NOT A ONE-SIZE-FITS-ALL APPROACH: BUILDING TRIBAL INFRASTRUCTURE FOR RESEARCH THROUGH CRCAIH

Melissa Buffalo, MS, Jessica Heinzmann, BA, DenYelle Baete Kenyon, PhD, Kathryn Blindman, Simone Bordeaux, LPN, Anita Frederick, MS, Erin Garrison, BS, Crystal Greensky, MSHA, Heather Larsen, MEd, Tonya Kjerland, MS, and Victoria Grey Owl, PhD, RDN

Abstract: The Collaborative Research Center for American Indian Health (CRCAIH) was created to foster tribal partnerships in the Minnesota, North Dakota, and South Dakota regions to increase capacity for tribal research. Since 2013, through community engagement and technical assistance from CRCAIH's cores and divisions, seven tribal partners have expanded research infrastructure and recognize the benefits of an established tribal research office. This manuscript showcases the unique approaches individual CRCAIH tribal partners have taken to build tribal research infrastructure. The unique experiences of the CRCAIH tribal partnership holds valuable lessons for other tribes interested in increasing research capacity through research review, regulation, and data management.

INTRODUCTION

As discussed in the introduction to this special issue, in September 2012, the Collaborative Research Center for American Indian Health (CRCAIH) was established through funding by the National Institute on Minority Health and Health Disparities (NIMHD). The two driving aims of CRCAIH has been to 1) build tribal research infrastructure and 2) increase the amount of transdisciplinary research in American Indian/Alaska Native (AI/AN) health. CRCAIH was designed to create a platform to connect tribal nations and health researchers from multiple disciplines to work in partnership to address significant health disparities.

Since 2013, the CRCAIH platform has fostered a tribal research partnership among seven tribes in the Minnesota, North Dakota, and South Dakota tristate region. The tribal partners include: Oglala Sioux Tribe, Cheyenne River Sioux Tribe, Turtle Mountain Band of Chippewa Indians/Tribal Nations Research Group (Turtle Mountain/Tribal Nations Research Group), Fond du Lac Band of Lake Superior Chippewa (Fond du Lac), Sisseton-Wahpeton Oyate of the Lake Traverse Reservation (Sisseton-Wahpeton Oyate), Spirit Lake Nation, and Rosebud Sioux Tribe.

Because an overview of the CRCAIH platform was previously detailed in Elliott et al. (2016), the emphasis and breadth of this manuscript focuses on how the CRCAIH tribal partners' capacity for research has increased and resulted in a lasting legacy of tribal research infrastructure. All CRCAIH partners approved of being named in this article and special issue.

The purpose of this manuscript is to: 1) detail the importance of building tribal infrastructure for research, 2) describe common/joint activities of the CRCAIH tribal partners, 3) showcase unique aspects of building tribal infrastructure, 4) highlight throughout how the CRCAIH cores and divisions helped tribal partners through capacity building technical assistance, and 5) feature unexpected outcomes and future directions for this work. Through sharing the common and unique activities of the CRCAIH tribal partners, this manuscript showcases how tailored approaches are optimal when developing and expanding tribal research infrastructure. Ultimately, by detailing these diverse processes, it demonstrates there is not a one-size-fits-all approach to building tribal research infrastructure. But the processes and lessons learned and described herein can serve as a guide to building or expanding tribal research infrastructure to fit the unique needs of other tribal nations.

The authors of this manuscript are the CRCAIH tribal partners and the CRCAIH staff from the Administration Division and the Community Engagement and Innovation Division. It is important to note and describe the authors because the focus of this paper is the partnerships and the tribes building their research infrastructure from their perspective. Each tribal partner utilized CRCAIH core and division support differently to best fit their infrastructure building needs at the time. As the tribal partners increasingly engaged with one another, the unique and broad support that was provided to them from each core and division became apparent, which heavily influenced this paper. Additionally, each core and division was accessed slightly different and some more than others. This paper would not be complete without the experiences from each tribal partner and sharing their processes and lessons learned.

Background

Past Tribal Research

Many tribal nations have faced a long history of unethical research occurring in their communities. High volumes of research conducted in tribal nations is due to many factors, such as the high prevalence of health disparities and the available funding from federal sources for research with diverse communities (Sahota, 2007). One often noted example of unethical research in a tribal

nation involves the Havasupai Tribe and researchers from Arizona State University. The Havasupai Tribe approved the collection of blood samples for a research project on diabetes. Researchers then used those blood samples for research in other areas counter to the tribes wishes and values, such as schizophrenia and population migration theory, and made the samples available to other researchers, all without obtaining tribal approval or consent of participants (Pacheco et al., 2013). These lines of research outside of the original diabetes project did not benefit the tribe, were stigmatizing, and did not include voluntary informed consent, resulting in highly unethical research and repercussions for years to come. Therefore, it is not surprising these types of ethical breaches, "have left AIAN communities wary of research practices based on exploitation, racism, and majority ethnocentrism" (Pearson, Parker, Zhou, Donald, & Fisher, 2018, pp. 28).

Historically, research done with tribal nations was almost entirely conducted by external researchers, who may have followed an external agenda and engaged in research that was not always in tribes' best interest (LaVeaux & Christopher, 2009). There was often little to no collaboration between the researcher and the tribe, and equal partnership was often not achieved. This type of exploitive, non-collaborative practice has been called "helicopter research," where a researcher comes in, conducts the research, gathers the data, and leaves (Oberly & Macedo, 2004). Helicopter research methods often do not report findings or provide valuable results back to the tribe, thus weakening trust (Lawrence, 2000). Research approaches like this err in not fully recognizing the strength of the tribe. Tribes and their respected members are essential to the research process. They are the experts and the storytellers of the people and the keepers of history and cultural knowledge.

Despite feelings of mistrust around research, tribes are tackling the challenge of building their research infrastructure in their respective communities because they feel research is an important and valuable tool. Tribal nations often face difficult challenges in conducting research or building research capacity, such as isolation due to their remote locations, having small populations, somewhat limited resources, protecting cultural knowledge, and facing frequent changes in tribal leadership, sometimes occurring every two years. Despite these challenges, tribes (such as the CRCAIH tribal partners) have begun to take more ownership of data and the research process. Increasing the capacity to build research is the result of tribes exercising their autonomy to make informed decisions that will benefit and protect their tribal nations.

Through this infrastructure building, tribes exercise their sovereign right to improve their quality of life, provide environmental protections, and work to address the ever-increasing health

disparities that affect their tribal members on a daily basis. Each CRCAIH tribal partner builds tribal infrastructure for research through community engagement, increased regulatory capacity, and data management to guide decision-making for tribal members. More importantly, as tribes build their infrastructure, they are taking ownership of the research data and establishing long-term relationships with researchers and institutions, so the benefit is mutual. From the researcher perspective, researchers can also benefit, as greater infrastructure for research results in higher quality research data. It also can result in stronger partnerships, where again, the quality of the data improves as it is more culturally appropriate (Oetzel et al., 2015). These long-term results can mean higher quality impacts on AI/AN community health outcomes.

Unique Tribal History

Across the United States, there are currently 573 federally recognized tribes, each having a special relationship with the government and their own traditions, histories, distinct languages, and ancestral lands. As a result of the General Allotment Act of 1887 (also known as The Dawes Act of 1887), tribes were forcibly displaced from 90 million acres of Indian land through the establishment of reservation lands and other various acts and treaties. The 24 tribal nations, spanning across Minnesota, North Dakota, and South Dakota, contain land with multiple types of ownership (i.e., trust, fee, restricted, tribal, individual Indian, and non-Indian), creating a checkerboard ownership pattern (Indian Land Tenure Foundation, n.d.). Seven of these tribal nations in the tristate region have been CRCAIH tribal partners. Each tribal nation is unique from one another, as is highlighted when examining the CRCAIH tribal partners' demographics (see Table 1). For example, the CRCAIH tribes differ greatly in tribal enrollment: the Spirit Lake Nation has an enrollment of 6,700, while the Oglala Sioux Tribe has almost 47,000 enrolled tribal members. This information is relevant to the research office as community engagement efforts will vary per community. Additionally, demographic location and number of tribal districts is information investigators may need to know. The CRCAIH tribes consist of Lakota, Dakota, and Anishinabe nations that share knowledge and lessons learned with one another while acknowledging each other's accomplishments in their respective tribal lands.

Tribal nations are tasked with making decisions that protect their citizens and benefit the whole community, ensuring their unique culture and traditions carry on and are taught to the younger generations, while simultaneously embracing technology and tools to better the overall health of the community. Tribal elders are often called upon to pass on traditional teachings to the next generation through providing knowledge and understanding of the past and emphasizing the

importance it has on today. Tribal leaders do their best to bring lasting positive impacts for the tribe using historical knowledge to guide and preserve balance in decision making to advance and improve the health of the whole nation. They are exercising their sovereignty, collaborating with external and internal organizations, preserving their culture, and working to address the various health disparities that often affect community members. As detailed in this paper, through a focus on policymaking, community engagement, and data management, each CRCAIH tribal partner works to balance the protection of their community with the potential benefits of research.

Table 1
Descriptive demographics for CRCAIH tribal partners

Tribal Partner	**Area**		**Population**			**Economy**			**Education**		
Name (Tribal Area)	*State*	*Total area (sq mi)*	*Density (PPSM)*	*Total (% AI/AN only)*	*Enroll-ment*	*Unemploy-ment rate*	*Median household income*	*% of families below poverty level*	*% high school graduate or higher*	*% bachelor's degree or higher*	*# of graduate or professional degrees*
Cankdeska Cikana Community College (Spirit Lake Reservation)	ND	399.63	10.9	4,399 (83.3%)	6,700[b]	9.0%	$31,447	39.7%	78.7%	12.5%	57
Cheyenne River Sioux Tribe (Cheyenne River Reservation[a])	SD	4,419.10	1.9	8,459 (75.9%)	15,993[b]	25.4%	$39,212	26.6%	85.1%	14.5%	171
Fond du Lac Band of Lake Superior Chippewa (Fond du Lac Reservation[a])	MN, WI	159.33	27.5	4,048 (39.1%)	4,146[c]	8.5%	$50,833	14.7%	87.7%	15.5%	126
Oglala Sioux Tribe (Pine Ridge Reservation)	SD	4,353.80	4.3	19,698 (83.8%)	46,855[b]	25.2%	$30,908	42.4%	78.7%	12.8%	243
Rosebud Sioux Tribe (Rosebud Indian Reservation[a])	SD	1,975.42	5.5	11,324 (78.7%)	35,062[d]	20.6%	$26,938	48.9%	77.9%	14.5%	199
Sisseton-Wahpeton Oyate (Lake Traverse Reservation[a])	SD, ND	1,508.73	7.5	11,269 (39.8%)	14,053[e]	7.5%	$48,236	14.3%	86.5%	17.0%	409
Turtle Mountain Band of Chippewa Indians / Tribal Nations Research Group (Turtle Mountain Reservation[a])	MT, ND, SD	237.43	38.1	9,303 (95.6%)	32,564[f]	5.7%	$32,665	33.2%	81.5%	21.6%	160

Note. Data for economy, education, and total population from U.S. Census Bureau 2012-2016 American Community Survey 5-Year Estimates accessed via My Tribal Area [web]. Data for total area and population density from U.S. Census 2010 Population and Housing Unit Counts. sq mi = square mile. PPSM = people per square mile. For population, percent AI/AN only does not include those indicating AI/AN in combination with some other race. Enrollment numbers include members living both on and off-reservation. Education level percent pertains to population age 25 years and over.

[a]Includes both on and off reservation trust land. [b]Bureau of Indian Affairs, Great Plains Region website (n.d.). [c]Fond du Lac Band of Lake Superior Chippewa BIA Enrollment Office (2018). [d]Rosebud Sioux Tribe BIA Enrollment Office (2018). [e]Sisseton-Wahpeton Oyate BIA Enrollment Office (2018). [f]Turtle Mountain Band of Chippewa Indians BIA Enrollment Office (2018)

Establishing CRCAIH Tribal Partnerships

CRCAIH invited applications from tribes in the three state region to join CRCAIH. Through the tribal selection process (Elliott et al., 2016), each tribe responded to questions on how this investment would leverage existing support and build on current capacity to foster research in the community. CRCAIH purposefully opted to limit the number of fully partnering tribes in order to maintain an appropriate level of the subcontract funding available to each partner. Although CRCAIH grant funding was limited to seven tribal nations out of the 24 total across the three states (see Table 1), those nations that were not selected or are no longer receiving funding are still supported with technical assistance for building tribal research infrastructure.

Each tribe's research infrastructure was at various stages when they partnered with CRCAIH and each differed in the vision for their research office. One commonality was that tribes first gained approval from tribal council through a tribal resolution, which is a standard practice when initiating partnerships and new plans. The tribal resolution was sought in order to assure broader support from tribal leadership to build research capacity and meet their research goals.

CRCAIH provided funding support for one full-time equivalent (FTE) employee per tribal partner as the Community Liaison. This critical position allowed the tribal partners to focus on working toward their goals of building infrastructure in research, rather than facing competing demands of other projects. Additionally, CRCAIH provided funding to each tribe for institutional review board (IRB) software, travel, and supplies (Elliott et al., 2016). Duties performed by the research office staff often began with developing or enhancing the tribal research review process, then moved into data management. Research office staff also conduct the day-to-day activities that keep their Research Review Boards functioning and monitoring current and past research.

TRIBAL INFRASTRUCTURE BUILDING

CRCAIH is comprised of three divisions (Administration, Community Engagement & Innovation, and Research) and three technical cores (Culture, Science, & Bioethics; Regulatory Knowledge; and Methodology). The primary aspects of tribal infrastructure building that the tribal partners dedicated their efforts to were research regulation and review, community engagement, and data management. Most tribes selected to focus primarily on research regulation and review at the beginning of their CRCAIH partnerships. In subsequent years, focus shifted to incorporate a greater focus on community engagement and data management. This is not to say that all tribal

research infrastructure building needs to follow this sequence, but for the CRCAIH tribal partners, addressing the elements in this approach at that time was the best fit for their communities in developing robust research infrastructure. The following sections will describe the tribal partners' commonalities as well as unique approaches used in the aforementioned three areas of infrastructure building (research regulation and review, community engagement, and data management).

Research Regulation & Review

A common theme among the CRCAIH tribal partners was that prior to the formation of the CRCAIH partnership, a mechanism for reviewing research was in place, in some capacity, within the tribe. For example, in October 2007, the Oglala Sioux Tribe created the Oglala Sioux Tribe Research Review Board (OSTRRB) to assist in controlling all research that was being conducted within the reservation boundaries. An important part of the purview of the OSTRRB was its responsibility for facilitating human subjects research and ensuring the rights and welfare of human subjects are protected during their participation. The OSTRRB was also created to secure the reservations' interests by making sure no false or misleading communication was being done in research.

Fond du Lac and Rosebud Sioux Tribe had a process in place (e.g., through tribal college) prior to the foundation of the CRCAIH partnership, but the boards had not been active for some time. Similarly, Cheyenne River Sioux Tribe, Spirit Lake Nation, and Sisseton-Wahpeton Oyate had informal processes in place (e.g., through the Cankdeska Cikana Community College and Sisseton-Wahpeton Oyate Human Services board), where final approval went before the tribal councils. Additionally, the Turtle Mountain research review process required tribal council approval.

Commonalities

This foundation of already established research regulation processes helped motivate the tribal partners to consider a range of options in research regulation approaches. Though the initial process may have been limited and informal, CRCAIH assisted the tribe in reviewing research processes, but tribes also understood the need and urgency to build upon their current processes. If tribal laws/codes, policies, and procedures for research were not already in place, creating them was significant and their first major task upon becoming CRCAIH tribal partners (see Table 2).

Table 2
CRCAIH tribal partner research review snapshot

	Fond du Lac Band of Lake Superior Chippewa	Oglala Sioux Tribe	Rosebud Sioux Tribe	Sisseton-Wahpeton Oyate	Turtle Mountain Band of Chippewa Indians
Research Review Body	FDL Human Services Division IRB	OST Research Review Board	RST Health Board	SWO Local Research Review Board	TMBCI Research Review Board (operated by Tribal Nations Research Group)
Approved Tribal Code	No	Yes	No	Yes	Yes
Registered FWA	No (in process)	Yes	No	No	Yes
Research Reviewed	Human Subjects	All	Human Subjects	Human Subjects	All
Number of Members	10	9 Current members with rotating Chair (could have 12 members so 3 vacancies)	11 (9 council reps, 2 at-large members)	5 minimum 8 maximum Chairperson serves six month term	10 members (7 members with 3 alternates) plus IRB Chair and IRB administrator
Frequency of Meetings	Monthly (every third Thursday of the month)	Monthly (every third Saturday of the month except in July) deadline for submissions on last Friday of previous month	Bi-Weekly (1st and 3rd Thursday of every month)	Monthly (4th Tuesday in 2019); Researcher's Submission Deadlines - Friday that occurs 3 weeks before the scheduled meeting	Monthly, (second Wednesday of each month) protocols due on the 28th of previous month
IRB Management	Axiom Mentor Software (not functioning; set up in process)	Axiom Mentor Software	Axiom Mentor Software (not functioning)	Axiom Mentor Software (not functioning; set up in process)	Axiom Mentor Software
Fee Structure	None	Sliding Scale 3% of total budget plus application fee (currently capped at $3,000)	Planned	In process of approval	Planned
Stipend for Board Members	No	Yes	No	Yes	No
Estimated Number of Protocols Reviewed per Year (last 3 years)	10-15	18	5-10	10-20	25

Note. Information provided by CRCAIH Tribal Partners as of May 2019.

Each tribe implemented their research codes slightly different. For the purposes of this paper, a research code is used generally and may refer to a tribal law, ordinance, protection act, or policies and procedures. A tribal research code protects the interest of researchers and the tribe by specifying all the responsibilities during the research project (Fisher & Ball, 2003). This code not only protects individual tribal members, but also plays a unique role compared to academic IRBs by taking into consideration the tribe as a community and protecting the knowledge and culture that each community holds. In general, the IRBs main goal is to protect the individual human subject's rights in research; however, many tribes have made the decision to take the additional step to review all research or data collection within their tribal nations. Whereas a tribal research code aims to guide research practice, a tribal research review board exists to review research protocols with an ethical and cultural lens. Tribal research review boards are often charged with protecting not only the individual research participant, but tribal communities as a whole, including the land, knowledge, and culture. This community level review provides additional protections and is the distinction that makes local, tribal research review so important. As the tribal partners became more established and passed their tribal research code, their finalized codes also provided the groundwork for other tribal partners. Research codes were shared among one another and were revised to fit the needs of each individual tribe.

Upon passing a research code and continuing to build their regulatory process, tribes wanted to create policies and procedures to guide and support a fully functioning research review board (RRB) to review, archive, monitor, and manage all research conducted within the reservation boundaries and on behalf of each respective tribe. Each RRB would recruit a diverse group of members, mostly tribal members, who represent a wide array of interests/expertise and who are highly qualified to serve on the board (OSTRRB, n.d.). In addition, the purpose of a qualified RRB was that every research proposal would receive a comprehensive, balanced, and thoughtful review (Sisseton-Wahpeton Oyate Research office, n.d.).

The role of the research office and RRB varies across the individual tribal partners. The tribal research office was often placed in a more administrative role as the RRB grew/adapted and RRB members became more knowledgeable of their role and duties to review new and ongoing protocols. The support the RRB gives to the research office is vital as the community members share their expertise and knowledge in order to make decisions that benefit the community at large.

Another major task in building research regulation for all tribal partners is creating a system to support the submission, review, and housing of research protocols. In the last few years, two tribal partners have been able to access and fully implement an online protocol submission software that has been key to streamlining some of the duties for staff (see Case Study 1 in the Appendix). The ability for external researchers to use an online submission process, complete with forms and guidance from afar, has been helpful for staff and RRB members. Initially, the transition to using an online submission software was very time consuming to implement; however, the tribal partners who utilize this system agree it reduces the burden of some tedious operations within the research office.

Core and Division Support

During this entire process, the Regulatory Knowledge Core (RKC) provided guidance and training in regard to ethics and regulatory support for both the tribal partners and their research review board members. The tribal partner RRB members would receive various ethical research trainings from CRCAIH cores and division staff and other external entities, such as Engage for Equity and the Indigenous Wellness Research Institute National Center of Excellence. Over the years of the CRCAIH partnership, RKC was instrumental in guiding tribal partners in regulatory processes through teleconferences, webinars, and in-person trainings to provide feedback and valuable resources.

Unique Aspects

One unique aspect specific to Oglala Sioux Tribe in supporting and sustaining the research office is the implementation of a fee structure for research reviews. This means Oglala Sioux Tribe charges a fee, assessed according to the current fee scale, to all approved research projects that occur within the exterior boundaries of the Pine Ridge Indian Reservation. This topic is often discussed during joint tribal partner meetings, and all tribal partners see the potential to benefit by planning to implement a fee structure in their community. Oglala Sioux Tribe has been the leader thus far in the conversation and providing guidance on the benefits of implementing a fee scale. Tribal partners need to determine whether the volume of research proposals exist in each tribe to implement a fee structure that would make RRB activities self-sustaining. In some tribal communities, utilizing this type of software may require tribal council approval in order to implement such a process.

Community Engagement

The tribal partners' community engagement efforts have been significant to building their tribal infrastructure for research. Tribal partners recognized the importance of educating and informing tribal members and stakeholders of the importance of promoting ethical research oversight throughout the years, but with a greater focus in the last few years. Helping tribal members of all ages understand the importance and benefits research can offer has taken time, and recognizing and understanding historical past harms is fundamental (Sapienza, Corbie-Smith, Keim, & Fleischman, 2007). In addition, these community engagement activities needed to occur as a continual process with each community, regardless of the longevity of the tribal research office.

Commonalities

Support from the community was crucial and involved more than just securing buy-in for CRCAIH activities. Engagement efforts also focused on including community members and informing them of the research processes, why research infrastructure was needed, and how beneficial it would be at present and in the future for considering participation in research projects. Additionally, gaining an understanding of the current knowledge and readiness for research from stakeholders was helpful and provided an understanding of the current processes. Outreach and engagement with tribal members is vital, not only from the start of establishing a research office, but throughout the process to increase the knowledge, understanding, and importance of research.

Relationship-building is complex, multi-faceted, and often time challenging. For tribes, relationships are historical, political, formal and informal, and personal (English et al., 2004). There are many various ways to engage and educate the community to build strong relationships, which often take time. Each tribal partner works with the community at large through various mediums such as attendance at local and district meetings, newsletters, maintenance of a current website, being inclusive with partners, and transparency with tribal members.

Some of the specific community engagement activities from the tribal partners included having a presence on social media (Tribal Nations Research Group has a website and a Facebook page), as well more traditional methods such as print (Sisseton-Wahpeton Oyate has a monthly newsletter shared with all the department administrators and is available on the research office website), and in-person methods (tabling at tribal health fairs). Tribal Nations Research Group utilized several community engagement methods in the process of gaining support for their Turtle

Mountain Band of Chippewa Indian Research Protection Act (see Case Study 2 in the Appendix). Other tribal partners, such as Sisseton-Wahpeton Oyate, used in-person, community engagement efforts to gather support for their research code. This required repeated visits to each of Sisseton-Wahpeton Oyate's seven districts to meet with the tribal membership and provide education on the importance of research projects, research oversight, and data sovereignty. In addition to this, the tribal membership was asked to carefully review the proposed Sisseton-Wahpeton Oyate Research Code and provide feedback and ultimately their approval.

Core and Division Support

The CRCAIH Community Engagement and Innovation Division (CEID) assists the tribal partners in coordinating community engagement activities, such as on-going dissemination efforts. The tribal partners' community engagement activities were not always the highest priority as other tasks became more urgent, such as establishing a research code and a RRB, which had impending timelines and concrete outcomes. Community engagement approaches vary at different stages in the journey of building research, and initially, the community engagement aims were to identify health priorities, establish community advisory boards, and assist community liaisons in developing strategies to address each tribe's health disparities, demonstrating flexibility and responsiveness. These initial plans were modified to meet tribes' differing needs and timelines. Regardless, community engagement has always been present, as CEID was tasked with the significant role of building relationships and trust with tribal partners, that is often relegated to multiple dialogues, which takes time (Wallerstein & Duran, 2006). Trust was key and needed in order to garner support from the broader community, which included not only tribal leadership, but elders, youth, department heads, and others who may not be directly tied to the research office, but who are members of each tribal nation.

Unique Aspects

Recently, the community liaison from Rosebud Sioux Tribe worked with staff from community engagement and the regulatory knowledge core to host a lunch and learn with the Rosebud Sioux Tribe Health Administration to discuss the proposed Rosebud Sioux Tribe Research Code and update the tribal Health Board on the work of the community liaison. The response and support from the board and their desire to push the code forward for approval was evident. The board understood the urgency for an approved code and brought leaders' attention back to the main reason for wanting to become a CRCAIH partner, which is to protect their tribal

nations from potentially harmful research and to increase the overall research capacity. Rosebud Sioux Tribe was the last tribe to partner with CRCAIH, and in 2016, they had the opportunity to conduct a comprehensive assessment of the tribe's readiness for research development and engagement and to develop a Tribal Research Infrastructure Snapshot through a supplement grant with support from CRCAIH cores and divisions (see Case Study 3 in the Appendix).

Three CRCAIH tribal partners hosted their own community research conferences, over the last five years, exemplifying their dedication to community engagement and the importance of bringing research results back to the community. CEID partnered with Oglala Sioux Tribe and Cheyenne River Sioux Tribe to hold community research conferences in the spring of 2015 through a NIH conference grant. The goal of these conferences was to bring together tribal leaders, community members, and research partners to report back to the communities what has been accomplished to address their health needs and future directions for continued health improvement. In subsequent years, Cheyenne River Sioux Tribe has continued to host an annual community research conference. In 2017, Tribal Nations Research Group coordinated and hosted their first annual Data Matters conference to showcase how data is used to address important health, environmental, cultural, educational, and economic development issues within the community. These conferences are exemplars of community engagement around research. They have featured presentations from nationally renowned researchers along with local programs and investigators showing the importance of research and how it can influence the community.

Data Management

In the last few years, a strong focus for CRCAIH tribal partners has been on addressing matters pertaining to data management, influenced by priorities of the tribe. The broad concept of data management encompasses a variety of tasks and holds different meanings for each partner, but is inspired by the underlying goal of exercising data sovereignty. Data sovereignty allows tribes to govern and oversee the collection, ownership, and application of their own data and research (USIDSN, 2018; NCAI/PRC, 2009). For one tribal partner, data management might mean how research results from a study will be given back to a tribe (timing, frequency, hard copy or digital, summarized or raw data). For others, data management priorities include deciding where the data will be stored, when the tribe does not allow a cloud-based server to be used, and who has access to that information.

Core and Division Support

At the outset, the Methodology Core (MC) was designed to employ statisticians to assist tribes in analyzing their data, which would fill a gap because not many tribes have access to epidemiologists. However, most tribal partners were not at that stage of data governance at the start of their partnerships with CRCAIH. Therefore, similar to the CEID, the MC adjusted their aims from study design, report generation, statistical analysis, and data collection form design, to meet the current needs of each tribal partner. Staff from the MC developed and delivered webinar trainings on topics related to research study design, literature searches, and computer software. At the request of tribal partners, in-person trainings were presented on other aspects of data management, such as use of office software programs (Microsoft Excel and Access) to store and manage information. Tribal partners know the value of the data they own and desire to find ways to use this data to drive decision-making, which begins with having a strong data management plan in place. One of the first steps for many was cataloging research conducted in their community, but there were still many other aspects of data management where infrastructure could be built.

In response to these needs, a data management toolkit was developed in 2016 that contains practical tools and guidance for tribal organizations in collection and sharing research data. During a careful review of the toolkit at a tribal partner retreat two years later, tribal partners and CRCAIH core and division staff discussed edits to improve its use and understanding so other tribal nations could build upon ongoing data efforts and work toward the goal to use research results to make informed decisions. These conversations between tribal partners after trying to utilize the toolkit shed light on what could be enhanced and improved as they began to focus more heavily on data management and data governance.

Commonalities

The policies and procedures around data use, return, and storage have a great impact on the usefulness of research data for the community. Recognizing the value of data in policy and decision-making, tribal partners are eager to find ways to store and utilize data collected during the course of research projects. Tribal communities oftentimes see a reoccurring theme, where inaccurate or an absence of data and/or reporting issues may exist (Espey et al., 2014). Lack of accurate data acutely impacts policy-making and program planning. It is critical for tribal nations to become drivers of data collection efforts that are not only accurate, but also meaningful in addressing pressing health needs.

The biggest outcome for the tribal partners in regards to data management has been working toward the results, through owning the rights to the data by established data sharing agreements, and the ability to work with researchers to return results that benefit the community and address solutions to addressing existing health disparities. This attention to increasing capacity will assist tribal leadership in understanding and addressing health issues in their communities through research results, while at the same time, assisting researchers who work with tribes to better understand the community and the resources available to them (English et al., 2004).

In an effort to get accurate data specific to their communities, tribes often will conduct a community needs assessment or community health assessment. This data is a valuable tool for tribal leadership and program directors to use in decision-making, gauging the progress towards community wellness goals over time, as well as being used in grant applications. The best way to accomplish this is to conduct a comprehensive culturally-appropriate needs assessment (see Case Study 4 in the Appendix). Often this research is redundant with previous research others have conducted; therefore, tribes cataloging past research and having a larger say in the direction of research for their tribe will only move science forward as well as push the timeline ahead to make a more immediate impact on their communities.

Unique Aspects

Tribal Nations Research Group has taken their focus on data a step further by applying for and receiving various foundation funding (e.g., the Bush Foundation) to support planning for a regional data hub. The implementation of a regional data hub would provide broader opportunities for building fruitful collaborations between partners and community empowerment. With the focus on data that is tribally-driven and controlled, members could have access to an online dashboard for timely data retrieval. In addition, using data to apply for service delivery grants, tribal leadership could use data to make evidence-based decisions about policies to positively impact their tribal members and address results from needs assessments.

KEY BARRIERS

Staffing

The process of building tribal research infrastructure requires a great deal of time and resources. In an environment that is short-staffed, community liaisons often have to take on a variety of roles. Prioritizing tasks and honing time management skills enable staff to meet the

needs of their growing offices. As each office grows in its capabilities, new responsibilities arise. This constant building and enhancing of regulatory systems benefits the tribe, but at the same time increases workloads and oftentimes puts pressure on the community liaisons charged with maintaining the office. Funding from CRCAIH supports one FTE employee, and some tribes have elected to utilize the FTE to partially support two staff with other funding picking up the balance. Being stretched too thin has led to requests for additional staffing by some partners.

Another staffing challenge relates to employee turnover. The specific set of knowledge and skills required to manage the operations of the research office takes time to acquire. Training on research ethics, computer software systems, and effective community engagement takes time, as does getting to know the general role and purpose the research office serves, as well as getting to know partners and core resources available for assistance. As many offices are housed under tribal government, the hiring process must follow certain guidelines for advertising open positions. The time needed to find someone with the qualifications to fill vacancies may not allow for an overlapped training period with departing staff, making transition memos and documentation of procedures essential for continued smooth operation of the office.

Tribal Leadership

Changes in tribal leadership also have the potential to impact the building of tribal research infrastructure. Having leadership support and buy-in legitimizes the office and highlights its value to the tribe. Changeover in elected leadership may lead to the need for liaisons to reorient the tribal council to the purpose and duties of the research office, as well as emphasize the importance of research in tribal communities (Burhansstipanov, Christopher, & Schumacher, 2005). For example, the Rosebud Sioux Tribe tribal council members are elected at-large by enrolled members, the President and Vice President are elected for a term of three years, and the Secretary and Treasurer are elected for two-year terms (Buffalo & Bordeaux, 2017). This underscores community liaisons' roles as advocates for research in addition to regulators of the research process. Additionally, tumultuousness in tribal leadership can push back action on certain items necessary to advance the progress of the research office, such as passing official laws/ordinances regulating research.

Sustainable Funding

As eluded to earlier, one key barrier to building tribal research infrastructure is the potential lack of adequate funding. In addition to the salaries of each community liaison, there is the cost for maintaining online IRB submission software, stipends/reimbursements for RRB members, office supplies, and facility operation costs, plus any costs associated with travel and professional development activities. If tribal resources are stretched thin, as they often are, it is challenging to make research infrastructure a funding priority. Some tribes are seeking to recoup operational costs in the form of fees assessed on research projects as they go through the IRB approval process. A challenge of using this funding stream lies in projecting operational costs and implementing a fee structure that brings in enough money to support the office while not being overly burdensome to investigators.

Institutional Infrastructure

Building optimal tribal research infrastructure requires institutional infrastructure already be in place, such as fiscal and technology infrastructure. Tribal offices comprised of staff with knowledge of grants contracting are needed if the tribe is partnering on grants or the many regulations surrounding management of Federal grant dollars. Hold-ups in processing and failure to be responsive can delay subcontract awards and funding allocation, putting the research office in jeopardy of temporarily closing. Also beneficial is having a mechanism in place that can relieve some of the expense burden incurred by staff in paying for travel and waiting for reimbursement.

Educating Researchers

Non-native researchers oftentimes have limited knowledge of the community they are interested in working with or preconceived notions of a community's problems, creating an instant barrier (Chadwick et al., 2014). This also applies to Native researchers from different tribes, who are less familiar with the tribal nation's culture or research processes they are interested in working with. Additionally, these researchers might have expectations that the community liaison will guide them to the correct people within the community, will answer every question they have, or sometimes have even assumed the liaison may assist in collecting data. The time needed to educate, guide, and direct interested researchers has become a need most community liaisons recognize, but in reality do not have dedicated time for, and in doing so, lose valuable time for other activities

within the research office. RRBs ask researchers how both the tribe and the researcher will benefit from the proposed project, and what is their current or prior knowledge they have about the tribal nation. Many times, the community liaison takes on a role that is not expected of other IRBs to guide and educate the researcher.

Without a doubt, tribal nations want support and solutions to the numerous health disparities that can exist, and oftentimes leadership, health boards, or the local research review boards encourage mindful researchers to build connections and lasting relationships. Researchers can make the most of their time in tribal communities if they take the necessary steps to educate themselves about the tribe prior to conducting research. There is understanding that some researchers face pressures to advance their knowledge and careers; however, this education is a key component of their professional and personal development (Bruggs & Missaghian, 2006). Learning about the community or tribal nations that the researchers are interested in will not only help them to be more knowledgeable, but their awareness of the tribe's history, past research wrongs and community strengths will show they have taken the time to understand the people and the tribe. Tribes will continue to expand and build research infrastructure, and as researchers continue to conduct research that benefits the tribe, they will together conduct better quality research.

RELATIONSHIPS

Tribal Partners' Relationships

Perhaps one of the greatest outcomes of the CRCAIH partnerships has been the relationships formed between tribal partners that not only flourished over time, but also created an invaluable network. The peer-to-peer guidance and support the community liaisons are able to provide to one another is unmatched. Initially, tribal partners participated in one-on-one calls with CRCAIH cores and divisions at frequencies each determined would be most beneficial to them. Quarterly teleconferences with all partners and cores and divisions were held as well as one large group meeting at the CRCAIH Summit. These infrequent large group calls and separate teleconference meetings served to build individual infrastructure, but weren't very conducive for tribal partners to get to know one another. In Fall 2016, the first of three tribal partner retreats was held. The retreat provided time for partners to gather face-to-face to share expertise, provide feedback on challenges, identify ways to serve as resources for each other, and ultimately foster

connections for future collaborations.

The following year, the tribal partners collaborated intensely on their group panel presentation, each completing a research poster and facilitating a workshop at the CRCAIH Summit. The engagement from audience members was greatly welcomed and brought many questions during the Q&A portion of the tribal partner panel presentation on sustainability, infrastructure, and the benefits of implementing a fee structure. This huge undertaking led to the establishment of a regular biweekly group teleconference with all tribal partners and some members of CRCAIH cores and divisions. These more frequent meetings helped foster tribal partners' motivation to find ways to be a support to other local tribes building their infrastructure for research. At the third tribal partner retreat, the idea arose for the development of a tribal partner toolkit, revising the current data management toolkit with all partners contributing and evaluating their partnership with CRCAIH and next steps as the original NIH funding comes to a close. Although support from CRCAIH cores and divisions is still relevant and maintained, having support from one another has proved invaluable and has created a stronger unified voice in becoming a part of the national movement in tribal research infrastructure.

CRCAIH Network Relationships

Much effort has been taken by CRCAIH over the last seven years to establish and foster relationships on the local level, not only with each tribal partner community liaison, but with the larger community, department heads, tribal colleges, and surrounding universities, to name a few. On a national level, CRCAIH works to build relationships with larger entities in support of tribal research infrastructure who see the need to support this work by attending and presenting at various conferences and sharing the unique work that each tribal partner is doing in their tribal nations. One example of this has been with the IRB toolkit, which has found an interested national audience.

It must be noted that the CRCAIH tribal partners also assisted CRCAIH cores and divisions in building and improving its own infrastructure and practices. As the tribal partners built their research infrastructure, CRCAIH core and division staff, the majority of whom were also conducting research with tribes on other projects, became more responsive to tribes and their needs in regards to research, data, dissemination, and assisting researchers and institutions in navigating and building relationships with tribes. Through working more closely on CRCAIH goals of building tribal research infrastructure, the CRCAIH core and division staff's research projects

likely became more responsive on issues of tribal data sovereignty and culturally respectful research protocols. Research liaisons from each tribe provided guidance and feedback so researchers approach tribes in a respectful and cultural manner. Tribes want research that benefits their tribes just as much as it will benefit researchers and institutions.

CRCAIH was built with the intention that it was to go beyond the life of the grant, and currently in place is a website that houses a number of research tools and resources for tribal leaders, interested researchers, and others interested in collaborating or connecting with a tribe or other researchers. Relationships take time, and that is something CRCAIH core and division staff have definitely learned as they worked with each tribal partner. Over the last two years, as previously mentioned, CRCAIH has held biweekly tribal partners conference calls to allow the partners to talk more often with one another and for CRCAIH core and division staff to take the time needed to hear from tribal partners as a group. This was a change in infrastructure building as limited time between partners was provided and has definitely made for a greater and deeper impact on relationships and research infrastructure building for everyone. However, trust needed to occur at a culturally appropriate pace, in order for the tribal partners to be comfortable in sharing and asking for assistance as best fit for each tribe.

Research Office Visibility

As tribes continually work to engage their peers, communities, and stakeholders on the importance of research infrastructure and sustainability, there are still instances where knowledge of infrastructure existence in their community goes unnoticed. At the end of the day, the research office must be readily identifiable in order to truly protect and benefit the entire community. There have been a few instances where proposals went before the tribal council or the tribal college, and the RRB coordinator or the community liaison hears about it after the research project has been approved and started. Securing their presence and the work of the office within the tribe is a constant job that they must balance with the rest of the necessary work in establishing and sustaining capacity of the RRB. CRCAIH continues to look for innovative and practical ways for each community liaison to network and reach as many tribal members, tribal departments, leaders, and potential investigators as possible. Developing relationships on a continual basis assists in the ultimate purpose of creating and expanding upon the need to build and sustain research infrastructure.

CONCLUSIONS & FUTURE DIRECTIONS

In conclusion, the lessons learned from the CRCAIH tribal partners' experience on research infrastructure building can be widely applied to Indigenous communities throughout the world. Control of research review and data governance is essential to the full realization of tribal sovereignty in the research context. Although all the tribal partners joined CRCAIH with different needs and strengths, they used the resources of CRCAIH initially to focus on research protections and then moved into development of data management policies and collection of data. The CRCAIH tribal partners have demonstrated it is possible to navigate the journey from passive recipients of research, to a fully engaged partnership on research projects. Steps that facilitated this process was the establishment of running a high-quality local research review process, organization of data clearinghouses, and leadership of independent research projects. For example, CRCAIH tribal partners focus on the positive outcomes from data, examine what currently works within their tribe, and reinforce the strength and resiliency that exists in tribal nations through cultural and historical knowledge, which helps increase the overall equity for tribal communities. Through tightened, more efficient, and well-informed research review processes, tribes have and will continue to approve research that truly benefits the community.

The NIH investment in CRCAIH resulted in a beautiful and dynamic partnership between an academic research entity, tribal nations, and a national-level AI policy research center. The administering of one-on-one, tailored technical assistance, in addition to the training opportunities, is one critical mechanism of investment for change that bears fruit. It is only through this crucial investment in community building that the needle will be moved on AI health disparities. Throughout CRCAIH's existence, 68-72% of the grant budget went outside of the CRCAIH core and division services to support tribal partners and research projects in building research capacity and infrastructure. These early investments in infrastructure and human capital helped position tribes to be more competitive for future funding opportunities and to engage in more equitable research partnerships. Having solid research infrastructure and positions dedicated to research oversight empowers tribes to advance research stewardship and to have a front seat in the decision-making process.

The CRCAIH tribal partners continue to demonstrate the benefit of investing in tribal research infrastructure through directing capacity-building efforts among their own nations, researchers, and other tribal nations. As recent recipients of the National Indian Health Board Area/Regional Impact award, the CRCAIH tribal partners are leaders who serve as mentors to

other tribes in the region who do not yet have the capacity or tools, but have the desire to take control of research on their lands, as well as mentors to researchers to improve the science of AI health research. At CRCAIH's annual research summits, the tribal partners have emerged as compelling storytellers, spreading their successes and lessons learned, which is a wonderful way to educate both audiences of other tribal nations interested in growing their research infrastructure and academic researchers.

As the tribal partners move forward and continue to support research projects for their tribe that may help reduce existing health disparities, continuing to increase the inclusion of tribal leaders and researchers in the design of projects and the contribution of multi-discipline research to develop methodology that speaks to the community as a whole and its citizens is necessary. This effort goes beyond the purpose of community-based participatory research and recognizes Tribal Nations' sovereignty, including the preservation of the cultural and traditional knowledge of tribes in the development of research projects.

Much of these tribal research infrastructure building processes can be replicated in other tribal nations. Like the CRCAIH tribal partners, many groups, such as the U.S. Indigenous Data Sovereignty Network through the University of Arizona, provide valuable resources, such as papers, articles, Indigenous Data Initiatives, and the opportunity to be part of their growing network through their website (USIDSN, 2018). The Saginaw Chippewa Indian Tribe of Michigan are dedicated to increasing tribal data governance, through efforts such as tribal data repositories and protecting their community, tribal sovereignty, and information (Henry, 2018).

Moving forward, CRCAIH will continue to engage not only tribal partner research coordinators in the mission of building tribal research infrastructure, but also through innovative community engagement methods to bring diverse groups of stakeholders together to discuss research to continue to build on this momentum on a national level. As this work continues, the tribal partners will continue to engage and support other tribal nations in this important and necessary work to increase tribal sovereignty, as some tribes are not yet at a place to begin building their tribal infrastructure for research or have access to the tools and resources (https://www.crcaih.org/training-and-resources.html), which we hope is one of CRCAIH's lasting legacies.

REFERENCES

Around Him, D., & Pickner, W. (2016). Cultural Narrative of the Spirit Lake Nation 2015 Comprehensive Community Assessment (CCA). Retrieved from http://www.littlehoop.edu/research.html

Brugge, D., & Missaghian, M. (2006). Protecting the Navajo people through tribal regulation of research. *Science and Engineering Ethics, 12*(3), 491-507. https://doi.org/10.1007/s11948-006-0047-2

Buffalo, M., & Bordeaux, S. (2017). Sicangu Oyate, Rosebud Sioux Tribe community profile. Report by the Rosebud Sioux Tribe Health Administration.

Bureau of Indian Affairs Enrollment Office. (2018). Fond du Lac Band of Lake Superior Chippewa. Cloquet, MN.

Bureau of Indian Affairs Enrollment Office. (2018). Rosebud Sioux Tribe. Mission, SD.

Bureau of Indian Affairs Enrollment Office. (2018). Sisseton-Wahpeton Oyate. Agency Village, SD.

Bureau of Indian Affairs Enrollment Office. (2018). Turtle Mountain Band of Chippewa Indians. Belcourt, ND.

Burhansstipanov, L., Christopher S., & Schumacher, A., (2005). Lessons learned from community-based participatory research in Indian country. *Cancer, Culture, and Literacy Supplement*, 70-76. https://doi.org/10.1177%2F10732748050120045S10

Chadwick, J., Copeland, K., Daniel, M., Erb-Alvarez, J., Felton, B., Khan, S., … Payan, M. (2014). Partnering in research: A national research trial exemplifying effective collaboration with American Indian nations and the Indian Health Service. *American Journal of Epidemiology, 180*(12). 1202-1207. https://doi.org/10.1093/aje/kwu246

Dawes Act of 1887, 25 U.S.C § 331 (2000). Retrieved from http://uscode.house.gov/view.xhtml?path=/prelim@title25/chapter9&edition=prelim

Elliott, A. J., White Hat, E. R., Angal, J., Grey Owl, V., Puumala, S. E., & Baete Kenyon, D. (2016). Fostering social determinants of health transdisciplinary research: The Collaborative Research Center for American Indian Health. *International Journal of Environmental Research and Public Health*, *13*(1), 24. https://doi.org/10.3390/ijerph13010024

English, K., Wallerstein, N., Chino, M., Finster, C., Rafelito, A., Adeky, S., & Kennedy, M. (2004). Intermediate outcomes of a Tribal community public health infrastructure assessment. *Ethnicity & Disease, 14*(S1), 61-69. Retrieved from https://www.ethndis.org/edonline/index.php/ethndis/pages/view/priorsuparchives

Espey, D., Jim, M., Cobb., N., Bartholomew, M., Becker, T., Haverkamp, D., & Plescia M. (2014). Leading cause of death and all-cause mortality in American Indian and Alaska Natives. *Research and Practice, 104*(S3), S303-S311. http://dx.doi.org/10.2105/AJPH.2013.301798

Fisher, P., & Ball, T. (2003). Tribal participatory research: Mechanisms of a collaborative model. *American Journal of Community Psychology, 32*(3/4), 207-216. https://doi.org/10.1023/B:AJCP.0000004742.39858.c5

Indian Land Tenure Foundation. (n.d.). Land tenure issues. Retrieved from https://iltf.org/land-issues/issues/

Indigenous Peoples Council on Biocolonialism. (n.d.). Indigenous Research Protection Act. Retrieved from http://www.ipcb.org/publications/policy/files/irpa.html

Henry, K. (2018). A winding path: Working to protect, use and manage data at the Saginaw Chippewa Indian Tribe of Michigan. [PowerPoint]. Retrieved from http://www.ncai.org/prc/2._KAH_NCAI_Presentation_-Final.pdf

LaVeaux, D., & Christopher, S. (2009). Contextualizing CBPR: Key principles of CBPR meet the Indigenous research context. *Pimatisiwin, 7*(1), 1-16. Retrieved from http://www.pimatisiwin.com/online/

Lawrence, J. (2000). The Indian Health Service and the sterilization of Native American women. *The American Indian Quarterly, 24*(3), 400–419. http://www.jstor.org/stable/1185911

National Congress of American Indians, Policy Research Center (NCAI/PRC). (2009). Research that benefits native people: A guide for tribal leaders. Module 1, foundations of research: An Indigenous perspective. Retrieved from http://www.ncai.org/policy-research-center/research-data/NCAIModule1.pdf

Oberly, J., & Macedo, J. (2004). The R word in Indian Country: Culturally appropriate commercial tobacco-use research strategies. *Health Promotion Practice, 5*(4), 355-361. https://doi.org/10.1177/1524839904267391

Oetzel, J., Villegas, M., Zenone, H., White Hat, E., Wallerstein, N., & Duran, B. (2015). Enhancing stewardship of community-engaged research through governance. *Research and Practice, 105*(6), 1161-1167. http://dx.doi.org/10.2105/AJPH.2014.302457

Oglala Sioux Tribe Research Review Board. (n.d.). [Brochure]. Pine Ridge, SD: Office of Health Board Administration.

Pacheco, C. M., Sean, M. D., Brown, T., Filippi M., Greiner, A., & Daley, C. M., (2013). Moving forward: Breaking the cycle of mistrust between American Indians and researchers. *American Journal of Public Health, 103*(12), 2152-2159. http://dx.doi.org/10.2105/AJPH.2013.301480

Pearson, C. R., Parker, M., Zhou, C., Donald C., & Fisher, C. B. (2018). A culturally tailored research ethics trainings curriculum for American Indian and Alaska Native communities: A randomized comparison trial. *Critical Public Health, 29*(1), 27-39. https://doi.org/10.1080/09581596.2018.1434482

Sahota, P. C. (2007). Research regulation in American Indian/Alaska Native communities: Policy and practice considerations. Washington, DC: National Congress of American Indians, Policy Research Center. Retrieved from http://www.ncaiprc.org/files/Research%20Regulation%20in%20AI%20AN%20Communities%20-%20Guide%20to%20Reviewing%20Research%20Studies.pdf

Sapienza, J., Corbie-Smith, G., Keim, S., & Fleischman, A. (2007). Community engagement in epidemiological research. *Ambulatory Pediatrics, 7*(3), 247-251. https://doi.org/10.1016/j.ambp.2007.01.004

Sisseton-Wahpeton Oyate Research Office. (n.d.). [Brochure]. Sisseton, SD: Department of Education Office.

Tri-Ethnic Center. (2014). Community readiness for community change. In *Tri-Ethnic Center community readiness handbook* (2nd ed.). Fort Collins, CO: Colorado State University. Retrieved from http://www.triethniccenter.colostate.edu/wp-content/uploads/sites/24/2018/04/CR_Handbook_8-3-15.pdf

United States Indigenous Data Sovereignty Network (USIDSN). (n.d.). [Website]. Native Nations Institute at The University of Arizona. Retrieved from http://usindigenousdata.arizona.edu/resources

U.S. Census Bureau. (2012). United States Summary 2010: Population and Housing Unit Counts, CPH-2-1. Washington, DC: U.S. Department of Commerce. Retrieved from https://www2.census.gov/library/publications/decennial/2010/cph-2/cph-2-1.pdf

U.S. Census Bureau. (n.d.). My Tribal Area [data source: 2012-2016 American Community Survey 5-Year Estimates]. Retrieved from https://www.census.gov/tribal/?aianihh

U.S. Department of the Interior, Bureau of Indian Affairs. (n.d.). Agencies in the Great Plains Region. Retrieved from https://www.bia.gov/regional-offices/great-plains/agencies

Wallerstein, N., & Duran, B. (2006) Using community-based participatory research to address health disparities. *Health Promotion Practice, 7*(3), 312-323. https://doi.org/10.1177%2F1524839906289376

ACKNOWLEDGEMENTS

Research reported in this publication was supported by the National Institute on Minority Health and Health Disparities of the National Institutes of Health under Award Number

U54MD008164. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. Authors would like to acknowledge all of the CRCAIH tribal partner research offices' former and current staff.

AUTHOR INFORMATION

Melissa Buffalo is the Cancer Equity Manager at the American Indian Cancer Foundation in Minneapolis, Minnesota. Jessica Heinzmann is a senior research specialist in Behavioral Sciences at Sanford Research in Sioux Falls, South Dakota.Dr. DenYelle Baete Kenyon is the Associate Dean for Diversity and Inclusion and Master of Public Health Program Director at the University of South Dakota, Sanford School of Medicine in Sioux Falls/Vermillion, South Dakota and an associate scientist in Behavioral Sciences at Sanford Research in Sioux Falls, South Dakota. Kathryn Blindman is a data research assistant for the Oglala Sioux Tribe in Pine Ridge, South Dakota. Simone Bordeaux is the tribal research coordinator for the Rosebud Sioux Tribe in Rosebud, South Dakota. Anita Frederick is the president of Tribal Nations Research Group in Belcourt, North Dakota. Erin Garrison is a community liaison for Tribal Nations Research Group in Belcourt, North Dakota. Crystal Greensky is the quality assurance coordinator for Fond du Lac Human Services Division in Cloquet, Minnesota. Heather Larsen is a research specialist for Sisseton-Wahpeton Oyate in Agency Village, South Dakota. Tonya Kjerland is a research specialist for Fond du Lac Human Services Division in Cloquet, Minnesota. Dr. Victoria Grey Owl is a former associate scientist at Sanford Research in South Dakota.

APPENDIX

Case Study 1: Oglala Sioux Tribe Implementing Axiom Mentor IRB

The transition from a paper-based system to an IRB tracking software has been invaluable to the Oglala Sioux Tribe Research Office and the Research Review Board (RRB). The Oglala Sioux Tribe (OST) was the first tribe in the Northern Plains region to utilize this electronic research management system for submissions, review, and tracking of all research that would be conducted within their reservation boundaries (Elliott et al., 2016). Upon implementing Mentor IRB, the process has been streamlined, and having a central system that is available online and fully supports building a tribe's research capacity is ideal and saves time for the OST RRB Coordinator. The software not only assists the community liaison in their day-to-day functions, but also allows potential and current investigators to submit and update their protocol with use of the online system, as well as allows IRB members to log in and review all protocols prior to a board meeting. Axiom Mentor IRB and its many features, such as reminders for invoicing and upcoming deadlines, auto-populating of information, and customizable notifications and tabs, assists the coordinator immensely.

Furthermore, the community liaison serves as support to the other CRCAIH tribal partners implementing the software. Not only has OST provided their knowledge and experience with Axiom Mentor, they have led key discussions on the importance this tool has in building capacity, emphasizing the efficiently and flexibility in the software. An instruction manual is currently in the works for new Principal Investigators working with OST as well as an orientation packet for new RRB members. Therefore, through capacity building with one tribe, the knowledge is spread and assists many others. Axiom Mentor IRB is the primary IRB software that assists CRCAIH tribal partners in managing and monitoring current and past research within their tribe. Additional CRCAIH tribal partners have implemented Mentor IRB software to different extents and have found it increases efficiency exponentially.

Case Study 2: Turtle Mountain Band of Chippewa Indians/Tribal Nations Research Group: Community Engagement to Approve and Pass the TMBCI Research Protection Act

The partnership between Turtle Mountain Band of Chippewa Indians (TMBCI) and CRCAIH began in August 2013, and within one year, TMBCI's Research Protection Act was approved and enacted. The tribe wanted to regulate all research within the reservation boundaries,

not just human subjects' research, and started first with an established code to guide research. From the start of the partnership, staff began drafting a research code modeled from the Indigenous Research Protection Act (Indigenous Peoples Council on Biocolonialism, n.d.) and made the necessary adjustments to reflect and protect the members of the TMBCI. Upon a rough draft being approved by the legal department, the code went into the local tribal newspaper for comment for 90 days. Additionally, copies were mailed to all tribal departments, current researchers engaging in research with the TMBCI nation, IRBs within the state, and academic institutions, such as University of North Dakota and North Dakota State University, for feedback and review. A public meeting was held in February 2014 to highlight and discuss the code and the importance of the regulated research and to respond to any feedback or comments from community members and leadership. Across the next five months, an additional three open public meetings were held, a 30-day comment went out to the Tribal Council, and on July 31, 2014, the Research Protection Act was approved and put into place. The community involvement was key in how quickly the code was passed and how supportive the tribe overall was in seeing the need to build research capacity for the members of the TMBCI.

Case Study 3: Rosebud Sioux Tribe Supplement Grant

In 2015, as the most recent tribe to partner with CRCAIH, Rosebud Sioux Tribe (RST) was best situated to conduct a comprehensive review of tribal readiness for research development, which was the second aim of the NIH CRCAIH supplement grant. Tribal community data was collated and nine stakeholders were interviewed regarding the community's perspective and knowledge of research and their readiness for research using the Community Readiness Model (Tri-Ethnic Center, 2014).

The RST Community Profile resulted in a 23-page document that included a tribal overview, demographics, health status, customs and traditions, current programming, and current research review process. This profile serves as a helpful tool for the researchers, stakeholders, and others new to the community. Additionally, results from the interviews revealed that although research is a low priority compared to other ongoing tribal health care crises, there is an understanding as to why it could be low and the immediate health needs of the community that take precedence. This profile is used both by community members and those new to working with RST and is particularly useful for potential researchers and staff working in such departments as the Indian Health Service, who currently uses the profile for staff orientation. The profile has been

referenced by a few reports and has also been used in conversations regarding the need to build research infrastructure with RST stakeholders and leadership, proving just how valuable this document is for the community. CRCAIH partners feel strongly that it is the responsibility of potential researchers to learn the tribal culture and context they want to work with, and resources such as this profile are essential to accomplish that goal.

Case Study 4: Cultural Narrative of the Spirit Lake Nation 2015 Comprehensive Community Assessment

In the summer of 2015, 285 tribal members completed the Comprehensive Community Assessment (CCA), a 111-question survey that asked about individual health status, factors that influence health, and opinions on critical needs for the Spirit Lake Nation (SLN) under the guidance of the Cankdeska Cikana Community College (CCCC). The resulting data was analyzed, interpreted, and compiled in to a lengthy final report. The CCCC went beyond simply reporting by also creating a "cultural narrative" to complement the report.

The Dakota cultural values provided a foundation for the CCA process and informed their approach to understanding the health and well-being of the community. The four directions (west, east, north, and south) and the four primary colors (black, yellow, red, and white) were represented as the individual, family, community level, and society. Findings were placed within a specific section to guide and support healthy change in the community, based on the results. Through Dakota teachings, health is defined as including spiritual, physical, emotional, and mental well-being, and applying these teachings, as did their ancestors, who were scientists, exhibits the resiliency and ingenuity that is still strong for the SLN people (Around Him & Pickner, 2016). This document was key in disseminating local findings that were culturally-tailored for their tribal members and guides the future work of tribal programs.