

Journal of Indigenous Research

Full Circle: Returning Native Research to the People

Volume 9 | Issue 2021

Article 5

February 2021

Post-Pandemic, Translational Research, and Indigenous Communities

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Recommended Citation

Haring, Rodney C.; McNaughton, Laticia; Seneca, Dean S.; Henry, Whitney Ann E.; and Warne, Donald (2021) "Post-Pandemic, Translational Research, and Indigenous Communities," *Journal of Indigenous Research*: Vol. 9 : Iss. 2021 , Article 5.

Available at: <https://digitalcommons.usu.edu/kicjir/vol9/iss2021/5>

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Post-Pandemic, Translational Research, and Indigenous Communities

Cover Page Footnote

Acknowledgements: Native American Grandparents Club, Native urban center partners, Native CIRCLE, Roswell Park's Cancer Center Support Grant NCI (P30CA016056) Disclaimer: Perspectives are those of the authors and do not necessarily represent the official position of respective author institutions.

INTRODUCTION

Da:h onēh dih əswe:he:k ɛdwajɛ:nō:ni' sga:d hɛdwa:yɛ' ɔgwa'nigöɛ' dɛdwadahno:nyö:' ha'deyögwe'dage:h. Da:h ne'hoh dih nɛyögwa'nigo'dɛ:ök. (So now, we will give it all our thought and carefully give thanks to all the people. Let it be that way in our minds.) *Da:h onēh dih əswe:he:k ɛdwajɛ:nō:ni' sga:d hɛdwa:yɛ' ɔgwa'nigöɛ' dɛyethinö:nyö:' ha'dewənödɛ:nö:de:' Johehgöh. Da:h ne'hoh dih nɛyögwa'nigo'dɛ:ök.* (And so now we will give it all our thought and carefully give thanks to Our Life Sustainers, the Three Sisters. And let it be that way in our minds (Bowen *et al.*, 2013)).

The Thanksgiving Address, or Ganö:nyök, is referred to in the Haudenosaunee Nations (Iroquois) as “the words that come before all else.” The above passage is only a small piece of the entire opening and translates into putting “all of our minds together” towards the appreciation of the relationships between our environment, populations, and celestial worlds, including the life-sustainers known as the staples of Haudenosaunee life: corn, beans, and squash. In ancient Haudenosaunee cultures, sustainability is represented in the original food sources, which continues to translate to modern-day practices of food use, medicine, and sovereignty movements. The definition of sustainability is the ongoing use of something meaningful, healthy, and continued, evident in Haudenosaunee cultures. Overall, this perspectives paper advances the conversation by discussing pandemic research, translation, and sustainability with a focus on post-pandemic behavioral

interventions and health promotion (e.g., cancer prevention, mental health, diet and exercise) beyond clinical trials and future COVID-19 vaccine dissemination.

HISTORY, PANDEMICS, AND INDIGENOUS COMMUNITIES

Indigenous peoples have a historically traumatic past with pandemics. These were directly related to new viruses emerging from North America's first visitors. Indigenous Peoples of what is now labeled as North American had never experienced smallpox, measles or influenza before, and the viruses spread across the continent, killing an estimated 90% of Indigenous Peoples. The most destructive diseases being smallpox with the first wave happening in 1518. The Lakota Nation called the disease, running face sickness, and it was deadly bringing continued waves, sweeping across the same Native Nation, repeatedly. In 1639, a smallpox epidemic devastated the Huron Nation in the St. Lawrence and Great Lakes regions. The disease reached the Huron Nation through traders returning from Québec who remained in the region throughout the winter. Disease cut the Huron population in half, going from 18,000 people in 1634 to nearly 9,000 just about five years later. The Haudenosaunee or Iroquois Nations faced similar losses. In the 1770s, smallpox wiped out an estimated 30% of the West Coast Native American Nations. A decade later in the 1880's the same disease devastated Indigenous Populations of the Great Plains (Marr & Cathey, 2010; PBS, 2005).

The disproportionate effect of infectious diseases on Indigenous Peoples can be linked to contemporary health disparities with higher risk due to chronic

disease disparities and to new microbes being introduced into an immunologically naive population. However, members of numerous populations exposed to these pathogens had no prior exposure to the contagion and did not display mortality rates equivalent to those of Indigenous Peoples after the same infection (e.g., smallpox). It has also been proposed that increased susceptibility of Indigenous Peoples to these infectious diseases could be attributed to genetic influences (Ghio, 2017). The devastation from disease and depopulation overwhelmed Indigenous communities in many ways. The division of labor and interdependence that was characteristic of many Indigenous cultures was greatly impacted by epidemics. Fewer people were available to hunt, plant crops, or support their community in other ways. Loss of Indigenous Knowledge transfer also impacted the population and cultural and ancestral continuance.

The current COVID-19 pandemic has caused many to reflect upon the nature of pandemics in the world. In summary, Indigenous Peoples were afflicted with many diseases brought to their ancestral homelands including smallpox, bubonic plague, chicken pox, flu, malaria, measles, scarlet fever, some sexually transmitted disease, and tuberculosis. These produced unspeakable destruction to Indigenous populations, in the form of disability, illness, and extensive deaths along with cultural loss. Present day pandemic statistics reveal that although non-Hispanic American Indian and Alaska Native (AI/AN)—Indigenous Peoples—account for 0.7% of the U.S. population, a recent analysis reported that 1.3% of

COVID-19 cases provided to the CDC with known race and ethnicity were among Indigenous persons. Historical trauma and persisting racial inequity have contributed to disparities in health and socioeconomic factors between Indigenous and white populations that have adversely affected Indigenous communities; these factors likely contribute to the observed elevated incidence of COVID-19 among Indigenous populations. These findings suggest that the Indigenous population in the 23 examined states, particularly Indigenous persons aged <65 years (e.g., wisdom keepers; language holders) were disproportionately affected by the COVID-19 pandemic, compared with the white population (Hatcher, Agnew-Brune, Anderson, et al., 2020).

TRANSLATIONAL SCIENCE AND INDIGENOUS COMMUNITIES

Translational science is a multidisciplinary collaboration approach and seeks to advance interventions for widespread community-based implementation for the improvement of health outcomes. The science follows an action-oriented four-step process: T1 → T2 → T3 → T4. T1 is research that may move from animal trials to human trials or research that is conducted with a small group of people to test safety and initial intervention procedure. T2 moves the research to patient or into pilot programs with small populations to test initial effectiveness. T3 is the dissemination and implementation research phase that tests effectiveness in larger populations and may compare the intervention to other interventions, while T4 moves the intervention into larger multi-site studies, population outcome studies,

and into the public health realm (Zerhouni, E.A., 2005; Morrow, G.R. & Bellg, A.J., 1994; Garfield *et al.*, 2003).

Translational research, including dissemination and implementation *specific* research, has had little mention in Indigenous communities. This includes pandemic translational research. However, there are frameworks that include components of translational research comprised of community-based participatory research and research-to-practice models (e.g., Kaholokula *et al.*, 2014; Crump *et al.*, 2017; Walters *et al.*, 2018). Jernigan *et al.*, (2018) also provides recommendations that included capacity-building and community-based participatory research (CBPR) to culturally tailor prevention strategies towards dissemination and implementation investigation. In the United States, there have also been funding initiatives aimed to encourage community-engaged science and sustainability (National Institutes of Health, Intervention Research to Improve Native American Health). However, an area of growing need can be found in Indigenous-specific translational, dissemination, or implementation science modeling that requires or requires T1 through T4 language or structuring.

In the forefront of the COVID-19 pandemic, the NIH awarded \$12 million for outreach and engagement efforts in ethnic and racial minority communities affected by the pandemic and created a support team across several states as part of the NIH Community Engagement Alliance (CEAL) Against COVID-19 Disparities (National Institutes of Health, 2020 September 18). NIH further

supplemented this with a release of nearly \$234 million to improve COVID-19 testing for underserved and vulnerable populations including the Rapid Acceleration of Diagnostics (RADx) initiative which collaborated with multiple institutions across the United States with a focus on populations disproportionately affected by the pandemic—including Indigenous groups (National Institutes of Health, 2020 September 30). Although there has been a national and international emergency response in pandemic research funding for COVID-19 with some targeting Indigenous societies, next steps may include Phase 2 set asides for specific sustainable Indigenous-based translational research related to post-pandemic health promotions.

POLICY IMPLICATIONS AND POST PANDEMIC RESPONSES

A national trend to improve population wellness is a focus of *Health in All Policies* (Rudolph *et al.*, 2013). For Native Nations, health policy occurs at multiple levels of government, including federal, state, and tribal. Adding to this complexity, the layered silos of policy—health, social, and education—each exist within federal, state, and tribal governments. Although systemic challenges are significant, we provide policy related perspectives occurring during the current pandemic response that may be helpful visioning forward towards post-pandemic policy initiatives and discussion.

The federal level of government primarily provides funding and broad regulatory oversight of programs and activities, and the states are generally given

policing power to enforce laws and policies, including public health. Key US federal funding agencies include the Centers for Disease Control and Prevention (CDC), Indian Health Service (IHS), the United States Department of Agriculture (USDA), and others. The Environmental Protection Agency (EPA), Food and Drug Administration (FDA), and other federal agencies provide and enforce regulatory guidelines. States are provided resources to develop and implement public health, education, and programs through block grants and related funding streams. However, Native Nations or Indigenous communities are typically not included in these funding streams, and the dearth of resources contributes to the inequities we observe in Indigenous health, education, and prosperity.

The relationship between tribal leadership and the federal government includes a trust responsibility to provide various social services and programs, including health, education, and housing. The Bureau of Indian Affairs (BIA) and IHS are the key federal agencies responsible for carrying out this trust responsibility. Hundreds of Indigenous Nations have treaties with the U.S. government that clearly outline this responsibility. However, significant and chronic [or decades-long] underfunding has resulted in longstanding disparities, including childhood obesity and poor outcomes in health and education, which have contributed to continued intergenerational effects. Native Nations or Indigenous governments do have the sovereign right to develop their own priorities and to implement health in all policies and arenas, including pandemic response initiatives

and community-based interventions for health promotion. Many Native Nations have done this successfully, and these programs have included access to pandemic response resources (e.g., hand-sanitizer, personal protective equipment, health food, stress reduction programs). Unfortunately, many tribes live with challenging social circumstances and poverty, and not every tribe has the resources to implement comprehensive pandemic response packages or programming. The federal government needs to continue to be held responsible for its role in underfunding their treaty obligations and to recognize its role in health disparities more broadly especially during pandemics.

Another option many Native Nations are turning to is state level support. At the state level, significant resources are distributed from the federal government in the form of pandemic response aid. As Native Americans or Indigenous Peoples, community members can be considered to hold a “tri-citizenship” in which Natives are citizens of the U.S., members of tribes, and residents of states. As state residents, Natives also have legal access to state-funded and sponsored public health programs. However, the implementation of these programs in Native Nations is variable by state. Some states are doing well in terms of investing in collaborating with Indigenous health programs, and these states should be considered “best practices” in tribal-state relations. Models for statewide health improvement programming that specifically engages Indigenous communities could provide

templates for other states regarding intergovernmental policymaking to improve Indigenous health outcomes.

Improving communities' economic, physical, social, and service environments can assist in promoting health and supporting positive behaviors. However, public health agencies at any level of government rarely have the mandate, authority, or infrastructure to achieve these outcomes. Entities with the greatest impact on the social determinants of health frequently fall within the purview of many partners outside of public health, such as housing, transportation, education, environmental quality, park systems, criminal justice, and workforce agencies. Solving the complex issues that lead to historical disparities and other health concerns requires collaborative efforts across multiple sectors and at numerous levels of government, as well as businesses, and grass-roots community organizations.

It is important to provide intervention over the entire lifespan not just at the forefront of pandemic responses. Health problems, concerns, and issues cannot be resolved via emergency and short-term response funding mechanisms. There must be an active process in place over a lifetime to see overall results and sustained relationships. Role-modeling is an important component of pandemic translational research. For example, Native Nation to Native Nation, Native Nation to county, or Native Nation to state relationships must be encouraged and empowered to create an inter-generational cycle of wellness for future generations. When taking action

during pandemics, we need to engage the whole community and beyond. This also includes addressing co-occurring prevention means. For example, it is important to recognize the connections between pandemics and other health concerns, including disparities in chronic diseases that adversely impact risk, and translational research must address these dynamic conditions over time to effectively promote population health.

This perspectives paper focuses on translation, dissemination and, ultimately, the sustainability of health promotion and behavioral intervention research programs. Nationally, there appears to be a shift in research funding allocated specifically for the dissemination and translation of health research, cancer disparities research, and obesity interventions. In fact, between 2007 and 2014, 146 projects were funded through policy dissemination and implementation research (D&I) funding announcements. During this time, funding specific to policy D&I totaled \$16,177,250, equivalent to 10.5 % of all funding through D&I funding announcements (Purtle, Peters & Brownson, 2016).

Based on NIH data (Fiscal Year 2018), there were three American Indian, Alaska Native or Indigenous awards based on categorical spending data. These included a conference grant, R13 (\$28K) and two UL1 grants (\$3.75M) for a total of \$3.85M (National Institutes of Health, 2020 February 24). “Moonshot Funds” also funded three cancer centers to work with Indigenous communities in

Oklahoma, Arizona, and New Mexico on colorectal screening and follow up care implementation studies (National Cancer Institute, 2020 September 24).

In other Indigenous communities around the world, a strategic priority in the New Zealand Health Strategy (2017-2027) included building and strengthening of pathways for the translation of research findings into policy and practice in and for Indigenous (Maori) landscapes. Although there is not a detailed mention of dissemination and implementation funding specific for the Maori, the New Zealand Health Research Councils funding in 2020 will be increased to \$120 million, which is part of a 10-year strategy. This includes a major strategy to include Maori partnerships, thus, making a conscious effort to include the Maori as part of their health research principles (Ministry of Business Innovation and Employment & the Ministry of Health, 2017).

Lastly, in January 2019, the government of Canada acknowledged Indigenous rights and traditional knowledge with an announced 116 new grants that were awarded, worth \$5.6 million, to “identify new ways of doing research with Indigenous communities.” This is the first Indigenous Research Capacity and Reconciliation – Connection Grant mechanism to help close the gap in social, economic, environmental, and health disparities between Indigenous and non-Indigenous peoples in Canada (Social Sciences and Humanities Research Council of Canada, 2019).

Globally, Indigenous communities are gaining more access to research funding opportunities. However, there has been little to no information on aggregated pandemic or post-pandemic related dissemination, translational, and implementation research science awards over time for Indigenous communities world-wide. Another limitation is inclusion in the greater portfolio of grants awarded that are not primarily focused on Indigenous populations but include Indigenous populations as part of a smaller sub-sample.

Sustained translational science needs to be a part of the final stages of research projects. By doing so, it, embraces working with Native Nations and Native based organizations in a collaborative partnership to integrate, implement, and continually evaluate pandemic responses in research that are diversity appropriate, science-based, evidence-based, practiced-based evidenced, and support some of the most vulnerable populations, which at times includes Indigenous peoples. This process includes the potential of fast-tracking evidence-based programs using a translational model of science, from pilot study to randomized controlled investigations to community partnership for dissemination and sustainability through such mechanisms as the U.S. Centers for Disease Control and Preventions call for proposals, which honors tribally-orientated and science-based interventions, titled: Tribal Practices for Wellness in Indian Country (Tribal practices for Wellness in Indian Country, 2018). These pathways often scientifically based through the NIH, CDC, or private foundation, put forth an

underpinning for Native initiated, evidenced-based models that break down the walls of conflicted understandings pertaining to diversity, gender honoring, women's health, and other research portfolios, in health care. To exemplify this movement, efforts must be made to encapsulate these findings and outlooks between research, translation, dissemination, sustainability and policies to increase the health of the more than 550 federally recognized and diverse Native Nations that exist in sovereign frameworks within the U.S. and the over 1000 Native Nations, bands, and communities across North American which are often ancestrally related across international waters.

CONCLUDING PERSPECTIVES

Translational research processes focused on pandemic outcomes should also be viewed through a social justice lens. "All methodologies carry within them underlying assumptions that shape both how information – 'data' – is gathered and the kinds of knowledges that are constructed by and through information-gathering and analysis" (Brown & Strega, 2005). Research processes in Indigenous communities should include tribal elders or other keepers of cultural wisdom collaborating with the academic institution, instead of the often one-directional practice of investigation. Pandemic translational science projects in Native communities should assess contemporary data, but these projects also should incorporate traditional and historical perspectives, including Indigenous methodologies, epistemologies, language, and knowledge. (Barker, 2005; Driskill,

2011). The resulting translational framework will be more culturally relevant and can reflect on the lessons learned from historical pandemics in Indigenous landscapes.

As members of the mainstream academic community, many Indigenous scientists are at once academicians, scientists and—in some respect—activists. Indigenous scientists are authors who write, teach, study, speak, and contribute literature for our colleagues and students to consume, but who are also deeply connected to and rooted in their home communities and identity as Indigenous people. A primary goal for most Indigenous scientists is to ensure that the knowledge they are producing is useful and applicable for Indigenous and non-Indigenous Nations. Scientific outcomes can and should be translatable to academia, adjacent communities, and Indigenous populations worldwide. It is also implied that as Indigenous citizens there remains a sense of advocacy for Nations' needs and causes that maintain a protective spirit towards continued sovereignty.

Smith's *Decolonizing Methodologies* (1999) was a groundbreaking work that encouraged Indigenous People to consider the colonizing effects of research and introduced new ways of approaching scholarship and research. Smith, a Maori scholar from New Zealand, contributed a significant piece of conversation to Indigenous studies that is still being discussed among critical thinkers within the field. She offers several suggestions for ways in which Indigenous research can be transformed into decolonizing efforts and notes that utilizing Indigenous

frameworks of knowledge and tradition may be the best way to undertake these. She describes these with a plethora of action verbs using the words “remembering,” “Indigenizing,” “revitalizing,” “intervening,” “reframing,” “restoring,” “returning,” “sharing,” and 17 other descriptions. These are meant to be collaborative activities that nurture and foster our relationships with Indigenous communities, and re-envisioning pandemic research as a shared, reciprocal process. Our paper, perspectives, and process take these methods into consideration by encouraging Indigenous community members to nurture and foster relationships back to the research community in a reciprocal process of re-envisioning results for translation, dissemination, and sustainability.

Translation, dissemination, and the sustainability of pandemic and post-pandemic research are the next likely steps for Indigenous communities. Many Indigenous communities face immediate challenges with pandemics such as COVID-19. However, the same communities continually face co-occurring situations of mental health, substance abuse, motor vehicle accidents, suicide, cancer health disparities, and several other chronic diseases that, in many cases, have reached late stages due to the lack of early screening, annual physicals, and early detection. To combat this, it is imperative to have research initiatives from nationally funded research mechanisms that ensure faster delivery of results back into communities, mobilizing community-based research directly into the community.

This will be best accomplished by federal and non-governmental funding agencies requiring a strong dissemination plan that includes sustainability to improve the health of Indigenous people and future generations. At the national level, there have been several emergency pandemic research funding (e.g., COVID-19) opportunities. Beyond pandemic research awards labeled as CBPR with immediate response, it is uncertain how many mid-to-long range dissemination- and implementation-specific grants have been awarded (or in process of development) to and for Indigenous communities, and what impact they have for the sustainable health of Native Nations. Future research needs to be aware and inclusive of sustainable interventions, pandemic research findings, and their continued and ongoing applicability to Indigenous populations. Developing research paradigms should bridge sustainability and accompanying infrastructure to resolve this need. In conclusion, to address the health and well-being of Indigenous Peoples and their societies, pandemic-related research, interventions, or prevention research needs to be released at a faster rate, once reviewed by the funder and, if found to be significant, also needs to be brought into the communities more quickly in order to meet their needs beyond current emergencies and disaster management.

Future pandemic translational research should focus on making policy changes to encourage research to reach communities in need at faster rates and to be inclusive of all aspects of translation, dissemination, and sustainability. These

policy changes should include both federally-funded and foundation-funded research projects. Pandemic translational research should also be inclusive of the varying administrative capabilities of smaller tribes and tribes with less grant administrative capacities. Pandemic research, in the form of translational research, also has to look forward in building community capacity and applicability of outcomes. Starting with the youth is an important lifespan process of intervention. School-age children who are facing abrupt social disconnection due to the pandemic will be the young adults of tomorrow. Pandemic translational research needs to reconnect with youth and focus on healthy lifestyles, leading to healthier individuals, leading to healthier families, and ultimately healthier communities. Reconnecting to ancestrally related healthy lifestyles including healthy eating and physical activity is imperative to combat obesity and, in the long run, prevents diabetes, heart disease, and weight-related cancers. Ultimately, it is important to link pandemic translational research to the challenges of co-occurring conditions and historical health inequities. Further, it is imperative that these programs continue to extend into other communities that face the same or similar challenges to societal wellness. The importance of translational research during pandemics should be measured by how research is applied, implemented, sustained and adapted for the control, prevention, and well-being of society for seven generations forward and beyond.

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