructure, which can present significant cost and logistic concerns for program implementation and data collection. Also, assembling a multidisciplinary team to conduct community-engaged research that is truly collaborative and respectful of diverse needs is a common objective. Other challenges include developing research designs and analysis plans involving relatively small sample sizes and close-knit networks (Korngiebel et al. 2015).

The IRINAH Network has provided investigators and NIH program staff a forum to share information and resources to meet common goals, such as supporting strength-based approaches to improve population health and identifying opportunities to support Native American early career scientists. Group interactions have been a catalyst for new scientific

partnerships among participating scientists. Discussions with investigators have helped program staff fully appreciate the importance of continuously assessing whether NIH programs and policies align with the needs of researchers working with Native populations. As science advances rapidly, it is critical that lessons from diverse populations that can inform our understanding of optimal health become a part of our broader knowledge base. It is also essential that populations facing overwhelming yet preventable health conditions are included in the discovery process that has dramatically improved health conditions in the USA (Rust et al. 2010).

The IRINAH funding initiative began as an effort to advance the body of scientific knowledge on health promotion and disease prevention in Native populations. Investigators conduct rigorous science while honoring the values of the community, acknowledging the impact of historical events, and recognizing the roles of culture and tradition in the support of and restoration of health and well-being. Through this effort, a rare opportunity has emerged for a network of dedicated scientists working across multiple disciplines and disease conditions to connect and collaborate in the interest of communities that are too often invisible in discussions of how to improve the health of the American population. The desired outcome of these projects is to build knowledge regarding how to promote health equity through sustainable, effective interventions that are relevant to communities, build upon their unique strengths, and will have meaningful impacts on health and well-being. This supplement offers a foundation for understanding the research approaches and findings of this work.

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