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An Intervention Science to Advance Underrepresented Perspectives and Indigenous Self-Determination in Health

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Abstract

This concluding article to the Supplemental Issue on *Promoting Health Equity through Rigorous, Culturally Informed Intervention Science: Innovations with Indigenous Populations in the United States* draws themes and conclusions from the innovative practices implemented by the National Institutes of Health *Intervention Research to Improve Native American Health* (IRINAH) consortium. The IRINAH work highlights promising practices for advancing the diverse and underrepresented perspectives essential to develop and test culturally appropriate, effective health interventions in American Indian, Alaska Native, and Native Hawaiian settings. Four emergent themes appear through the IRINAH work. First, community-based participatory research (CBPR) has provided projects an intersectional worldview for bridging cultures and informing an ethics of local control. Second, culture is fundamental as a central organizing principle in IRINAH research and intervention implementation. Third, crucial demands for sustainability of interventions in Indigenous intervention science requires a rethinking of the intervention development process. Finally, tensions persist in Indigenous health research, even as significant strides are made in the field. These themes collectively inform an ethical and rigorous Indigenous intervention science.

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Collectively, they suggest a roadmap for advancing Indigenous perspectives and self-determination in health intervention research. IRINAH studies are leading innovation in intervention science by advancing applications of CBPR in intervention science, promoting new directions in small populations health research, and demonstrating value of participatory team science.

Keywords

American Indian/Alaska Native/Native Hawaiian; intervention science; community based participatory research; team participatory science; ethics; sustainability; Indigenous knowledge systems

“I should braid my hurts into my hair so that they wouldn’t get loose.”

Teresa Moses, Toksook Bay (Rearden et al., 2009, p. 333).

Yup’ik Alaska Native Elder Teresa Moses’ observation is part of a rich, multi-layered reminiscence on sources of strength in the face of adversity. Through it, she reflects on teachings from a childhood during which community life centered around the seasonal subsistence activities, practices, and cultural worldview of traditional Yup’ik systems and structures that organized individual lives within the collective. The complete passage from which this statement is drawn alludes to a distinct cultural logic (Airhihenbuwa, Ford, & Iwelunmor, 2014) about health, healing, and well-being in this Yup’ik context, a logic embedded in community bound through connectedness with the human and the broader natural world. In her own life time, Moses witnessed tremendous change as Yup’ik communities became re-organized around a Western model of settlement life. During this period of imposed change, an existing Yup’ik cultural system would become fragmented as new systems were introduced from outside. These new structures would often be in open conflict with a Yup’ik Indigenous cultural logic that placed people and their problems within social and environmental engagements. Among these newly introduced structures was the system of Western medicine.

In the time before Western medicine was known to the original people of North America, health care was rooted within Indigenous systems (Waldram, 2004). We adopt the term Indigenous to refer to American Indian, Alaska Native, and Native Hawaiian (AIANNH) ethnocultural groups. While the local perspectives regarding health and health care varied widely across the broad diversity of different AIANNH cultural groups, all Indigenous cultures possessed existing practices for preventing, treating, and caring for those suffering from health maladies, misfortunes, and disturbances. Often ecological and holistic (N. V. Mohatt, 2014), these Indigenous perspectives frequently emphasized collective well-being (Jernigan, D’Amico, Duran, & Buchwald, 2019), and interventions drawn from these perspectives included restoration of communal balance and harmony in efforts to impact individual health.

Cultural system fragmentation and decentralization, as reflected in this Yup’ik example, can be found in Indigenous communities across America. While some groups retained stronger hold over their Indigenous health care beliefs and practices, others were forced to end

completely what they believed and had practiced for millennia. Concomitant to colonization, Indigenous groups were additionally impacted by new diseases, and along with new disease came other new challenges to health. Indigenous peoples in North America have displayed remarkable resilience capacities during the ongoing period of colonial transition. Nonetheless, there were significant costs, and current health inequities that burden Indigenous America (Stanley et al., 2019) must be understood as aftermath. The resulting cultural, historical, and socioecological context calls for distinct, innovative ways of intervening to effectively address health inequities, to bring about healing, and to restore Indigenous peoples' health and well-being.

Promising Practices for an Intervention Science for Indigenous Communities Advanced by the *Intervention Research to Improve Native American Health* (IRINAH) Consortium

The National Institutes of Health (NIH) *Intervention Research to Improve Native American Health* (IRINAH) consortium (Crump, Etz, Arroyo, Hemberger, & Srinivasan, 2017) seeks to advance efforts of Indigenous communities to address their most urgent health priorities and reduce the unacceptable burden of health inequities. The IRINAH consortium currently represents 27 projects funded through PAR-11-346 and PAR-14-260 *Interventions for Health Promotion and Disease Prevention in Native American Populations*. This concluding article to the Supplemental Issue on *Promoting Health Equity through Rigorous, Culturally Informed Intervention Science: Innovations with Indigenous Populations in the United States* provides a summary of themes and offers reflections on IRINAH experience to date.

Crump et al. (2017) note the historical record with Indigenous people and the aligned legacy of mistrust between Indigenous communities and researchers. They assert this requires research approaches to address this history and these concerns through (a) respect for tribal sovereignty, (b) use of community-based participatory research (CBPR; Wallerstein, Duran, Oetzel, & Minkler, 2018), and (c) respect for cultural and local knowledge and its specificity. Through the conviction and persistence of Institute leadership, two groundbreaking NIH funding announcements emerged responsive to these requirements. The IRINAH initiative provides an essential resource for communities to engage in tribal-university partnerships. Through these partnerships, IRINAH projects seek to design and implement CBPR health interventions addressing locally defined health priorities using approaches that incorporate Indigenous knowledge, values, and practices.

CBPR, Role of Culture, Sustainability, and Enduring Tensions in the IRINAH Initiative

The IRINAH initiative is uniquely positioned to bridge gaps in knowledge and remedy impassos to an effective intervention science for Indigenous communities. A primary accomplishment of this effort to date provides a set of promising practices for an intervention science that truly advances underrepresented Indigenous perspectives. A review of the papers in this Supplemental Issue identifies four key themes that emerge from the collective work of IRINAH investigators. The themes are relevant to researchers working

with Indigenous populations along with intervention researchers working with other health inequity communities. These themes are (a) role of community-based participatory research (CBPR) as an intersectional worldview bridging worldviews and informing an ethics of local control, (b) culture as a central organizing principle for research and intervention implementation, (c) sustainability of interventions as a critical design consideration, and (d) tensions in Indigenous health research that persist, even as significant strides are made in the field. The themes encompass promising intervention research processes and practices, and highlight challenges to be addressed in advancing Indigenous perspectives and self-determination in health intervention research.

CBPR as an Intersectional Worldview in Indigenous Intervention Science

A first theme universal to all IRINAH projects was key role of CBPR. CBPR in the IRINAH initiative occurs across a spectrum of community engagement, with variation in the depth of engagement and extent of local control. However, the critical role of CBPR perspectives to each IRINAH project in producing effective and truly sustainable services is invariant. In addition to providing working examples of different strategies through which to engage communities (Whitesell, Mousseau, Parker, Rasmus, & Allen, 2018), the IRINAH portfolio outlines next steps in a broader examination of CBPR intervention science.

CBPR can be more completely understood as a bridge across a range of epistemological perspectives. Notably, the deep community engagement processes in IRINAH positions CBPR as intersectional worldview, bridging western and Indigenous knowledge systems and practices. Community engagement in IRINAH makes possible synergistic research collaborations, allowing cultural bridging and creating avenues wherein research incorporates local Indigenous concepts and structures in intervention design and implementation. As one outcome of these intersectional CBPR processes, all the IRINAH projects document local control and community decision-making in the research. Community engagement plays a pivotal role in each IRINAH project, reflecting the centrality of CBPR as a best practice for intervention research with Indigenous communities.

Diversity of CBPR on a continuum of practice.—The articles in this Supplemental Issue describe community engagement as a shared value among all IRINAH investigators and universal practice across the studies (Whitesell et al., 2018). Most IRINAH teams have at least one co-investigator or named key personnel from the collaborating communities, and several teams are led by Indigenous principal investigators (PIs).

Despite uniformity in the commitment to community engagement, there is notable diversity across IRINAH projects in the process of engagement. Not all project teams are configured in the same way nor do they conform to the same set of CBPR practices. IRINAH teams instead utilize dynamic strategies to respond flexibly to unique local histories, cultural and contextual characteristics, and events in the communities. These fluid, relational, and dynamic practices emerge through negotiation with community prerogatives, values, and cultural protocols. This flexibility becomes particularly important when IRINAH project aims and research designs prove incompatible with these prerogatives, values, and cultural protocols.

CBPR implemented in IRINAH is best understood through approaches occupying a continuum of community engagement and local direction. Some project settings are characterized by consistently high engagement and local control. This is particularly the case in interventions designed and developed by community members focused on social determinants and community-level factors, or that directly utilize culture and cultural practices as the basis for intervention activities (Walters et al., 2018). Other IRINAH intervention science efforts include trials adapting evidence-based practices to new settings, such as to Tribal or urban Indigenous health clinics. These later projects may employ high community engagement in key parts of the research process, such as during cultural and linguistic adaptation of the intervention, but then may have less community direction in research design and assessment of fidelity and outcomes.

The projects also demonstrate how specific challenges and limitations are inherent within all research relationships. For example, high engagement and strong local control may lower potential for ethics breaches in communities and tribal contexts, while at the same time introducing challenges within a research funding context characterized by timelines and grant requirements. Tribal-university partnerships are often negotiated around these ethical and institutional terms (Gittelsohn, et al., 2018), with CBPR as the means of navigating and translating between the value systems and priorities of the partners.

Cultural bridging and an intersectional worldview.—Engagement often grows and intensifies in the IRINAH experience following an initial relationship building stage. Several IRINAH projects provide exceptional examples of long term CBPR. These projects span decades of collaboration prior to the current IRINAH grant award, and have resulted in deep levels of relational engagement between tribal communities and organizations, and their university partners (Ivanich, et al., 2018; Walters, et al., 2018). These projects provide examples that go beyond community engagement and cultural adaptation or grounding, and transform the CBPR into a process facilitating and navigating an intersectional world. At the center is cultural bridging through the meetings and intersections of western and Indigenous core epistemologies, values, and practices (Dickerson et al., 2018).

‘Cultural bridging’ is an essential step within a CBPR worldview that seeks to facilitate community priorities into a translational pathway, over one in which engagement is simply used as an instrumental strategy to accomplish pre-determined aims of researchers that are not collaboratively developed and locally defined (Trickett, 2011). In service of an intersectional worldview, CBPR in many IRINAH projects seek out and construct translatable spaces where concepts or ideas may speak meaningfully to individuals across knowledge systems. The IRINAH initiative sheds new light on translational research with Indigenous communities, demonstrating how cultural bridging, defined as the intentional creation of shared and co-valued spaces where western and Indigenous knowledge can co-exist, occupies a fundamental role in (a) tribal capacity building (Gittelsohn et al., 2018), (b) cultural adaptation of evidence-based interventions (Ivanich et al., 2019), (c) development and evaluation of culturally-grounded interventions (Walters et al., 2018), (d) implementation and dissemination of interventions (Jernigan, D’Amico, et al., 2019), and (f) sustainability of interventions (Jernigan, D’Amico, & Kaholokula, 2019). Cultural bridging and intersectional worldview are essential components enabling Indigenous communities,

tribes, and organizations to assume local control and determine pathways to sustainability once the grant has ended.

An ethics of local control and tribal self-determination.—The IRINAH projects demonstrate how tribal capacity building and local control are fundamentally contingent on the unique cultural characteristics and contact histories of each community. The IRINAH consortium represents a vast diversity of Indigenous communities. All Indigenous cultures and systems were impacted by colonial disruption and influx of new populations into Indigenously inhabited areas. However, AIANNH communities have diverse, and in some cases, unique structures and systems differentially impacted by waves and types of colonial processes and outcomes. Resulting changes to the Indigenous systems are often forced and involuntary, then formalized through agreements with the U.S. government. These can heavily influence ability and capacity of a tribe or Indigenous community to regain and assert local control and self-determination over health services. Some communities face additional challenges, including higher dispersion and internal diversity (urban Indigenous communities), or current denial of formal federal tribal status recognition (NH). As a collective representation of Indigenous intervention science initiatives, the IRINAH consortium highlights important differences between AIANNH groups in community structures and systems. Acknowledging and understanding these differences can inform effective strategies for tribal capacity building (Gittelsohn et al., 2018). Capacity building promotes local control, which fosters ownership and tribal self-determination of both the intervention and the research.

Culture as Organizing Principle

A second cross-cutting theme emergent through the IRINAH work is the centrality of culture. Culture has been as closely and consistently examined through the research described in the IRINAH Supplemental Issue as in any comparable initiative in the NIH portfolio. Implicit in implementation of a CBPR perspective across the IRINAH projects is recognition of culture as fundamental to effective intervention design, implementation, and research in Indigenous settings. This focus on culture as key to successful intervention implementation and health outcomes is evident in all the IRINAH projects and highlights the importance of culture as a core organizing principle of Indigenous intervention science.

As with their approach to CBPR, IRINAH projects adopt a spectrum of approaches and perspectives with regards to cultural orientation and cultural grounding of its interventions. Some projects focus on cultural contextual factors in the implementation of evidence-based interventions, others examine cultural adaptations, while others examine culturally-grounded and Indigenously developed frameworks (Dickerson et al., 2018; Ivanich et al., 2019; Walters et al., 2018). While each of AIANNH communities represented in IRINAH has a unique culture with a distinct set of norms, teachings, and practices, all Indigenous communities are organized around their cultures in functional ways. These organizing principles of culture can include, in a partial and incomplete listing, such factors as collectivism, orientation to the land and seasons, connection to ancestry, kinship, extended families, valuing of ceremony, ritual and spiritual beliefs. These factors may all appear in different forms, yet often function in similar or generalizable ways within each community

and intervention research process (Trickett, 2011, Hawe, et al., 2004). So, even as Walters et al. (2018) report on the different ways IRINAH interventions are culturally-grounded within their specific contexts and systems, there arise clear and potentially measurable connections within the process each community and intervention team is taking and the function these forms serve as integral to achieving health outcomes.

IRINAH projects provide numerous examples of strategies to effectively address key gaps identified in a recent NIH Office of Behavioral and Social Sciences Research (OBSSR) technical report promoting broader adoption of a cultural framework for health research and program design (Kagawa-Singer, Dressler, George, & Elwood, 2015). One outgrowth of IRINAH points intervention science to next steps in more critical examination of the concept of culture as advocated in the report, including its measurement, engagement in intervention design and implementation, and translational implications (Dickerson et al., 2018).

Understanding culture as organizing principle, rather than as a discrete set of practices, values, norms, and traditions, can facilitate transportability of interventions across cultural groups. By expanding focus from adaptation to a translation between underlying western and Indigenous cultural systems it can inform and guide implementation (Bernal & Adames, 2017). Cultural translation between organizing principles and knowledge systems can also at times reveal that what on the surface may look quite different, on closer examination may represent shared, mutually valued, and even concurrent positions. The IRINAH projects are breaking ground in translational research within intervention science through this type of intersubjectivity guided by CBPR perspectives, positioning culture as key to health outcomes for all populations.

Sustainability of Intervention in Indigenous Settings

A third theme, emphasized by all the papers, spotlights critical need and associated challenges with intervention sustainability, defined as capacity of an intervention to be continued by community systems (Rabin et al., 2008). Indigenous communities, while home to significant cultural strengths and community resilience, are at the same time often confronted by scarcity of resources to address significant and unmet need. It has been a rare accomplishment in the published literature to demonstrate intervention effectiveness through trials research in an Indigenous setting; and an even more difficult to attain standard involves sustainability of these efforts following the trial, when the infusion of research resources ends.

The funding of health services in many Indigenous communities is dependent on external sources, a large portion of which are federal programs and grants. Researchers generally have significant grant writing experience. Because of this, at the end of an intervention science project, it has been quite typical in Indigenous community-researcher partnerships, and is the experience of the majority of IRINAH researchers, to be asked to assist in services grant writing to sustain the intervention, and development of a business plan for services following the trial. Researchers are often called upon to provide their understanding of funding source options, and co-devise often innovative and creative solutions involving mixed sources of funding, blending diverse elements that can include local programs,

organizations, and services, with such mechanisms as foundation support, third party billing, and federal services grants.

Intervention science in settings of scarcity.—Important ethical considerations associated with intervention science among historically underserved, marginalized, and oppressed communities emphasize the critical importance of these sustainability efforts following demonstration of intervention efficacy. Without sustainability, intervention science efforts can perpetuate the historically negative views of research in many Indigenous communities as extractive and exploitative. Failure in sustainability reproduces stereotypes of research as using community members to test research questions of interest to scientists, who part ways at the end of funding to advance their careers through the outcomes of the research, while leaving little of direct benefit with the community in which they have worked. Additional ethical concerns arise through risk of doing harm; when intervention is not sustainable through the resources accessible to the community, demoralization can result in the collapse of a valued and effective intervention originally established through hard work and sacrifice of community members. Further, departure of the research team alongside such collapse can be experienced as a betrayal of trust, putting future research and the trusted community project staff and advocates who encouraged the collaboration at risk. To first do no harm implies not starting something that will in high likelihood cease with the end of the study.

A sustainability before scalability model for an Indigenous intervention science.—No community wishes to be treated as a laboratory. Further, though intervention effects may be measurable in the short-term of the one to five-year time frames of most trials research, health problems that an Indigenous intervention science seeks to address include a complex set of social determinants that require long-term solutions. While gains have been made in changing the negative perspectives about research in AIANNH communities (Rasmus, 2014), growing concern around ‘grants coming and going’ (Allen, et al., 2012), and in the case of intervention research, taking the services with them, threatens to overturn these positive movements. Many Indigenous communities operate in a setting of scarcity; grants coming and going perpetuates a cycle familiar to many Indigenous communities, where hope is introduced when potential solutions and resources for solution arrives, only to be dashed when resources are again withdrawn. These ethical considerations, often part and parcel of Indigenous intervention science, pose significant additional challenges, and advocate for a ‘sustainability before scalability’ model for intervention research efforts in these communities.

Fundamental to the sustainability before scalability model is planning forward as part of the intervention development stage. Planning forward involves some fundamental realignments of the process sequence in intervention research by building sustainability considerations into the initial processes of intervention design. This allows consideration sufficiently early in the development process of an intervention to systematically identify, then address potential challenges and barriers to sustainability through a detailed assessment of community resources and capacity. In contrast to sole focus on proof of concept of the intervention theory of change through efficacy trial under ideal conditions, this requires

planning for fit of concept to context, including the local ecology of services and its funding environment. A sustainability before scalability model also serves as an instrumental strategy by facilitating the alteration of a scarcity and deficit framework into strengths-based, resource building structures.

This contrasts with current practices in intervention development, which approach sustainability almost as afterthought. In the conventional approach, sustainability enters serious consideration only after intervention is demonstrated efficacious under the ideal conditions of an efficacy trial. The approach has been challenged by sustainability theorists (Chambers et al., 2013), there exists limited literature to guide this alternative intervention development approach (Wiltsey et al., 2012), with similar limitations in the research on the sustainability of culturally adapted programs (Barrera, Berkel, & Castro, 2016). Many of the IRINAH studies provide models of this approach dissemination and implementation considerations in parallel with intervention development and effectiveness trials while also highlighting the value of community engagement in understanding how interventions fit community needs and resources in ways making intervention not only more effective but more viable (Jernigan, D'Amico & Kaholokula, 2018). Designing for sustainability is particularly critical for interventions with under-resourced Indigenous communities.

Cultural and relational dimensions of sustainability.—These sustainability criteria are also inextricably linked to centrality of culture. Sustainability is understood as deeply influenced by characteristics of the setting including its community and institutions (Cooper et al., 2015) and requiring of efforts to boost fit with this community context (Chambers et al., 2013). Sustainability demands understanding of the deep influences that cultural and contextual factors exert on intervention in Indigenous communities. This process of fit to community of the intervention requires detailed knowledge of the context carrying capacity for each element of the intervention as part of the planning and design process. This requires that researchers know the community context well, and develop trusting and honest relationships with local expertise who know it even better (Cooper et al., 2015). Understanding how these factors impact implementation and the capacity to sustain implementation is an essential step in a translational science within AIANNH community settings.

A second dimension of culture that exerts additional influence involves relationships with community partners. Research with Indigenous communities, rural and urban alike, comes with relational and ethical imperatives often unacknowledged and typically not supported within the culture of western university and academic systems. Time away from the office is required to establish ongoing community presence, demonstrate long-term involvement, and develop personal relationships that all extend beyond the life and scope of the research or grant. These are standards in an ethics of sustainability that can come to count against a researcher, particularly one positioned in an academic environment with an 'up or out' promotion process. Being in the community for weeks at a time will inevitably conflict with expectations for teaching, dissertation supervision, advising, and university service, and can impact teaching evaluations, publication rate, and professional recognition. While there exists recent interest in engaged scholarship at many Universities, there is often less full understanding of its demands. Current assessment benchmarks of scholarly productivity do

not account for the relationship development element of this work. This is all particularly true for investigators who are members of Indigenous communities themselves. While local Indigenous researchers can contribute lived experience and knowledge to the implementation and application of science in Indigenous communities, they must often navigate enhanced accountability and added expectations of group co-membership and kinship. How to not make ethical Indigenous intervention science a professional liability is an unfinished agenda and a work in progress.

An ethic of sustainability.—These considerations of sustainability transform research into a science for communities consistent with the CBPR worldview. In the ethics of intervention science within a community engaged, CBPR framework, sustainability at the local level is a necessary first step and a milestone in the progression of efforts to achieving broader generalizability of the intervention. Sustaining interventions at the local level will often inevitably involve issues of generalizability as the intervention is sustained generationally across time in the same community, or through dissemination and implementation to other local communities interested by its success, or to other cultural groups. The IRINAH initiative presents a rare opportunity to expedite and expand a dissemination and implementation science within Indigenous and other health disparities populations through multiple rounds of funding under its NIH mechanism (Jernigan et al., 2018).

Tensions in Contemporary Intervention Science with Indigenous Communities

A fourth emergent theme encompasses enduring tensions that accompany these promising practices in intervention science for Indigenous communities. Notable frictions reverberate through the articles in the IRINAH Supplemental Issue surrounding an interrelated set of controversies the research teams continue to encounter surrounding biases regarding generalizability, narrow definitions of methodological rigor, and dismissive attitudes toward local explanatory models and knowledge systems. These challenges reflect inadequate consideration of culture and context in current intervention science practices.

Generalizability of research findings is often an important consideration for NIH review panels as a criterion for funding. Tensions inherent in a primary emphasis on generalizability of the research among the IRINAH grantees reflects broader opposing perspectives within science (Hall, Yip, & Zarate, 2016). One perspective, a generalizability approach, aims to discover similarities and universalities across diverse groups, attempting to establish whether a theory, model, or intervention developed for one group generalizes to others. A second perspective, a group differences approach, explores variability of a theory, model, or intervention developed in one group in another group, and attempts to determine the generalizability and limits to generalizability across different groups, including different cultural groups.

A third perspective, a multicultural approach, focuses on specifying and measuring the mechanisms of culture impacting health among ethnocultural groups that are underrepresented in the research; implicit in this stance is no assumption that characteristics in one group necessarily exist in others. Many of the IRINAH researchers align with this

third perspective, adopting an “inside-out” model (Hall et al., 2016) that emphasizes Indigenous perspectives underrepresented in the intervention research, and places a secondary emphasis on generalizability. There are numerous reasons for this alignment. Universal approaches instead aligned with the first perspective can privilege research that overlooks group differences responsible for differential intervention outcomes. In contrast, IRINAH projects emphasize understanding of the deep cultural and contextual influences in intervention as an essential first step in translational research. Underlying the approach is a valuing of underrepresented Indigenous health and health beliefs models, viewpoints, and worldviews, and of local strategies for intervention guided by such models. These are valued because the worldviews and aligned underrepresented viewpoints have merit independent of their relationship to other groups, and are likely critical to understanding factors important in IRINAH intervention effectiveness. What is generalizable to other populations in IRINAH interventions are not necessarily their intervention components, meaning the specific activities, practices, and content, or the form of the intervention, but instead the functions (Hawe et al., 2004; Trickett, 2011,) they serve in promoting health. Function includes the guiding theories of change and organizing processes of implementation that may prove transferable and resonate across diverse sociocultural, geographic, and ethnic contexts.

A second set of tensions arises in response to current standards defining methodological rigor, which often determine the types of research designs endorsed by review panels for funding. Dickerson et al. (2018) note in their review of the current IRINAH portfolio that randomized controlled trial (RCT) designs were employed in 81% of the projects. However, in many of the settings and for many of the questions for which research with Indigenous communities is conducted, “it is counter-productive to insist that RCTs are the gold standard” (Deaton & Cartwright, 2018, p. 14).

Reasons for this are manifold. Purposeful exclusion from intervention viewed as beneficial can raise ethical concerns (Harding et al., 2012). These concerns arise within a context of historical distrust of research by communities (Pacheco et al., 2013) and a history of recent researcher misconduct in tribal settings (G. V. Mohatt, 1989; Sterling, 2011). Additionally, implementation of RCTs is not always feasible nor desirable from scientific perspectives. RCTs possess several methodological deficiencies relevant to Indigenous research settings, and more generally to community-level or population health intervention. The RFA funding IRINAH stipulates all intervention efforts be multi-level. RCT assumptions can often not be met when the social unit of analysis is clusters of individuals; bias is introduced through differences in sample sizes across clusters (Eldridge, Ashby, & Kerry, 2006) or with fixed numbers of clusters (Hemming et al., 2011), which is often the case in community-level intervention research among culturally distinct rural tribal groups with limited numbers of communities. Further, instead of description and modeling of context, RCTs attempt to control for variation across units. In group level interventions such as community interventions across culturally distinct settings, this results in attempt to control for the local distinctiveness central to the community intervention paradigm (Trickett et al., 2011), and potentially, to intervention effectiveness. Group randomization may not even be pragmatically possible on the level of population health research (Sanson-Fisher, Bonevski, Green, & D’Este, 2007), and randomization of individuals, families, or groups so only some benefit may similarly not be feasible or even ethical, particularly within small communities

(West et al., 2008) that are typical to Indigenous health research. Finally, RCTs are inefficient in their use of statistical power (Henry, Fok, & Allen, 2015), in poor match to the small populations and samples common to Indigenous health research, and this increases the likelihood of underpowered studies. This mismatch with context is all the more notable given current re-examinations of the RCT as gold standard within mainstream medicine (Frieden, 2017), preventative medicine (Sanson-Fisher et al., 2007), social science (Deaton & Cartwright, 2018), public health (West et al., 2008), and prevention science (Henry, Tolan, Gorman-Smith, & Schoeny, 2017), all converging on the same conclusion that, “There is no single, best approach to the study of health interventions” (Frieden, 2017, p. 472).

Unintended consequences of this over reliance on RCT designs has implications for Indigenous health research. Current standards can unintentionally privilege particular intervention approaches. For example, individual-level interventions may be emphasized because they are easier to test using an RCT design, not because they are the most appropriate or potentially most effective for the health problem and the community context. Research on promising context responsive interventions, based in Indigenous theories of change and implementation models may be meanwhile passed over as too complicated to undertake within the RCT design framework. In addition, easier to study groups that can produce larger easily accessible sample sizes reap benefits of intervention research while small, culturally distinct AIANNH communities facing substantial health inequities are passed over (Henry et al., 2015; Whitesell et al., 2018). These consequences impact the capacity of intervention science to effectively study populations, models, and solutions of potentially greatest societal importance (West, 2009), and often, of greatest importance to the Indigenous communities of concern.

A final set of tensions emerge as health researchers engage with Indigenous explanatory models and knowledge systems. Current standards defining methodological rigor make study of many potentially effective health promotion and prevention approaches difficult. As a result, some of the most creative and potentially effective work in Indigenous communities involves grassroots efforts largely absent from the intervention science literature. Instead, these promising intervention efforts, while enjoying significant local buy-in and enthusiasm, remain understudied, poorly disseminated, and poorly understood by mainstream intervention science.

IRINAH Innovations in Community Based Participatory Research, Small Population Research, and Participatory Team Science

The IRINAH initiative, as a collective, represents one of the most broad-scale, multi-site applications of CBPR to date. It spans an entire program of research, funded by a substantial NIH investment (Whitesell et al., 2018). The IRINAH projects have significantly advanced AIANNH health research; driving innovations in prevention and intervention science, small populations research, and participatory team science. Pervasive across the diverse IRINAH projects is the strong presence and growing leadership of Indigenous PIs, co-investigators, and community collaborators in intervention science and health disparities research. The community engagement and leadership in IRINAH serves an important function by creating

a shared start point for western scientific perspectives and Indigenous knowledge working together. Starting with the same basic premises and goals, this engagement has facilitated methods and processes in the production of new knowledge and effective practices in which both perspectives provided contribution. While science and the scientific method may not always be perceived as inherently opposed to Indigenous worldviews and knowledge systems, some applications have most certainly been deleterious and disruptive to communities (Mohatt, 1989). An important paradigm shift that has occurred in part through the IRINAH consortium and other like initiatives; many researchers have reframed their approach from conducting research in the service of science towards enacting a science in the service of communities.

A second innovative contribution of the IRINAH projects reflected in the Supplemental Issue articles is the critical importance of small populations research to health disparities science (National Academies of Sciences, 2018). IRINAH showcases a variety of methods and ethical considerations in research with small and difficult to access populations, and with small samples. Many of the IRINAH projects are required to consider efficiency at every step in design and analytic choices as they confront statistical power considerations. IRINAH small sample studies with culturally distinct Indigenous groups have led to community and population level interventions with broad potential societal impacts, and provide intervention science innovation in methods using empirical data to guide development of intervention and to establish what is effective for health inequities groups. IRINAH projects make use of a variety of promising practices in optimization strategies that include contemporary statistical and measurement approaches, alternative research designs that make more complete use of available information, and mixed methods that provide new possibilities in qualitative research (Henry et al., 2015). The IRINAH research also highlights additional challenges associated with a biases regarding generalizability, what constitutes acceptable knowledge, and research designs with limitations to fit with context, cultural protocols, ethical concerns, and local practices (Etz & Arroyo, 2015).

A final innovation documented in the IRINAH Supplemental Issue is the formation of one of the first participatory team science efforts across a program of research in the U.S. Interdisciplinary team science (National Research Council, 2015) involves a collaboration across disciplinary traditions to interdependently produce shared understanding in regards to a scientific question, or a social or health problem, then blends disciplinary approaches and methods to address the problem. Team science is intended to study scientific problems in new ways through unique combinations of disciplinary perspectives. Participatory team science (Tebes & Thai, 2018) is a type of team science in which public stakeholders are included on teams. In IRINAH, high levels of community engagement have been instrumental in creation of trust and research that is more consonant with cultural practices and protocols. Engagement has been critical to identification of important and potentially overlooked ethical considerations, and perhaps most novel, the promotion of new shared understanding melding western scientific perspectives with Indigenous knowledge systems. Participatory team science has important distinctions from CBPR (Wallerstein et al., 2018) in that inclusion of public stakeholders in all phases of the research occurs for its potential added scientific value. What CBPR and participatory team science share are the value of equity; equity is expressed in how power is shared across the collaboration and in how each

collaborator is acknowledged as having important expertise and perspective to contribute (Tebes, 2018). Community participation on science teams can occupy an important and critical role in the co-production of knowledge and more broadly, the promotion of social justice and health equity. In addition to its example as a large-scale application of CBPR, the NIH *Interventions for Health Promotion and Disease Prevention in Native American Populations* grant mechanisms have funded one of the first large scale implementations of participatory team science. Collectively, IRINAH provides the broader scientific community with an early example of participatory team science that serves as model for future scientific collaborations, including large scale center and center grant efforts.

The innovative work of individual research teams addressing health inequity within AIANNH communities has been amplified and consolidated through the collective network of the IRINAH consortium. The papers in this Supplemental Issue catalog innovation in this work to distill key lessons learned and share strategies developed. More broadly, the IRINAH work provides guidance to all researchers working with communities to achieve health equity. IRINAH has advanced several promising practices and articulates challenges for an Indigenous intervention science of great potential, in which much work remains to be accomplished.

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