

THE COLLABORATIVE RESEARCH CENTER FOR AMERICAN INDIAN HEALTH'S PARTNERSHIP RIVER OF LIFE: SPECIAL ISSUE INTRODUCTION

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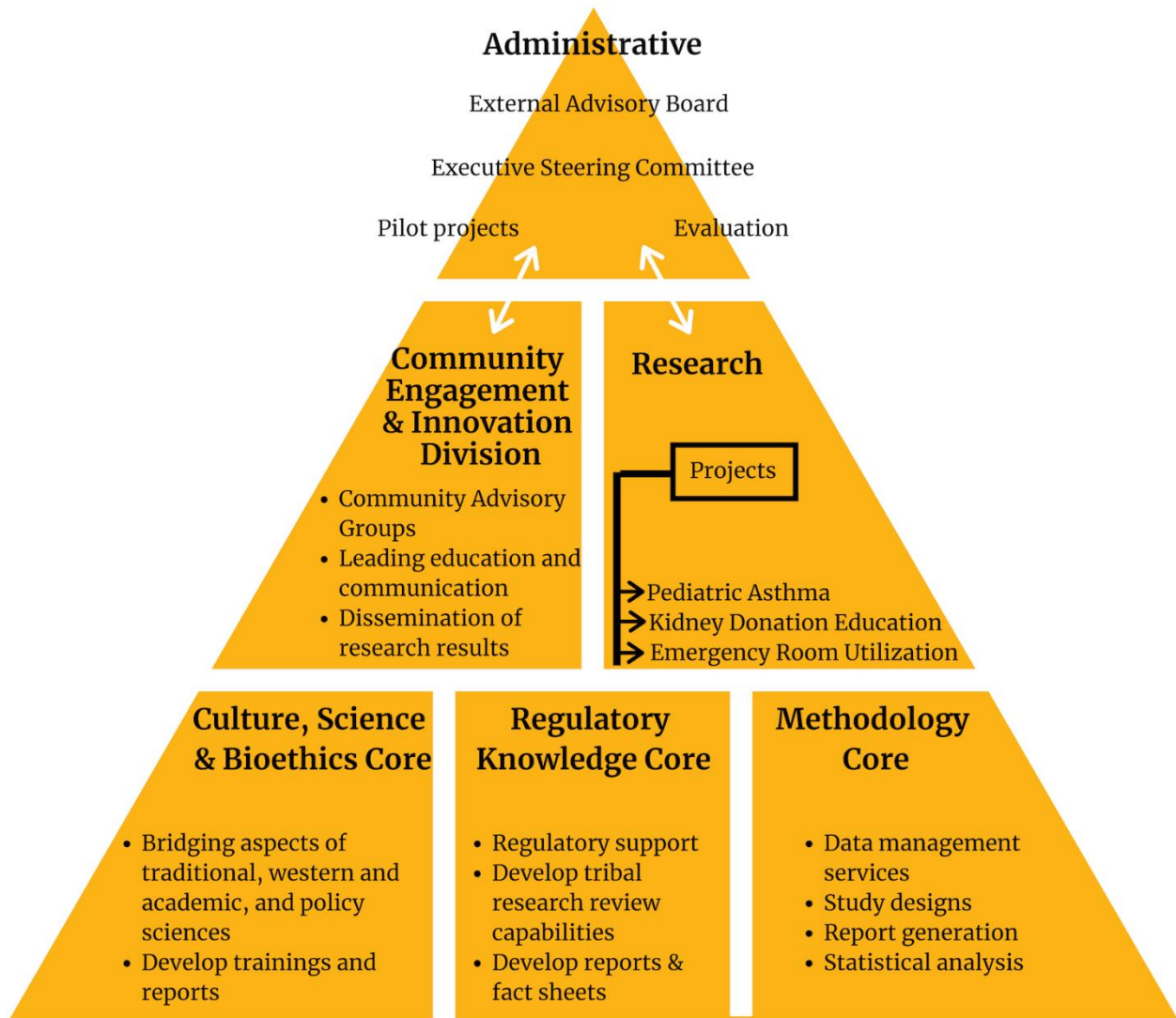
Abstract: In 2012, the National Institutes of Health funded the Collaborative Research Center for American Indian Health (CRCAIH) to work toward two broad goals: 1) to build tribal research infrastructure, and 2) to increase research on social determinants of health in American Indian communities. As the introduction to this special issue of American Indian and Alaska Native Mental Health Research, we highlight results from the Partnership River of Life evaluation tool in order to provide broader context for the other manuscripts presented here. Insights were gained during the Partnership River of Life group discussion and evaluation process of combining the groups' rivers to create one representation of the CRCAIH partnership. Detailed results underscore insights for similar transdisciplinary groups.

CRCAIH OVERVIEW

In 2012, the Collaborative Research Center for American Indian Health (CRCAIH) was funded by the National Institutes of Health (NIH), National Institute on Minority Health and Health Disparities (NIMHD) to provide an infrastructure for building coalitions of stakeholders from multiple disciplines to interact in conducting cutting-edge transdisciplinary research. The coalition would include tribal communities, health and transdisciplinary researchers from academic institutions, community organizations, service providers and systems, government agencies, and others. The goal of this research was to eliminate health and other disparities experienced by American Indian (AI) communities in South Dakota (SD), North Dakota (ND), and Minnesota (MN). The goals of CRCAIH are two-fold: 1) build tribal infrastructure for research, and 2) increase research on social determinants of health in AI nations. CRCAIH encompasses an interdisciplinary team of diverse investigators whose research focus is on improving health and health outcomes in AI populations. CRCAIH embraces three values: tribal sovereignty,

transdisciplinary partnerships, and sustainability to address social determinants of health through strategic investment in building tribal research infrastructure. Community-based participatory principles guide the partnerships with tribal communities to advance regional and national capacity for research on social determinants of health specific to AI tribes.

Figure 1. Collaborative Research Center for American Indian Health Organizational Chart

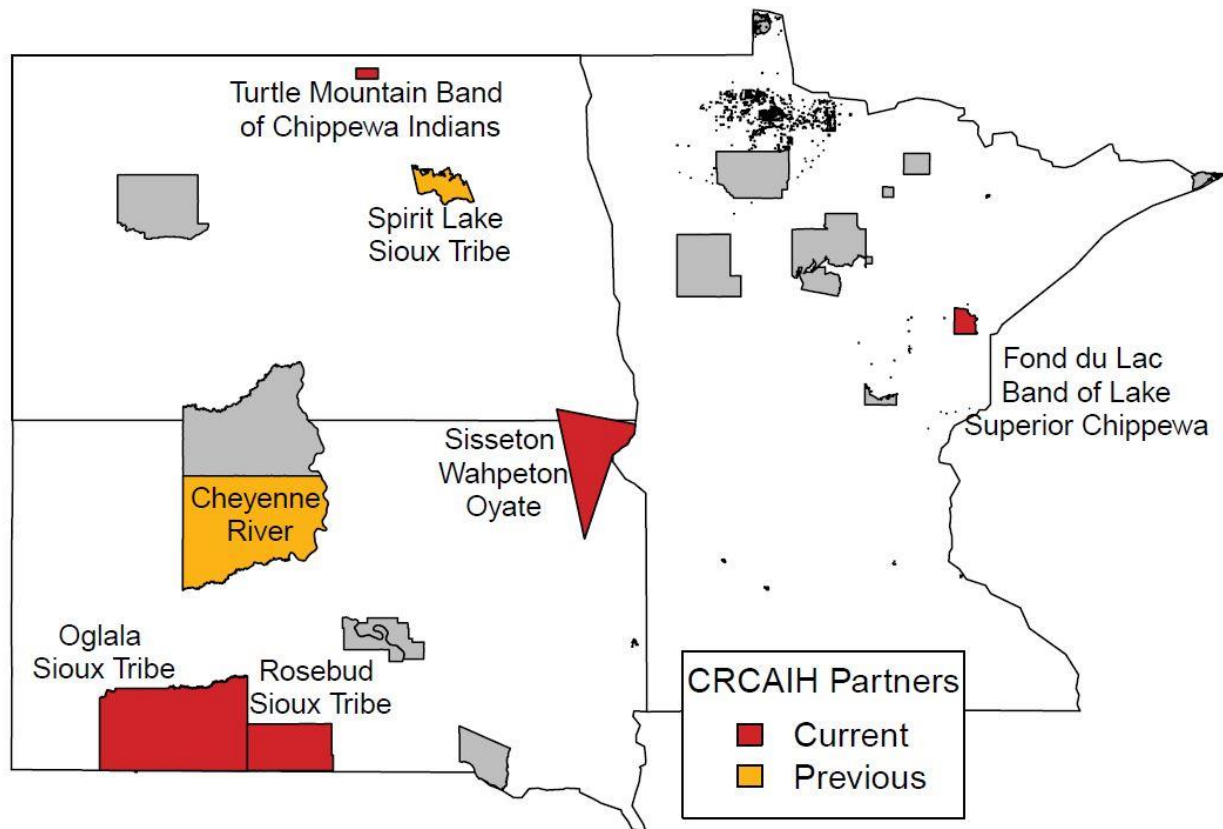


To accomplish these goals, CRCAIH assists tribes and researchers through three divisions (Administration, Community Engagement & Innovation, and Research) and three technical cores (Culture, Science, & Bioethics; Regulatory Knowledge; and Methodology; see Figure 1). CRCAIH currently works with five tribal partners: Oglala Sioux Tribe, Turtle Mountain Band of Chippewa Indians, Fond du Lac Band of Lake Superior Chippewa, Sisseton-Wahpeton Oyate, and

Rosebud Sioux Tribe, and previously also worked with Cheyenne River Sioux Tribe and Spirit Lake Nation (see Figure 2). This regional center started with strong researcher-tribal health partnerships in SD, and extended to ND and MN to address AI health disparity rates to become truly regional. This three state region also mirrors the main footprint of the lead health care organization (hospitals and clinics), which helped facilitate partnerships. For more details on the tribal nations' context, such as size of tribal lands, population, and economy, see "Not a One-Size Fits All Approach: Building Tribal Infrastructure for Research through CRCAIH" (Buffalo et al., 2019) in this special issue. All CRCAIH partners approved of being named in this article and special issue.

To invest in social determinants of health research, CRCAIH supported three large-scale research projects and fifteen pilot grants (for more details, see Elliott et al., 2016). Much care was taken to establish CRCAIH as a regional center and give it a separate identity from the institutional lead site (Sanford Research).

Figure 2. Map of Collaborative Research Center for American Indian Health Tribal Partners



NIMHD Goals

CRCAIH has been funded by an NIMHD initiative to support transdisciplinary targeted research, implementation, and dissemination activities that transcend customary approaches and “silo” organizational structures and to address critical questions at multiple levels in innovative ways. This was accomplished through the support of Transdisciplinary Collaborative Centers (TCC) focused on health policy research and social determinants of health research (U.S. Department of Health and Human Services [DHHS], 2012). The initiative sought to ensure that culturally appropriate and relevant research would be conducted at the regional level and that findings could translate into sustainable individual-, community-, and system-level changes that improve population health.

Regional collaborative centers provide opportunities for institutions to achieve a broader reach than is otherwise possible while combining expertise and resources. At the same time, they foster applied research that is uniquely responsive to specific population-based, environmental, sociocultural, and political factors that influence health within a particular region. The concept of regional collaborative centers is structured around an overarching goal delineated in the NIH Health Disparities Strategic Research Plan (DHHS, n.d.), integrating research, capacity building, and outreach/dissemination to 1) develop a coordinated interdisciplinary approach to reduce and ultimately eliminate health disparities; and 2) develop opportunities to leverage resources and enhance collaboration.

Original CRCAIH Vision

The original vision for CRCAIH emerged over 10 years of collaborative work on various research projects with tribes (e.g., Angal, Petersen, Tobacco, & Elliott, 2016; Dukes et al., 2014; Hanson, Miller, Winberg, & Elliott, 2013; Kenyon & Carter, 2011; McMahon, Hanson, Griese, & Kenyon, 2015) and was at the forefront of the application to NIMHD. These early collaborations led to identification of the three primary values that became the overarching considerations for every component of CRCAIH. First, community engagement and establishing true partnerships based on mutual understanding and respect is essential. Second, sound research design, implementation, and analysis of research studies is necessary to answer important questions to improve AI health, with an emphasis on bringing results to the intervention stage. Third, the

researcher-community relationships need to result in equitable fiscal relationships and sound administrative management.

Once these foundational values were identified, the core service areas of regulatory, culture, and methodology services were developed by asking, “What do we wish had been in place 10 years ago?” These conversations between researchers and tribal collaborators led to identification of gaps in tribal research infrastructures and struggles with collaborating with investigators. These gaps included funding concerns, cultural knowledge deficits, and a strong desire from tribes to have a higher level of regulatory control over research happening on their lands and with their people. An example of a common funding gap is that unless a subcontract is issued, tribes do not get indirect costs for grants awarded to academic institutions. Given institutional review boards (IRB) are often supported, at least in part, through indirect funds obtained from external funding, this lack of funding makes the establishment and maintenance of a tribal regulatory infrastructure quite difficult. As detailed throughout this special issue, CRCAIH was designed with researchers and tribal partners specifically to fill these gaps and create a foundation for healthy and productive partnerships.

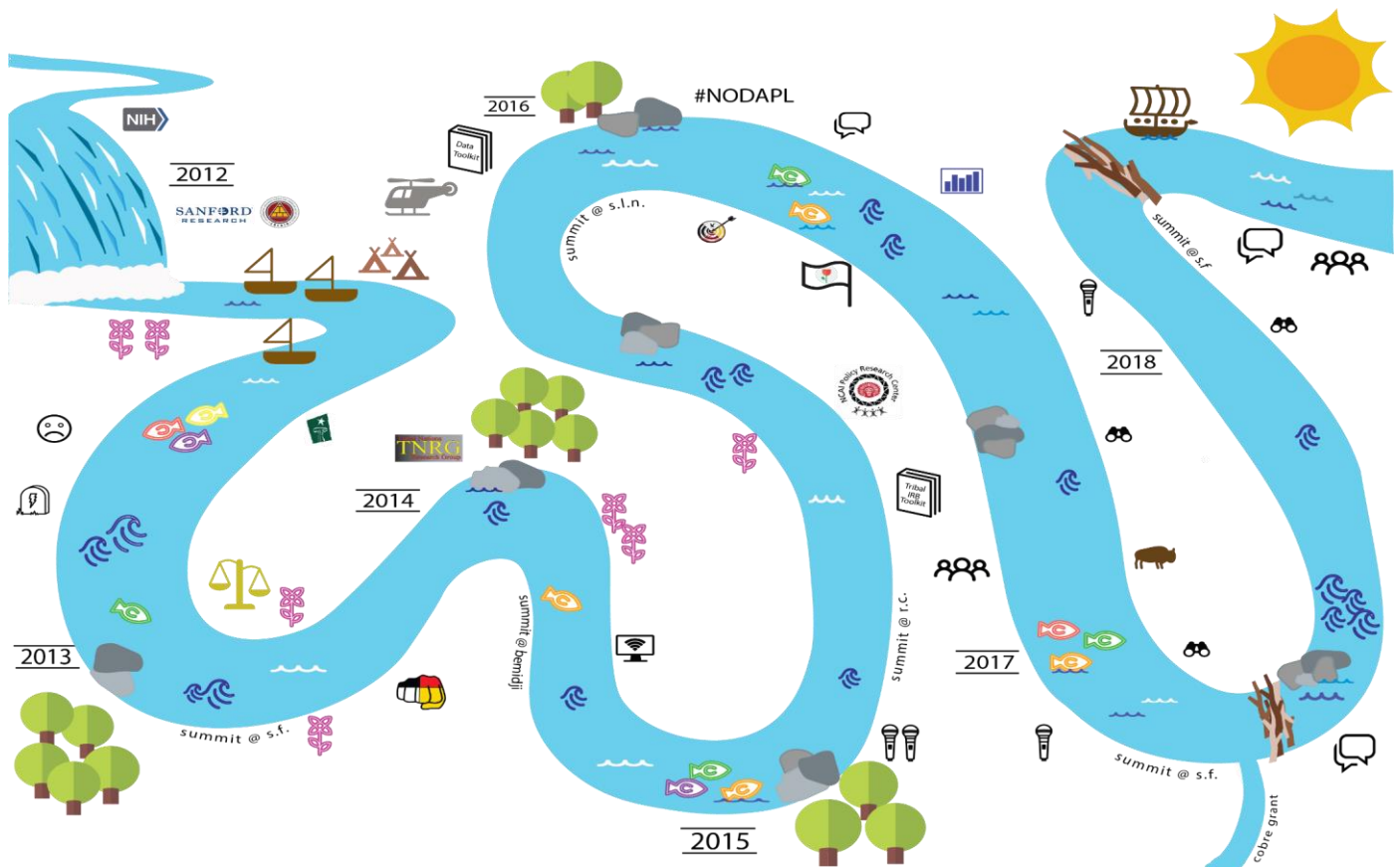
PARTNERSHIP RIVER OF LIFE EVALUATION

Through yearly work plans and strategic planning with the Executive Steering Committee, CRCAIH has continuously incorporated self-reflection and evaluation into the administration of the center. In addition to internal evaluation activities, CRCAIH twice worked with external evaluators to refine metrics of impact and assistance in articulating goals. In fall 2017, two CRCAIH staff (one representing the community engagement and innovation division and one tribal partner) attended an Engage for Equity (E2) workshop led by Dr. Nina Wallerstein and colleagues. One activity they participated in was the Partnership River of Life, a visual, narrative evaluation tool that helps partnerships tell the story of their journey through a river metaphor (Partnership River of Life Activity, n.d.). These CRCAIH representatives later facilitated this activity with the broader CRCAIH team at the summer 2018 tribal partner retreat. There were 12 total participants, 6 of those were researchers, 4 tribal partners, and 2 undergraduate summer interns. Conducting this activity when most partners were in person helped achieve an excellent dialogue that is paramount to in-depth topics such as this. The goals of utilizing this evaluation tool at the retreat was to review the six-year history of CRCAIH, facilitate the CRCAIH team

members’ reflections on previous accomplishments, and help plan for the future. Attendees were split into three groups, mixing more seasoned members with newer members, and were given 45 minutes to create a river that visualized, from their perspective, the CRCAIH partnership over the years. While creating these visualizations, groups were told to reflect on the goals, processes, barriers, important or influential stages, factors that facilitated the work, obstacles that were challenging, and the future direction of the partnership. Upon groups’ completion of the activity, the facilitators first shared their Partnership River of Life from the E2 workshop and guided conversation as the other three groups presented their rivers.

There were four very different rivers and approaches to the visualization, which was incredibly informative to see the groups’ different perspectives reflected and which key aspects they chose to represent. To further utilize the tool for planning and reflection, the cores and divisions created a combined CRCAIH Partnership River of Life (see Figure 3) after the tribal partner retreat. For brevity and clarity, Figure 3 encapsulates the major events and reoccurring themes, but does not include all of the aspects in the four groups’ various rivers.

Figure 3. Collaborative Research Center for American Indian Health Partnership River of Life – Summer 2018



Key Constructs

Beginning

Most of the groups started their river in 2012 when the grant began, but the group that had the member with the longest tenure with CRCAIH included a small stream leading up to the waterfall representing the years of partnerships, discussions, and collaboration building that led to the establishment of CRCAIH. Examples of these early important factors included the Principal Investigator's and large project leaders' research (represented as three boats) and partnerships with the original tribal partners (symbolized by flowers), CRCAIH members' experience with previous employers (e.g., tribal colleges), and previous funding relationships with NIH and the National Science Foundation. The CRCAIH team readily acknowledged how the TCC grant from NIH was clearly instrumental in establishing CRCAIH.

CRCAIH experienced both positive and negative aspects after the funding commenced. The pervasive feeling was one of excitement about the NIH funding and momentum and promise that comes with growing partnerships. However, the new center also came with challenges of immediate need for hiring new staff to fill key organizational and support roles, such as the tribal research liaisons and project manager. At times, some aspects of building the center, such as the logo design discussion, seemed to take longer than planned. The largest setback early on was not solidifying the partnership with a tribe due to leadership turnover after the grant was submitted. Fortunately, this tribe later became a CRCAIH partner after further discussions.

Important Achievements

The groups' rivers had several instances of peaceful times where there were smooth waters, pooled water, fish, and thriving ponds, which represented bringing on new partners and solidifying partnerships. Important successes represented during these times included the Annual Summit, which was a time for everyone to come together to connect and network with others outside CRCAIH staff and disseminate successes. The tribal partners were highlighted as large flowers, to emphasize their integral role in the success of CRCAIH. Other important successes mentioned were the tribal selection process (including interest from many other regional tribes); building research review boards, tribal codes/ordinances (represented by scales of justice); review board processes becoming electronic (represented by computer with Wi-Fi symbol); Tribal Nations Research Group becoming a 501(c)3 non-profit (represented by logo); tribal community conferences (represented by microphones); research publications, presentations, pilot grant projects (represented by trees); tribal partner retreats (represented as discussion bubbles);

regulatory and data management toolkits (represented by books); NIH supplement grant (represented as a flag); new partnerships (e.g., National Congress of American Indians); external evaluations (represented by logos); and coordinated response to the proposed common rule changes. The regulatory toolkit was noted as an incredibly useful resource, not just for CRCAIH partners, but for tribes across the United States. The value of the toolkit helped provide CRCAIH a national presence with organizations, such as Public Responsibility in Medicine and Research (PRiM&R). A buffalo was included in one group's river to represent the tribes working for the protection and benefit of their tribes, and there was a movement toward data governance (represented by bar chart) near the end of the river. One group had represented a disagreement between the tribe and researchers early on and showed their positive partnership further down the river (represented by a sad emoji and groups of three people, respectively).

Influential Context

Particularly for the group who developed their river at the E2 workshop, there was much emphasis on the context of the importance of why CRCAIH was developed. They included aspects such as the negative perspective of research that tribes can have, due to cookie cutter approaches, helicopter research (represented by helicopter and teepees), researchers highly benefitting from research, and tribes being over researched (symbolized by the headstone—being researched to death). Other important contextual factors included historical trauma and the impacts of current events of the Dakota Access Pipeline movement (symbolized by #NODAPL). Another influencing factor included tribal sovereignty, which is integral to the rationale of why tribes wanted to be involved with CRCAIH and initiating laws and codes to regulate research (represented by a medicine wheel fist). A key event that emerged was the award of a large NIH Centers for Biomedical Research Excellence (CoBRE) grant to Sanford Research that created some confusion surrounding its relationship to CRCAIH, especially with the overlap of some staff and core services between the two Centers. This CoBRE grant was awarded around the same time the original PI (senior author - Elliott) moved to a different institution, creating difficult transitions, but also the opportunity for new voices and vision.

Challenges/Obstacles

Challenges were represented as boulders, pollution, rough waters, and river currents. In one, splashes and a swamp represented missed opportunities (not formalizing a tribal partnership in year 1, discontinuing partnerships). Notable challenges frequently mentioned were turnover in

staff (e.g., core directors), lack of funding opportunities (e.g., discontinuation of TCC mechanism), and unfunded continuation grants. Other challenges less frequently mentioned by groups were partnership disagreements, building trust, and tense debates over vision during partnership-building. Notably, one group highlighted how CRCAIH overcame a challenge by drawing two dams with the river flowing over it to represent the carryover funding and no cost extension that allowed CRCAIH to continue two additional years.

Future

In representing the end of the river, some groups focused on the need for grant funding, with one group symbolizing the importance of grant writing by a person fishing (represented in Figure 3 as binoculars). Additional themes that arose were a new energy, focus for shared vision, represented by staff on boats with the new PI (first author – Kenyon) leading. Unlike the earlier representations of the calm water after the earlier challenges, this later time was represented as a sense of stronger bonds, tighter collaboration, and focus on the work of obtaining more funding to continue the partnerships. A couple groups used the sun to represent nourishment and brighter days in the future. One group integrated question marks and depicted several smaller flowing streams to show it likely will not be another large grant to fund CRCAIH, but other smaller revenue streams.

Reflections

The evaluation tool was not only an opportunity to reflect and share memorable moments, but also as a time to discuss beginnings, influences, obstacles, and successful moments CRCAIH has had over the last 6 years. Unexpectedly, it also provided opportunity for renewed investment. Many of these aspects will be highlighted throughout this special issue. Completing the Partnership River of Life evaluation was particularly helpful to those staff newer to the CRCAIH partnership. Much of the debrief discussion focused on the large successes of CRCAIH, such as the Annual Summit. A sense of resilience and purpose was felt at the conclusion of the conversation. Despite key staff turnover, the group realized that the partnership is stronger than any one person due to the mission and overall purpose of CRCAIH. Another important recognition of a major successful outcome of the center was that the five tribal partner relationships were stronger than ever. Although CRCAIH's mission was to fund both research projects and tribal infrastructure building, the group felt the lasting effects on the tribe's infrastructure (e.g., research review board processes) would be CRCAIH's unique legacy.

Weeks later, important insights on the CRCAIH partnership continued during additional evaluation reflections on the Partnership River of Life outcomes with the core and division staff. As the main NIH funding stream to this partnership comes to an end, the two years of extension dollars have helped the transition, where members feel fortunate to have additional time to accomplish goals and process that the partnership will be irrevocably changing. An additional reflection was that members might feel a more urgent need or motivation to accomplish tasks in this final no cost extension period. It was not an initial goal for the tribal partners to work together in their efforts; however, the peer-to-peer assistance has been an unexpected and welcome outcome the past couple of years of the CRCAIH partnership. The cores' and divisions' work is now much more integrated (e.g., joint tribal partner calls are held bi-weekly), compared to earlier in the partnership where the cores and divisions worked more separately with each tribe, and quarterly tribal partner calls were held. Calls are more focused on joint product development (e.g., presentations, toolkit revisions), rather than building individual tribal research review board infrastructure. Having a smaller group of staff makes communication across the group easier. For example, projects are a more frequently combined effort due to the smaller core and division staff. As work is more integrated across core, division, and tribal partners, there is less of a distinction between CRCAIH administration and tribal partners. Tribal partners are more directly involved with the process of developing products and disseminating lessons learned, and with the opportunity to be co-authors, they have greater buy-in and satisfaction with products.

SUMMARY

In large, complex partnerships, it is very important to undergo regular self-reflection and dedicate time and attention to the operation of these partnerships. The Partnership River of Life is a helpful tool for strategic planning, which is particularly important in times of shifts in partnerships. For all the CRCAIH members, this exercise provided new vision and energy. Therefore, the Partnership River of Life evaluation tool proved useful for reflection on partnership building and continued work toward shared goals and vision. Utilization of this as a historical documentation and reflection tool is highly recommended to guide group conversation and strategic planning.

Goal of Special Issue/Structure

The main goal of this special issue of the *American Indian and Alaska Native Mental*

Health Research journal is to convey the immense impact of the creation of CRCAIH and resulting long-lasting impact. For example, CRCAIH's original funding through NIMHD of \$13.5 million yielded a return on investment of over \$26 million through partners' subsequent grant awards. CRCAIH became a hub of information, disseminating research on resources, trainings, grants, and research findings through the website (www.crcaih.org), twice-monthly listserv, social media (Facebook, twitter, LinkedIn), and Annual Summits.

This special issue aims to showcase the areas of impact and applicability to other partnerships, synthesize lessons learned, create a vision for future partnerships, and provide directions for future investment in tribal infrastructure and research in AI health. The issue continues with a manuscript extolling CRCAIH's fundamental values and detailing how AI community-based research is uniquely transdisciplinary (Heinzmann, Simonson, & Kenyon, 2019). The next manuscript discusses aspects of tribal partner research infrastructure building (Buffalo et al., 2019). The following manuscript represents the cores' work in building capacity in tribal research regulation and oversight (Around Him et al., 2019). The final section of the issue holds contributions from several CRCAIH pilot grant program (Becker, Heinzmann, & Kenyon, 2018) awardees. These papers detail important findings exploring concepts of Wicozani (overall health and well-being; Peters, Peterson, & the Dakota Wicohan Community, 2019), Wac'inyeya (hope for the future; Gray, Schrader, Isaacs, Smith, & Bender, 2019), and describes two parts of the intervention project, We RISE: indicators of health behavior change (McCormack, O'Leary, Moran, & Hockett, 2019) and development of a resource guide and training (O'Leary et al., 2019).

We hope the readers find the information detailed here helpful for their own social determinants of health work. There is much work to be done to continue to make progress in AI health equity, and an important factor is for tribes to continue building tribal research capacity.

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