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Promising Practices for Promoting Health Equity Through Rigorous Intervention Science with Indigenous Communities

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Abstract

Research in indigenous communities is at the forefront of innovation currently influencing several new perspectives in engaged intervention science. This is innovation born of necessity, involving efforts to create health equity complicated by a history of distrust of research. Immense diversity across indigenous cultures, accompanied by variation in associated explanatory models, health beliefs, and health behaviors, along with divergent structural inequities add further complexity to this challenge. The aim of this Supplemental Issue on *Promoting Health Equity through Rigorous*, *Culturally Informed Intervention Science: Innovations with Indigenous Populations in the United States* is to highlight the promising new approaches and perspectives implemented by a group of engaged researchers and their community partners, as they seek to move intervention research forward within indigenous communities. Case studies presented are from projects led by members of the National Institutes of Health *Intervention Research to Improve Native American Health* (IRINAH) consortioum, investigators who conduct health promotion and disease prevention research among American Indians, Alaska Natives, and Native Hawaiians. The promising practices profiled include new strategies in (a) community partnerships, engagement, and capacity building; (b) integration of indigenous and academic perspectives; (c) alignment of interventions with indigenous cultural values and practices; and (d) implementation and evaluation of multilevel interventions responsive to complex cultural contexts. The IRINAH projects illustrate the evolution of an intervention science responsive to the needs, realities, and promise of indigenous communities, with application to health research among other culturally distinct health inequity groups.

Keywords Indigenous populations · Intervention research · Health equity · Community-based participatory research · American Indian/Alaska Native/Native Hawaiian

The aim of *Promoting Health Equity through Rigorous*, *Culturally Informed Intervention Science: Innovations with Indigenous Populations in the United States*, a Supplemental Issue of *Prevention Science*, is to disseminate promising practices for an intervention science with indigenous populations in the USA. We use the term indigenous to include all American Indian, Alaska Native, and Native Hawaiian ethnocultural groups of the USA. The innovations described in the papers of this issue have been developed through partnerships among indigenous communities and health researchers, on projects funded by the National Institutes of Health (NIH), PAR-11-346 and PAR-14-260, *Interventions for Health Promotion and Disease Prevention in Native American Populations*. Researchers funded under these mechanisms have come together to form the *Intervention Research to Improve Native American Health* (IRINAH) consortium (Crump et al. 2017). IRINAH fosters collaboration and exchange of information across these research teams, driven by a critical necessity to mount efforts to effectively redress some of the most significant population disparities in health outcomes in our nation.

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The IRINAH Consortium represents a broad cadre of health equity teams from numerous academic, research, and tribal organizations in the USA, working with a large and diverse group of indigenous communities. IRINAH investigators are evaluating the impact of a variety of health interventions. Each of these interventions addresses a significant inequity in the health outcomes of indigenous groups. In the long tradition of community-based participatory research (CBPR), the IRINAH efforts focus on implementing promising solutions to longstanding health inequities that have persisted despite gains in intervention science in other populations.

The papers in this Supplemental Issue contribute to new knowledge through the use of case studies as their primary data source. The case studies describe the work of the IRINAH consortium and provide a vehicle to disseminate new ideas and fresh strategies in intervention research. Each of the papers will describe a set of issues, introduce strategies devised by research teams to address the set of challenges these issues posed, and conclude with specific recommendations for future research that can better serve indigenous communities. The promising practices profiled here address four critical areas for intervention science with indigenous communities: (a) community partnerships, engagement, and capacity building; (b) integration of indigenous and academic perspectives; (c) alignment of interventions with indigenous cultural values and practices; and (d) implementation and evaluation of multilevel interventions that are responsive to complex cultural contexts. This Supplemental Issue is intended to have immediate relevance for researchers working with indigenous communities in the USA. It will also have implications for health equity research with other diverse groups, both national and global.

Foundational to all of the papers in this Supplemental Issue and to the work of IRINAH investigators is the role of community engagement in indigenous intervention science. Thus, before introducing the papers to follow in this issue, we provide context for the collective work by describing the role of community partnerships. We will provide more information about the IRINAH consortium and how this group has worked together to tell the stories of their respective projects, collectively, in this issue. Next, we introduce each of the papers composing the Supplemental Issue, providing an overview of what will follow. We conclude with reflections on what the IRINAH initiative represents, both within the framework of recent progress in indigenous health research, and as part of broader efforts to develop a more engaged intervention science.

The Fundamental Role of Community Engagement

Efforts to improve health equity for indigenous populations through intervention research occur within a historical context. Indigenous populations have long been the subjects of research and rarely have had meaningful input in research decision-making processes. Researchers have gained significant advantage from these studies, profiting financially and through professional accolades, while removing data, cultural knowledge, and artifacts from indigenous communities that have too seldom derived any benefit of research findings. In the extreme, this has led to several notable violations of research ethics (Allen et al. 2012; Trimble 2008). As a result, research is often understandably met with suspicion, and its value to the local community is questioned.

A further complication lies in the diversity across American Indian, Alaska Native, and Native Hawaiian populations. While there are shared elements of history in relation to the US government, a complex array of cultures, languages, and geographies characterize indigenous communities. Thus, the objectives of health equity efforts cannot be uniform across these communities; projects must instead address a wide spectrum of local priorities and unique histories and adapt interventions and research strategies to local cultures and contexts.

To be effective in such contexts, and to meaningfully address the historical harm perpetuated within these populations, prevention science must genuinely engage indigenous communities. Researchers must understand the history and work needed to restore communities' trust in the research process. This requires research that honors local voices and cultural protocols and that returns meaningful data and substantive benefit to communities. Researchers must bring the best science has to offer, but in doing so recognize the difference between scientific rigor and scientific rigidity. Research designs, study protocols, measures, and dissemination plans must be tailored to ensure scientific rigor within each of these diverse cultural contexts; a one-size-fits all methodology approach will not result in good data or useful findings. Perhaps most central to these concerns, CBPR principles permeate the work of the IRINAH projects. Such approaches integrate community and cultural perspectives with local control into study aims, and into designs optimized to produce data and findings to address questions of meaning to the community.

Crump et al. (2017), in introducing the Supplemental Issue, describe how the NIH created the IRINAH Funding Opportunity Announcements (FOAs) in recognition of this need for an engaged intervention science. The authors describe how the FOAs prioritized meaningful indigenous community input, transparency throughout the research process, tangible research outcomes, community dissemination of results, data ownership, and encouraged CBPR as an underlying and pervasive approach to intervention research with indigenous communities. Over the past decade, CBPR has moved from the margins to the mainstream in intervention science (Horowitz et al. 2009). This has been particularly evident in intervention research with indigenous communities, where some of the most interesting examples of CBPR efforts can be found and has been exemplified in the IRINAH projects through their

universal adoption of CBPR approaches. CBPR is an approach or orientation (as opposed to a method) that provides structures and mechanisms ensuring collaboration. Foremost is open dialog and decision-making among community and academic research partners, including bidirectional learning and communication about power in these relations (Wallerstein et al. 2017). The foundational principles of CBPR (Israel et al. 2017) maintain research relationships with an eye toward equity, community input, and mutual respect and recognize different perspectives and ways of knowing. One key element includes the rejection of privileging western over indigenous methods and practices, and instead, building on the strengths of both traditions in gathering trustworthy evidence.

It is important to note one particular challenge often encountered by intervention researchers working with indigenous communities. While the health and mental health disparities in indigenous communities have demonstrated a clear need for rigorous intervention science that can inform practice, many of the current conventional approaches for evaluating intervention effectiveness, namely research designs that randomize some study participants to no-intervention control groups, have often proven untenable in indigenous communities. Designs that involve knowingly withholding or significantly delaying treatment thought to be effective to some, but not to others, have often been seen in indigenous communities as exploitative, irresponsible, impractical, culturally unacceptable, or ethically questionable. This has been particularly true in settings with both scarcity of resources and high immediate need for services. Building trust and capacity to implement such designs, overcoming understandable resistance, can take significant time. Further, as many of the authors in the Supplemental Issue will argue, "special status for RCTs is unwarranted" (Deaton and Cartwright 2018, p. 2). Alternative designs including regression discontinuity, interrupted time series designs, and roll-out randomization designs have now demonstrated ability to estimate intervention effects with limited bias, while acting more in congruence with community values (Henry et al. 2017). Moreover, without significant investment in finding solutions to these and other challenges, indigenous communities will be left behind, without sound scientific guidance to inform their intervention efforts; existing, significant health disparities are likely to persist (Whitesell et al. 2018). Creative approaches to engaging communities in locally feasible intervention science approaches are needed, and in response, IRINAH investigators are at the forefront of generating promising new methods.

Sharing the Collective Experience of IRINAH Research Partnerships

The cadre of researchers around the country who have been working to understand health inequity in indigenous communities, and to develop and test interventions to address them, is relatively small. This group includes Native and non-Native investigators, working in partnership with one another and with diverse indigenous communities around the country. Many have been funded under the IRINAH initiative. One goal of this NIH initiative is to grow and strengthen the size and reach of this cadre. The IRINAH group has developed an array of strategies for addressing some of the challenges of this work, as part of their efforts to find solutions to the significant health disparities experienced by indigenous communities and to lay the foundations for health equity. As members of the IRINAH consortium, we recognized the importance of sharing the collective wisdom of this group experience more broadly, to inform future efforts with indigenous populations as well as with other groups that are marginalized and deal with health inequities. Dissemination of promising approaches being used in the IRINAH projects, demonstrating rigorous culturally informed science, has the potential to improve the quality of research with indigenous populations, with potential for generalizability to other health inequity research. We have and will continue to learn from one another.

In considering what the papers in this Supplemental Issue have to offer, it is important to recognize the collective experience of the research partnerships represented across the IRINAH projects and their commitment to sustained collaboration with indigenous communities. Strong university-community partnerships are a keystone to successful CBPR, and IRINAH projects exemplify these elements of partnership. We highlight three examples here, but they are typical of the work across the 27 IRINAH projects. First, Dickerson and colleagues [R01AA022066-01] began working with the Los Angeles urban indigenous community over 5 years prior to securing funding for their project *Motivational Interviewing and Culture for Urban Native American Youth* (*MICUNAY*). Their efforts included consultations with two community advisory boards across the Los Angeles community (Dickerson et al. 2016), as well as intensive efforts to ensure representative sampling in qualitative data collection efforts aimed at assessing community needs and priorities (Dickerson and Johnson 2011) and informing cultural tailoring of substance use interventions for youth (Brown et al. 2016). Second, Walters and colleagues [R01DA037176-01] developed *Yappalli: Choctaw Road To Health*, a community-based intervention from an indigenous perspective over a 4-year period, drawing on CBPR principles as a framework for working with the Choctaw community to ensure community participation and equity in the research process (Schultz et al. 2016). Finally, Whitesell and colleagues [R01DA035111] worked with a community advisory board for more than 3 years to develop the grant application funded under the IRINAH initiative. This developmental work built on a 25-year history of a sustained research presence (including the continuous operation of a university field office) in the reservation community

where the intervention is taking place (Beals et al. 2003; Whitesell et al. 2018). This project encompassed CBPR and research capacity building in its many forms; a tribal member who grew up in the community and became a faculty member at the University of Colorado led the intervention development and implementation from her office on the reservation.

In designing this Supplemental Issue, the investigators across the 27 IRINAH projects worked together to identify key areas in which they and their community partners shaped intervention science to enhance the validity of research in indigenous cultures and contexts. These papers illustrate not only the challenges of this work but, more importantly, effective and innovative strategies developed to help ensure that research on indigenous health—specifically research on interventions to improve health—was optimized through both high-quality, rigorous scientific methods and authentic incorporation and respect for cultural contexts and protocols, fostered within genuine and sustained community-researcher partnerships. By way of introduction, we provide an overview of the papers written to tell the collective story of the first 5 years of IRINAH.

Papers in the Supplemental Issue

The Health Equity Context of Indigenous Health Research in the USA

The first paper, Stanley et al. (2017), sets the stage for the rest by describing the current status, and the human and economic costs of health inequity among US indigenous populations. The authors emphasize and provide examples highlighting the limited existing evidence base for effective interventions addressing these massive inequities, as well as ways in which population uniqueness often made the transfer of existing intervention models difficult and ineffective. In doing so, the authors present the case for increased intervention research in indigenous populations, and for an approach to intervention research built on a respect for indigenous wisdom, knowledge, values, traditions, and aspirations. The authors document significant health inequities in indigenous populations, the lack of etiologic and intervention evidence specific to these populations, and reasons for this lack of evidence. They conclude by describing an urgent need for intervention research focused on indigenous communities as a social justice imperative.

Community Partnerships, Engagement, and Capacity Building

Gittelsohn et al. (2018) discuss how the particular contexts of indigenous communities have impacted intervention research and the importance of intentional efforts to develop capacity at both community and university levels to support effective research partnerships. They describe the history of engagement of indigenous communities with research, advances in recent years, and remaining challenges to effective and sustainable research partnerships. IRINAH studies are used as case examples of innovative strategies for building and enhancing partnerships, targeting seven key goals. These include training and career development (including academic promotion) of indigenous scientists, university policies that are responsive to indigenous research contexts; research designs that are both culturally and scientifically appropriate, alignment of human subject research oversight across university and tribal institutions, and dissemination of research findings to relevant audiences and with credit given to all research partners. This paper concludes by discussing remaining areas where researchers are left to grapple with the different priorities of communities and academia, including dissemination, academic promotion, and sustainability.

Integration of Indigenous and Academic Perspectives

Dickerson et al. (2018) collected in-depth data from 21 of the investigators of IRINAH projects, allowing analysis of characteristics of these studies, including their methods. The authors concluded that these studies all, at least to some degree, shared four characteristics: (a) a desire to benefit from culture-centered knowledge and perspectives from communities, (b) an approach of combining indigenous-based theories and knowledge systems with Western-based intervention paradigms and theories, (c) the use of Western-based methodologies, and (d) the cultural adaptation of evidenced-based interventions. Qualitative methodologies and community-based participatory research (CBPR) approaches were universally used in these IRINAH projects. In addition, various indigenous-based theories and knowledge systems were used alongside or in place of Western-based theories and methods. Cultural adaptations often used formative mixed qualitative and quantitative methods. The authors provide an exploration of a number of the challenges faced when using Western-based scientific methods in the development and analyses of interventions that seek to apply indigenous traditional cultural concepts, values, and practices. The article explores some of the strategies IRINAH investigators employed to address these challenges. The authors used IRINAH case studies to review current scientific practices and explore innovations in these practices. They conclude by suggesting future directions for innovation in intervention science in indigenous settings.

Adaptation of Evidence-Based Interventions with Indigenous Communities

Ivanich et al. (2018) provide two case studies of IRINAH projects that culturally adapted the same evidence-based program through community-engaged collaborative processes with two different indigenous populations. This paper illustrates strategies for adaptation that blended community and cultural strengths with rigorous prevention science approaches. It also illustrates the importance of tailoring adaptations to community context; while beginning in the same place and following similar processes, these two projects ended with quite different interventions, each responsive to the unique needs and strengths of the communities involved. Implications for building evidence around effective methods for cultural adaptation are discussed.

Creation of Interventions from Indigenous Cultural Values and Practices

In the second paper addressing culture in intervention, Walters et al. (2019) note that adapted interventions have shown mixed success in indigenous settings. In response, indigenous communities have called for development of indigenous health promotion programs, and the interest from within communities to participate in this type of research has been noteworthy. In these programs, the local community's cultural worldviews and protocols are prioritized. Drawing on five diverse community-based IRINAH health intervention studies, the author group, comprised of teams of academic researchers and community partners from each of these five communities, describes strategies used to design and implement culturally grounded, in contrast to culturally adapted, models of health promotion. The article highlights an "Indigenist" worldview and protocols defined or characterized through an emphasis, with varying degree and combination, on "original instructions," relational restoration, narrative transformation, and an Indigenist community-based participatory research (ICBPR) process. Each of these five case examples prioritized local indigenous knowledge and positive, strengths-based approaches in constructing multilevel community interventions. This article provides an important first summary in a topic of significant current interest by documenting efforts in indigenous communities to develop culturally based intervention from the "ground-up," describing common elements and defining characteristics of these efforts, along with recommendations for future work.

Implementation of Multilevel Interventions Responsive to Complex Cultural Contexts

Jernigan et al. (2018a) address the importance of considering not just individual-level risk and protective factors but also family-, community-, and policy-level determinants of health in constructing health equity interventions in indigenous communities. Their article focuses on some of the unique challenges in implementing research on these types of multilevel interventions in indigenous settings, a topic not currently adequately addressed in the existing multilevel intervention literature. As such, the article provides a first contribution to the literature in describing common challenges and recommendations for implementation of community-level and multilevel health strategies in indigenous communities. The authors highlight strategies employed by four of the IRINAH grantees as case studies, describing specific challenges each faced and the ways each project responded by intervening on multiple levels within complex systems to impact the health of indigenous community members. These studies emphasized the importance of community-based participatory policy work, the development of new partnerships, and reconnection with cultural traditions in this work. The experience of these four projects highlights the critical need for multilevel interventions to examine both contemporary and historical factors that constitute the social determinants shaping current conditions of health inequity in indigenous communities. These case studies also highlight the importance of sustainability planning in multilevel intervention. Community context and needs must be considered. Sufficient time must be allocated to collaborate with tribal entities and work within systems that all too often operate within environments of scarce resources, insufficient infrastructure, and a history of distrust of outside researchers. The authors conclude that given how we have only now begun to address these challenges, it is understandable we continue to lack a solid evidence base on what works in tribal settings. The projects highlighted here, and the IRINAH work in general, point to examples of efforts that can finally address this need.

Dissemination of Interventions in Indigenous Communities

Jernigan et al. (2018b) describe IRINAH projects in light of dissemination and implementation (D&I) science, emphasizing how little is known about successful scale up of interventions within and across indigenous communities. The authors note that interventions have typically been designed without consideration of their D&I, rendering these interventions fundamentally misaligned with real-world settings issues so often amplified in indigenous communities and contexts. Further, few examples of successfully adapted evidence-based

interventions in indigenous settings have been published, and general literature on the adoption and implementation of evidence-based interventions in indigenous communities is scarce. As a result, the feasibility of scaling-up successful interventions is poorly understood. The IRINAH partners have been generating efficacy data on community-responsive and engaged interventions. These efforts have also been designed to facilitate future D&I, reducing the time between research to practice to benefit indigenous communities, should the intervention prove effective. The authors provide an overview of two key challenges for D&I science with indigenous communities: what constitutes an evidence-based practice in an indigenous setting, and the significant cultural, political, and geographic diversity across indigenous communities. They then use three IRINAH case studies to highlight strategies for scale-up and implementation and conclude with five recommendations to inform future D& I efforts in indigenous settings. These recommendations call for expansion of the use of evidence frameworks that build capacity and allow flexibility, adoption of a CBPR orientation, enhancing sustainability of the intervention in the community of concern, emphasizing external validity in the intervention trial, and prioritizing community member voices in dissemination publication and presentations.

Recommendations for an Engaged Intervention Science with Indigenous Communities

Rasmus et al. (2019) in the concluding paper in this Supplemental Issue summarize major themes across papers and include an overview of some of IRINAH's primary accomplishments to date. The authors offer perspectives on effective strategies for intervention and community-engaged research, recognize persistent challenges, and suggest next steps for advancing indigenous perspectives and frameworks in health intervention research. The discussion critically engages the concept of culture and examines practices of community engagement in indigenous intervention science as occurring along a spectrum as opposed to a static orientation or implementation of approaches. It also questions the standard emphasis on generalizability in intervention research, suggesting that a "sustainability before scalability" model may be more appropriate for intervention science in indigenous and health inequity groups—if not within all groups. In contrast to generalizability, this approach emphasizes and advocates for an understanding of the deep cultural and contextual influences in intervention as an essential first step toward translation and generalizability into other indigenous and diverse community settings. The paper concludes with the implications of this alternative model for the ethics of intervention research in indigenous communities and its imperatives for local control, for culture as a central organizing principle, for optimal levels of community engagement, and for the development of effective strategies for sustainability.

Two commentaries on the Supplemental Issue, by Spero Manson and Joseph Trimble, offer additional perspectives on the future of this work.

IRINAH and the Evolution of Indigenous Health Research

The IRINAH initiative has been the product of several decades of incremental work in indigenous health research. As an initiative, IRINAH reflects the convergence of several forces. Most notably, indigenous communities have asserted their voices, and where applicable, their tribal sovereignty to demand more responsible research practices. There have been important developments at the NIH in response, including the IRINAH grant mechanism highlighted in this Supplemental Issue, and on a broader level, in 2015, the establishment of the NIH Tribal Advisory Committee and the Tribal Health Research Office, located in the Office of the Director. Restorative action by individual researchers and universities, in response to a legacy of distrust, has also been evident over recent years and has resulted in many of the longstanding partnerships foundational to the IRINAH projects. Advances in the CBPR movement have been critical to this process, as evidenced by adoption of CBPR principles by virtually all the IRINAH studies. Application of CBPR has become mainstream in research with indigenous populations (Brockie et al. 2017; Lewis and Boyd 2012; Rasmus 2014) and is a key element of all IRINAH FOAs. Parallel to advancements in CBPR approaches have been methodological innovations for small samples and alternative research designs (Henry et al. 2015; National Academies of Sciences, E.,, and Medicine 2018) that have opened new doors for researchers working with indigenous communities, making rigorous studies more feasible in culturally distinct and diverse settings.

By sharing the promising practices of the IRINAH Consortium, our hope is to support the continued forward momentum of an indigenous intervention science. Together, the articles of the Supplemental Issue offer guidance on strategies for the creation of an engaged intervention science more fully reflective of local cultural preferences, interests, and priorities. Research with indigenous communities should enhance local control, ownership, direction, and self-determination. This alone will ensure that data collected and conclusions drawn will be valid and meaningful and will greatly increase the likelihood that interventions developed will be effective and sustainable. Our hope is these IRINAH case studies provide both a call for action and a roadmap for next steps in the evolution of an intervention science more responsive to the needs and realities of indigenous communities.

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