

## INTRODUCTION TO THE SPECIAL ISSUE

### IMPACT OF THE COVID-19 PANDEMIC ON RESEARCH WITH AMERICAN INDIAN AND ALASKA NATIVE POPULATIONS

Deana Around Him, DrPH, and Amy J. Elliott, PhD

*Abstract: The COVID-19 pandemic forced health research programs across the world to close or pause, threatening the progress of basic science, clinical and social science research, and research careers. Impacts of the pandemic on research occurring with American Indian and Alaska Native (AI/AN) peoples, which is often conducted using community-based and -engaged approaches, offer an opportunity to understand how community-research partnerships shaped decision-making and facilitated adaptations to study design, recruitment, data collection, program implementation, and analyses. The COVID-19 pandemic disproportionately impacted AI/AN peoples, exacerbating many of the health and social inequities already being examined in community-based and -engaged research projects. The nine articles in this special issue share insights from research focused on a variety of topics from food security to diabetes prevention and parenting skills training. In the face of the pandemic, the research teams drew on experience and skills garnered by engaging the perspectives and wisdom of community partners and rooted in the principles of community-based participatory research to respond to shifting research priorities, new processes for remote consent and data collection, and increased needs for clear communication, connection, and support. Lessons from these research teams challenge us to think about how we can carry forward beneficial adaptations to best serve community needs, especially as the pandemic continues and the potential for similar global crises increases.*

Health research faced an unprecedented challenge during the COVID-19 pandemic, with travel restrictions and strict lockdown measures forcing academic institutions to close or pause research programs around the world. All types of ongoing research were interrupted during this

time and onset of new studies delayed. Numerous articles have been published on the effects of the pandemic on basic science, clinical research, and the impact on researchers (e.g., constraints on publication opportunities, funding, networking, hiring) (Sohrabi et al., 2021; Boughey et al., 2021; Fleming et al., 2020; Weiner et al., 2020), but far less attention has been paid to the effects on community-based research. This special issue of *American Indian and Alaska Native Mental Health Research* focuses on the impact of the COVID-19 pandemic on American Indian and Alaska Native (AI/AN) health research, which oftentimes draws on community-based and community-engaged research approaches. Research teams were encouraged to reflect on changes to study design, data collection, participant engagement, and analytic strategies prompted by the pandemic to share how adaptations were made and explain lessons learned.

The COVID-19 pandemic served to highlight and exacerbate health disparities, with AI/AN populations suffering a disproportionate burden of COVID-19 illness, death, and economic ramifications (Arrazola et al., 2020). The Centers for Disease Control and Prevention (CDC) reported an overall COVID-19 incidence that was 3.5 times higher for AI/AN persons (Hatcher et al., 2020). The pandemic layered upon existing economic struggles, health care access challenges, and health inequities, challenging even the most resilient.

It is now common practice that community-based approaches, including community-based participatory research (CBPR), within AI/AN health research is most successful when driven by the community and true collaborations are apparent at all stages (Holkup et al., 2004). This shift in thinking has been driven by Tribal Nations insisting on changes to how research was historically conducted to help prevent misuse and misrepresentation, and to ensure the research is relevant to the needs of AI/AN peoples. The National Institutes of Health (NIH) and other federal entities have involved Tribes to a greater degree in recent years through various initiatives (e.g., Environmental influences on Child Health Outcomes [ECHO] Program), and there are now specific funding mechanisms to support AI/AN health research (e.g., Native American Research Centers for Health [NARCH]).

Researchers that use a CBPR, or related, framework often find these studies have extended timelines to adequately engage key partners and ensure community participation at all stages of the research process (Holkup et al., 2004; Christopher et al., 2011). Typically, multiple regulatory bodies are involved, and may even require individual review of study protocols (Around Him et al., 2019). It also takes time to establish trust and common understandings. It can take a research team years to develop the necessary relationships and earn trust and collaboration from Tribal

Nations and community members prior to the initiation of a project. The infrastructure to support this work is often complex, with multiple sites involved in studies and sometimes great distances separating data collection sites, study personnel, and researchers.

This special issue was conceived by looking at the ramification of COVID-19 on our own AI/AN research programs and speculating how others approached and dealt with this challenging time. Oftentimes journals are limited in space, and publications of study results may not allow adequate room to describe the changes to research design and data collection that occurred in response to the pandemic. Questions like, “Did the pandemic serve to weaken study designs? Were there cases where study designs were, in fact, strengthened as a result? What was the impact and role of the community partnerships?” came to mind. We wanted to give researchers an opportunity to tell their stories of this unique time in history and share lessons that can be carried forward to continue shaping a research environment that benefits AI/AN peoples.

The articles selected for inclusion in this special issue reflect a wide range of study designs, populations involved, and topics of interest. The research teams come from vastly different geographical regions and have varying compositions of institutions involved, including Tribal entities, academic centers, health systems, and community agencies. Despite this diversity and the unique circumstances in each project, clear themes emerged. These overarching themes included shifting of research priorities, pivoting to remote consenting and data collection, and improved communication, connection, and support.

The spring of 2020 required all of us to dramatically shift our day-to-day activities as major areas of society were shut down and travel became severely restricted. Many studies that were in the early stages of their work pivoted their research priorities to better serve their partners during this extremely trying and stressful time. This shifting of research priorities was particularly apparent in the Maudrie et al. (2022) project on food security with the Baltimore Native community. The investigators kept with the original topic of study, as food security issues have been exacerbated with the pandemic, but they shifted their research design and purpose to understand how the pandemic impacted food security to help inform community efforts. Rink et al. (2022) were also able to expand the purpose of their study to inform how public health disasters impact sexual and reproductive health among AI/AN youth. These are just a couple of the examples of how the research teams were able to meet current needs and provide timely information during this unprecedented time.

Others also adapted their research programs but focused on resiliency and the role of culture in responding to the pandemic. Kelley et al. (2022) were in the process of implementing a program with the goal of increasing cultural resilience and sustaining cultural participation over time with four Tribes in the Northern Plains. The pandemic required a shift to remote modalities for mentoring sessions and trainings, but the researchers did find the program could be successfully delivered in a virtual format, although not as optimal as in-person sessions. Patel et al. (2022) also shifted rapidly to a virtual format in their project on sexual reproductive health for Native youth. They found benefits of the virtual format in flexibility for scheduling and coordination and even cited the virtual format was preferred by some participants. However, concerns with the virtual format included struggles with engaging some youth.

Other projects were well into study implementation when the pandemic hit, requiring shifting of research protocols and data collections methods mid-stream. Sinclair et al. (2022) were in their third year of a study on diabetes prevention for AI/AN men when they were forced to pivot to remote enrollment and implementation processes. While they found many advantages to the remote data collection strategies, challenges were found for participants juggling multiple personal and work demands on their time, particularly for those considered essential employees. The editorial written by Hunter et al. (2022) summarizes many of these themes in their descriptions of the challenges in adapting study protocols to remote implementation and the challenges of maintaining CBPR best practices.

Sahota et al. (2022) also shifted delivery of their Positive Indian Parenting curriculum to a virtual format but delivered boxes of supplies for each family so they could retain the hands-on and kinesthetic activities of the program. They used more videos and provided tablets to families to ensure access to the online environment. This pilot study demonstrated the importance of the foundational relationships established with both the collaborating entities, as well as the funders, in being able to make the necessary adaptations to the program during an evaluation study. Bec et al. (2022) also reported on the importance of these community relationships in their adaptation of an educational curriculum on suicide prevention and how shifting to a remote environment impacted the delivery and types of individuals able to participate. Similar themes of the importance of strong community connections are emphasized in Steinberg et al.'s (2022) manuscript on Tribal Turning Point, a lifestyle intervention to reduce risk of type 2 diabetes in AI/AN youth.

As you read through these diverse studies and experiences, we hope they will challenge you to think about lessons learned from conducting research with AI/AN populations during the COVID-

19 pandemic and how we can carry forward beneficial adaptations to best serve community needs. Each research team represented in this issue faced significant challenges to established programs, while balancing the unprecedented personal and community demands of the pandemic. While it is unknown how prominent remote enrollment and data collection will be in the future, it is clear the pandemic will have lasting effects on how community-based research is conducted. Which study aspects are better suited for in-person delivery? Which are better suited for remote delivery? Do certain populations respond better to one format over another? How can we ensure adequate access to online environments for all? These questions, amongst many others, are likely to become topics of future conversations that should serve to enhance AI/AN health research going forward. Community-based and -engaged research is in the unique position to rapidly respond to needs and increase, even more, the relevance of this important work to the health research enterprise.

## REFERENCES

- Around Him, D., Aguilar, T. A., Frederick, A., Larsen, H., Seiber, M., & Angal, J. (2019). Tribal IRBs: A framework for understanding research oversight in American Indian and Alaska Native communities. *American Indian and Alaska Native Mental Health Research*, 26(2), 71-95. <https://doi.org/10.5820/aian.2602.2019.71>
- Arrazola, J., Masiello, M. M., Joshi, S., Dominguez, A. E., Poel, A., Wilkie, C. M., Bressler, J. M., McLaughlin, J., Kraszewski, J., Komatsu, K. K., Pompa, X., Jespersen, M., Richardson, G., Lehnertz, N., LeMaster, P., Rust, B., Keyser, A., Doman, B., Casey, D., Kumar, J., Rowell, A. L., Miller, T. K., Mannell, M., Naqvi, O., Wendelboe, A. M., Leman, R., Clayton, J. L., Barbeau, B., Rice, S. K., Warren-Mears, V., Echo-Hawk, A., Apostolou, A., & Landen, M. (2020). COVID-19 mortality among American Indian and Alaska Native persons—14 states, January–June 2020. *Morbidity and Mortality Weekly Report*, 69(49), 1853-1856. <http://dx.doi.org/10.15585/mmwr.mm6949a3>
- Boughey, J.C., Snyder, R.A., Kantor, O., Zheng, L., Chawla, A., Nguyen, T.T., Hillman, S.L., Hahn, O.M., Mandrekar, S.J., & Roland, C.L. (2021). Impact of the COVID-19 pandemic on cancer clinical trials. *Annals of Surgical Oncology*, 28, 7311-7316. <https://doi.org/10.1245/s10434-021-10406-2>
- Christopher, S., Saha, R., Lachapelle, P., Jennings, D., Colclough, Y., Cooper, C., Cummins, C., Eggers, M.J., FourStar, K., Harris, K., Kuntz, S.W., LaFromboise, V., LaVeaux, D., McDonald, T., Real Bird, J., Rink, E., & Webster, L. (2011). Applying Indigenous community-based participatory research principles to partnership development in health disparities research. *Family and Community Health*, 34(3), 246-255. <https://doi.org/10.1097/2FFCH.0b013e318219606f>

- Fleming, T.R., Labriola, D., & Wittes, J. (2020). Conducting clinical research during the COVID-19 pandemic: Protecting scientific integrity. *JAMA*, 324(1), 33-34. <http://jamanetwork.com/article.aspx?doi=10.1001/jama.2020.9286>
- Hatcher, S.M., Agnew-Brune, C., Anderson, M., Zambrano, L.D., Rose, C.E., Jim, M.A., Baugher, A., Liu, G.S., Patel, S.V., Evans, M.E., Pindyck, T., Dubray, C., Rainey, J., Chen, J., Sadowski, C., Winglee, K., Penman-Aguilar, A., Dixit, A., Claw, E., Parshall, C., Provost, E., Ayala, A., Gonzalez, G., Ritchey, J., Davis, J., Warren-Mears, V., Joshi, S., Weiser, T., Echo-Hawk, A., Dominguez, A., Poel, A., Duke, C., Ransby, I., Apostolou, A., & McCollum, J. (2020). COVID-19 among American Indian and Alaska Native persons—23 States, January 31-July 3, 2020. *Morbidity and Mortality Weekly Report*, 69(34), 1166-1169. <http://dx.doi.org/10.15585/mmwr.mm6934e1>
- Holkup, P.A., Tripp-Reimer, T., Salois, E.M., & Weinert, C. (2004). Community-based participatory research: An approach to intervention research with a Native American community. *ANS Advances in Nursing Science*, 27(3), 162-175. <https://doi.org/10.1097/00012272-200407000-00002>
- Sohrabi, C., Mathew, G., Franchi, T., Kerwan, A., Griffin, M., Soleil C Del Mundo, J., Ahsan Ali, S., Agha, M., & Agha, R. (2021). Impact of the coronavirus (COVID-19) pandemic on scientific research and implications for clinical academic training - A review. *International Journal of Surgery*, 86, 57-63. <https://doi.org/10.1016/j.ijssu.2020.12.008>
- Weiner, D.L., Balasubramaniam, V., Shah, S.I., & Javier, J.R. (2020). COVID-19 impact on research, lessons learned from COVID-19 research, implications for pediatric research. *Pediatric Research*, 88, 148-150. <https://doi.org/10.1038/s41390-020-1006-3>

### ACKNOWLEDGEMENTS

We offer a special thank you to Ms. Sara Mumby, Publications Manager and Media Coordinator, Centers for American Indian and Alaska Native Health, for her incredible effort in shaping and guiding this special issue from start to finish.

### FUNDING INFORMATION

None to report.

### CONFLICT OF INTEREST

The authors declare that they have no conflict of interests.

**AUTHOR INFORMATION**

Dr. Deana Around Him (Cherokee Nation) is a Senior Research Scientist at Child Trends in Bethesda, MD. Dr. Amy Elliott is the Chief Clinical Research Officer at the Avera Research Institute in Sioux Falls, SD and holds professor and research positions in the Department of Pediatrics at the University of South Dakota.