Moving Forward: Evaluating the Great Lakes Native American Research Center for Health, 2003-2019

Great Lakes Inter-Tribal Council

Lac du Flambeau, WI

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Abstract

The Native American Research Centers for Health (NARCH) pursue a mandate to improve Native American participation in biomedical sciences as well as support American Indian/Alaska Native (AI/AN) health priorities. The Great Lakes Native American Research Center for Health (GLNARCH) promotes this mission in the Laurentian Great Lakes Region. This report describes ongoing outcome measures from an established evaluation plan. These data confirm that GLNARCH is meeting educational and health research promotion goals. Other recent endeavors have included a health and wellness pilot to identify areas for further innovation and promote culturally responsive research and education to serve the Great Lakes Native American communities.

Keywords: community-engaged research, program evaluation, wellness, culture, American Indian/Alaska Native

A Culture and Wellness Pilot to Guide Native American Research Centers for Health Evaluation

INTRODUCTION

The Native American Research Centers for Health (NARCH) pursue a mandate to improve Native American participation in biomedical sciences as well as support American Indian/Alaska Native (AI/AN) health priorities. The National Institute of General Medical Sciences (NIGMS) and several other National Institute for Health (NIH) Institutes and Centers partner with the Indian Health Service (IHS) to support the NARCH program. The NIH oversees the funding and management of the NARCH grants while IHS oversees the interactions between the AI/AN organizations and research-intensive partners. The NARCH initiative supports partnerships between AI/AN tribes or AI/AN-based organizations that conduct biomedical research. The NARCH funding mechanism provides opportunities to conduct research, enhance research training and support professional development to meet the needs of AI/AN communities. The NARCH program also provides opportunities for tribes and tribal organizations to build both research infrastructure and capacity to address the health disparities prevalent in AI/AN communities and increase trust of research within the AI/AN communities. As of 2019, 14 NIH-funded NARCH centers exist. The Great Lakes NARCH (GLNARCH) is the only such center east of the Mississippi (National Institute of General Medical Sciences, 2019) and therefore provides crucial support to AI/AN health initiatives in the Bemidji (Great Lakes) service area. Many of the AI/AN groups and AI/AN-serving institutions within the GLNARCH/Bemidji service region are geographically isolated from large research institutions with greater capacity for biomedical science and training.

These centers face multiple challenges that are in many ways unique to the AI/AN context. The unique circumstances of AI/AN health promotion have been discussed by our

GLNARCH team (M. Dellinger & Dellinger, 2018; M. J. Dellinger et al., 2016; Jackson et al., 2015) and others extensively (Solomon et al., 2014). The best practices for meeting these challenges may overlap with other ambitious health and wellness promoting efforts. This report describes evaluation of numerous GLNARCH efforts to meet the programmatic goals of NARCH in various geographies and populations. We also present an exploratory analysis of a pilot health and wellness questionnaire with an emphasis on culture. The results are consistent with our previous GLNARCH program evaluations that cultural context greatly influences how program goals and concepts of health are interpreted in AI/AN communities. The observations regarding cultural context are significant because global efforts to pursue health promotion and capacity can be compared conceptually to the NARCH efforts to identify common best practices. Therefore, the outcome measures recorded and proposed herein can be adapted to culturally and socially diverse contexts to pursue either the NARCH mandates or other largescale efforts such as: United Nations Sustainable Development Goals, Global Health educational efforts, and the NIH Strategic Plan for Tribal Health Research 2019-2023.

Previous efforts have established that digital storytelling and other participatory evaluation methods provided novel insights for GLNARCH program evaluation (M. J. Dellinger et al., 2016; Jackson et al., 2015). At the start of the most recent funding cycle (2018) the team expanded culturally responsive programming to measure perceived health and wellness and to increase satisfaction and engagement with the program. The longstanding, evolving, program evaluation protocols were not initially optimized to capture metrics of health, wellness, and cultural responsiveness. To address this need, the GLNARCH team is working to understand the role of culture in wellness in the Great Lakes AI/AN context. The following program evaluation goals were adapted from grant objectives:

GOAL 1: Update Program evaluation surveys to include information about health and wellness to reflect emergent themes in current program evaluation surveys and digital stories.

GOAL 2: Use digital storytelling interview scripts to inform questionnaire items that address health, wellness and culture of tribal populations in the Bemidji region.

The results of this evaluation describe recent innovations to partnership building under GLNARCH and how these strategies overlap with other similar health and wellness promoting initiatives. These strategies were evaluated in alignment with the United Nations Sustainable Development Goals and the NIH Strategic Plan for Tribal Health Research 2019-2023.

The GLNARCH Model and its Origins

GLNARCH grew from interest in research identified during a strategic planning session held between the Wisconsin Tribal Health Director Association and Great Lakes Inter-Tribal Council, Inc. (GLITC) Indian Health Program in fall 1999 (M. J. Dellinger et al., 2016). The current funding is a partnership between GLITC and the Medical College of Wisconsin (MCW). The center also coordinates with regional partners from both academic and AI/AN institutions. Figure 1 outlines the key GLNARCH partners and their institutions as of 2019.

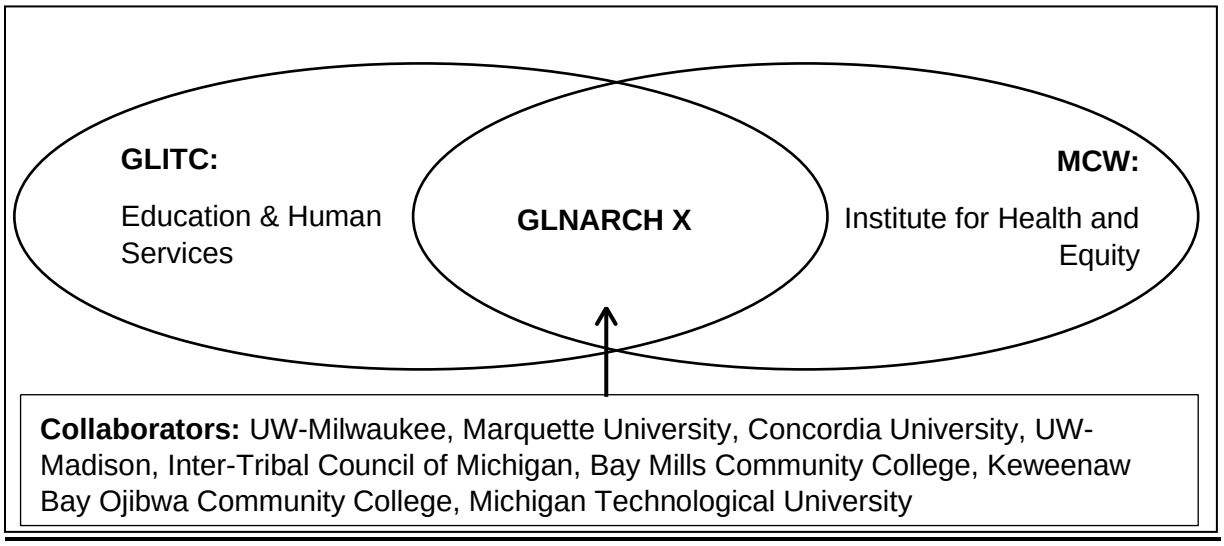

Figure 1: Institutional Setting for GLNARCH X

Housed at GLITC, GLNARCH relies on a model of academic and tribal community partnerships that evolved from a combination of leadership from the tribal partners and

adherence to community-engaged participatory research principles by the academic partners. The center currently consists of four core components: 1) the administrative core, who oversee the overall center; 2) research projects, conducted by various academic-tribal partnerships in the region; 3) a student career enhancement component, that exposes tribal students to academic opportunities, and 4) a capacity building component, that seeks to extend research opportunities for researchers and trainees engaged in relevant projects. The capacity team also leads an effort to encourage tribal college/universities (TCU) partnerships with all GLNARCH activities.

METHODS

Adapting Program Evaluation and Activities Based on Evaluation

The GLNARCH program evaluation has evolved over the years and has consistently focused on the experiences, accomplishments, and satisfaction of students and mentors. This has provided valuable data to track the Center's progress towards stated goals. However, the historical program evaluation priorities (focusing on accomplishments and satisfaction metrics) was noted to lack key insights (Table 1). Therefore, the GLNARCH Capacity team piloted a new culture and wellness survey instrument at two events in 2019: 1) the GLNARCH Open House which engages with educational and research partners, and 2) the Bear River Powwow in which the team engaged directly with tribal community members. Both events were held on-site in Lac du Flambeau, WI. The pilot results provide key insights towards the feasibility and importance of routine data collection methods on tribal culture and wellness. These data will inform health research programming that serves diverse cultures with the goal of promoting health and wellness regionally and globally.

Priority	Opportunity	Proposed Solution
More efficient cultural tailoring of research from academic partners	Comprehensive, respectable GLNARCH network and knowledgebase to share	Increased face-to-face opportunities for academic and community collaborators
Demand for diverse methods to deliver technical assistance and training	GLNARCH academic partners willing and eager to share skills and resources	Provide seminars, guest lectures, and workshop on health research methods
Improved assessment of community engagement/impact of GLNARCH	Rich cultural events near GLITC which would welcome GLNARCH involvement	Participate in cultural events such as Powwows and ceremonies and initiate dialogue, promote trust
Understand existing online footprint and potential to share resources nationally	Existing social media services, ongoing digital storytelling work, partnership with other NARCH awardees	Expand online presence, find ways to collaborate via internet/social media, partner with other NARCHs
Ensure sustainability of GLNARCH collaborations and resources	GLNARCH well-regarded in region, many successes to report (including student placements), past and present participants can collaborate	Establish dedicated effort to reporting and disseminating successes, possibly using new and existing evaluation outcomes

Table 1: Summarized priorities, opportunities, and possible solutions identified in GLNARCH program evaluations leading up to the current (2018) funding cycle

Participants and Key Informants

Participants were from the Bemidji area and most participants were AI/AN, though non-Natives were not excluded. Based on input from tribal partners, it was important to include non-Native spouses or adopted children of tribal members living in tribal communities and those who live and/or work in the Bemidji region. Only those who did not engage in GLNARCH activities within the time frame were excluded. Surveys and Digital Stories were conducted in English since that is an in-common language among AI/AN populations in the region.

Recruitment

Participants in wellness surveys and digital storytelling were identified by participation in other GLNARCH programming, such as interns and mentors in the internship programming of the student career enhancement component of GLNARCH X. GLNARCH-GLITC coordinators conducted site visits to tribes, tribal colleges and universities (TCUs), and tribal health fairs as part of normal GLNARCH activities. This included meetings, booths at events, etc. During this time, subjects were asked to participate in surveys and/or digital storytelling. Individuals were also recruited in person at GLNARCH events. Participants were provided with an information letter about GLNARCH projects and signed a waiver to participate in digital storytelling. Participants were incentivized to complete surveys and interviews with various gift items such as MCW and GLITC water bottles, shirts, or bags.

Survey Development

Legacy Evaluation Materials (Mentors and Students)

The student and mentor evaluations are deployed annually to monitor and adapt the program to the student needs. These assessments also determine if the program is achieving its objectives and goals. The evaluation plan includes process and outcome evaluation, using quantitative and qualitative methods and include but are not limited to the following data sources: post evaluations, key informant interviews, and tracking of social media. For the current assessment, quantitative data were collected using Excel.

The mentors and students also provide written feedback on intern competencies in key areas at the end of each summer. This was previously the primary source of qualitative data to follow GLNARCH progress towards issues of cultural diversity, partnership, fidelity, contribution to the health field and community engagement. Other metrics from these assessments describe: the quality of training, including supervision, didactics, and role modeling. This documentation

shows that the intern has reached an appropriate competency level by the end of participation in the program and demonstrates new skills acquired over the summer.

For the data presented here, student and mentor surveys were administered as paper questionnaires either in-person or via e-mail. GLNARCH staff (housed at GLITC) collected these surveys via personal contact with each mentor and/or student. Starting in 2018, a REDCap (Harris et al., 2009) survey data entry tool was created and GLITC staff entered the survey responses into the online database by hand. Survey responses are summarized using descriptive statistics, such as total counts and prevalence of agreement to items, to match important program evaluation themes. Accomplishments of program participants, i.e. academic presentations, publications, abstracts, and reports are also noted cumulatively since 2003.

Wellness and Culture Survey Development

To explore health and wellness, contextualized to Anishinaabe culture, questions were developed in consultation with members of the GLNARCH team who themselves are Anishinaabe and/or work and live at the Salish Kootenai or Lac du Flambeau reservations (all authors). The survey was developed in iterations, by consulting internal expertise as well as reviewing qualitative insights from GLNARCH digital story interviews. Over the years GLNARCH digital story participants have mentioned about traditional words or phrases to describe wellness. Those insights were used to guide questionnaire development and format. Ten questions concerning wellness and culture used a Likert Scale to rate level of agreement, while one question asked general health status (See Table 2 in Results).

Human Subjects Protections, Special Considerations

It was possible that some participants might have felt uncomfortable being asked about their health in the context of culture. Interviewers ensured that these key informants understood that answering any question was optional and that their responses might be shared with a larger

audience. Participants in digital storytelling could not be de-identified for analysis because they are filmed, and they agreed to that by signing a waiver. The all programmatic questionnaire data are de-identified. Digital story interviews were conducted by GLITC staff who work in the community to increase comfort of participants speaking about their wellness in the context of their culture. The questionnaires were also distributed by the GLITC staff during interviews.

RESULTS

Ongoing Program Evaluation Metrics: Highlights

Academic Outputs

Types of publications, authorship of those publications, and students' progress toward terminal degrees are all key performance indicators to measure GLNARCH outcomes. These indicators align with the evaluation goals of providing: research experience and exposure to AI/AN trainees and students, improving educational attainment in AI/AN populations, supporting research pursuant to tribal health goals, and improving professional development in AI/AN trainees. The quantification of academic output also demonstrates overall productivity for the grant. When considered collectively, these accomplishments are distributed almost evenly across three categories of participants: GLNARCH personnel, Students, and Partners (Figure 2). This productivity demonstrates progress by GLNARCH and partners to strengthen the next generation of biomedical researchers and practitioners in a culturally relevant way.

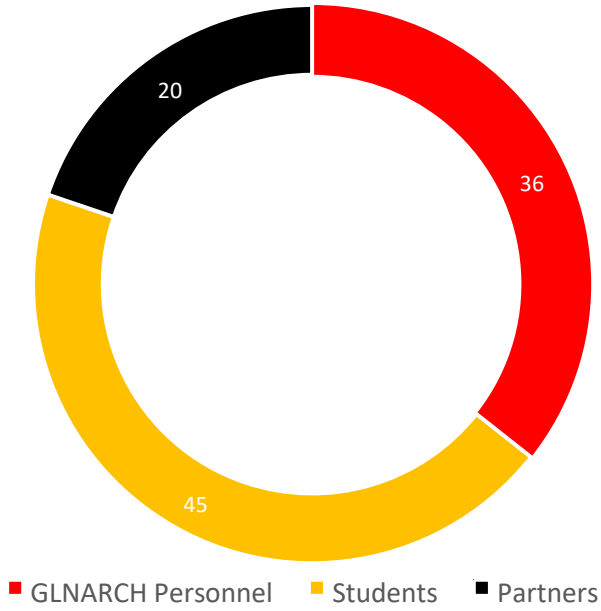

Figure 2: Academic productivity as measured by types of author(s) of disseminated information, 2003-2019

Cumulative accomplishments since 2003 appears in Figure 3. These include written publications (n=19; peer reviewed journal articles, technical reports, and community-focused reports) and in-person dissemination of information (n= 53; presentations and posters). In the first four cycles of GLNARCH funding, students were placed in 169 research undergraduate and/or graduate internships. Project topics focused on health issues unique to Native American tribes and cover diverse priorities as well as disciplines. These included, but were not limited to ecological health, natural resources, behavioral and mental health for indigenous youth and adults, participatory research methods, epidemiological research on birth defects, health disparities, smoking cessation, cultural competency, and indigenous agriculture.

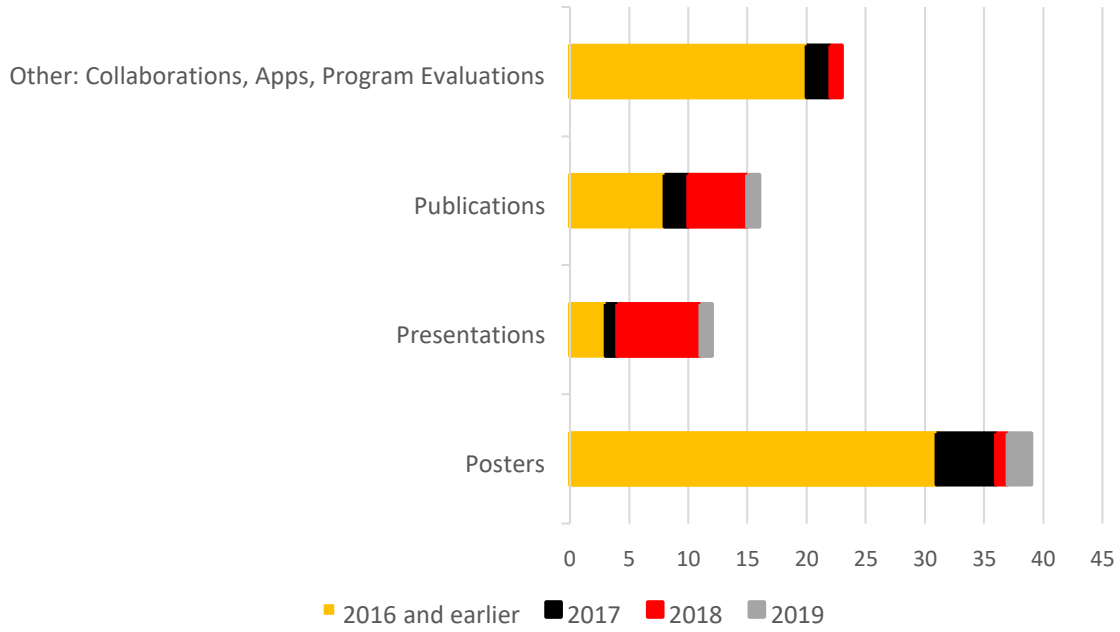

Figure 3: Accomplishments as measured by types of disseminated information, 2003-2016, 2017, 2018, 2019

Figure 4 illustrates the progress of GLNARCH student interns working within the GLNARCH network. Many students pursue PhDs indicating an emphasis on research and reflects the strengths of the mentor-student relationship. The model has also supported medical students interested in research. Several students have taken career paths other than biomedical research and include Doctor of Veterinary Medicine (DVM), Juris Doctor (JD), and Master of Divinity. Efforts to track the careers of students who left biomedical fields for other pursuits are ongoing.

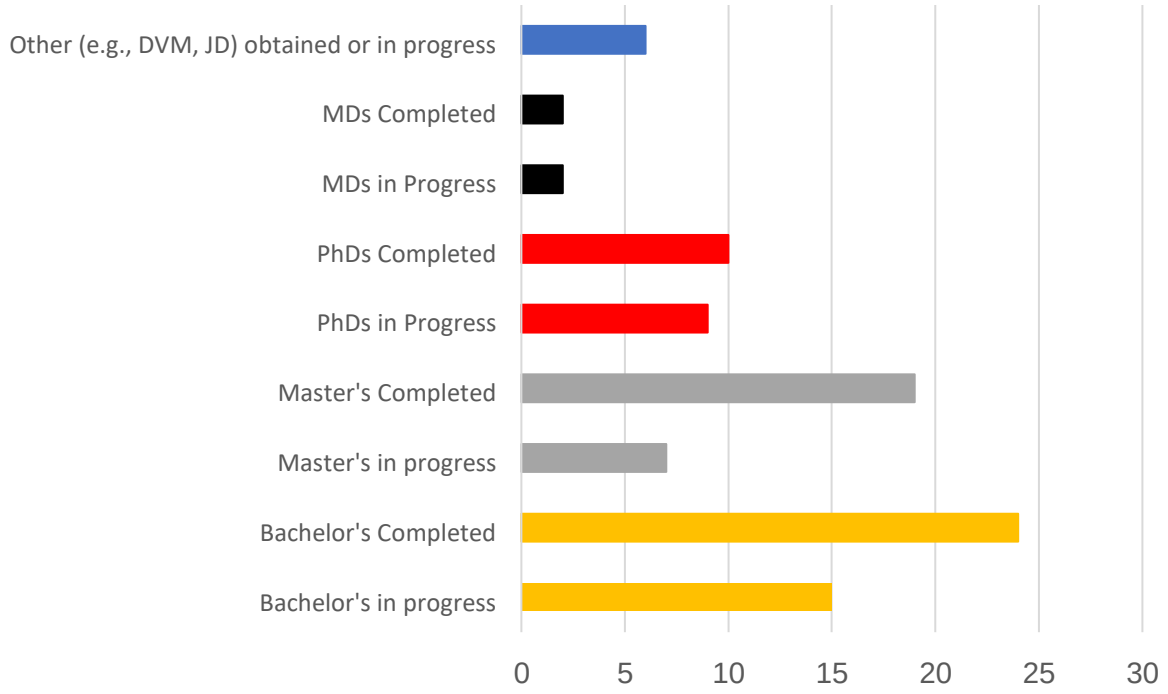

Figure 4: GLNARCH Student Progress in Higher Education, 2003-2019

Feedback from 12 students who participated in GLNARCH internships between 2014 and 2017 (more recent internships are ongoing) provided insight both into measurable productivity of students and the quality of students' experiences. These results showed students had opportunities to disseminate their research, cultivate better understandings of research and community engagement, and develop valuable skills they would take further into their academic careers. Evaluation from GLNARCH interns who have participated since 2014 indicate broad satisfaction with the program as well as perceived self-efficacy. These satisfaction metrics reflect a congruence with NARCH values of helping the community and cultural sensitivity (Figure 4). These gains can be expected to grow as most students expressed plans and desires to expand their academic efforts (Figure 5).

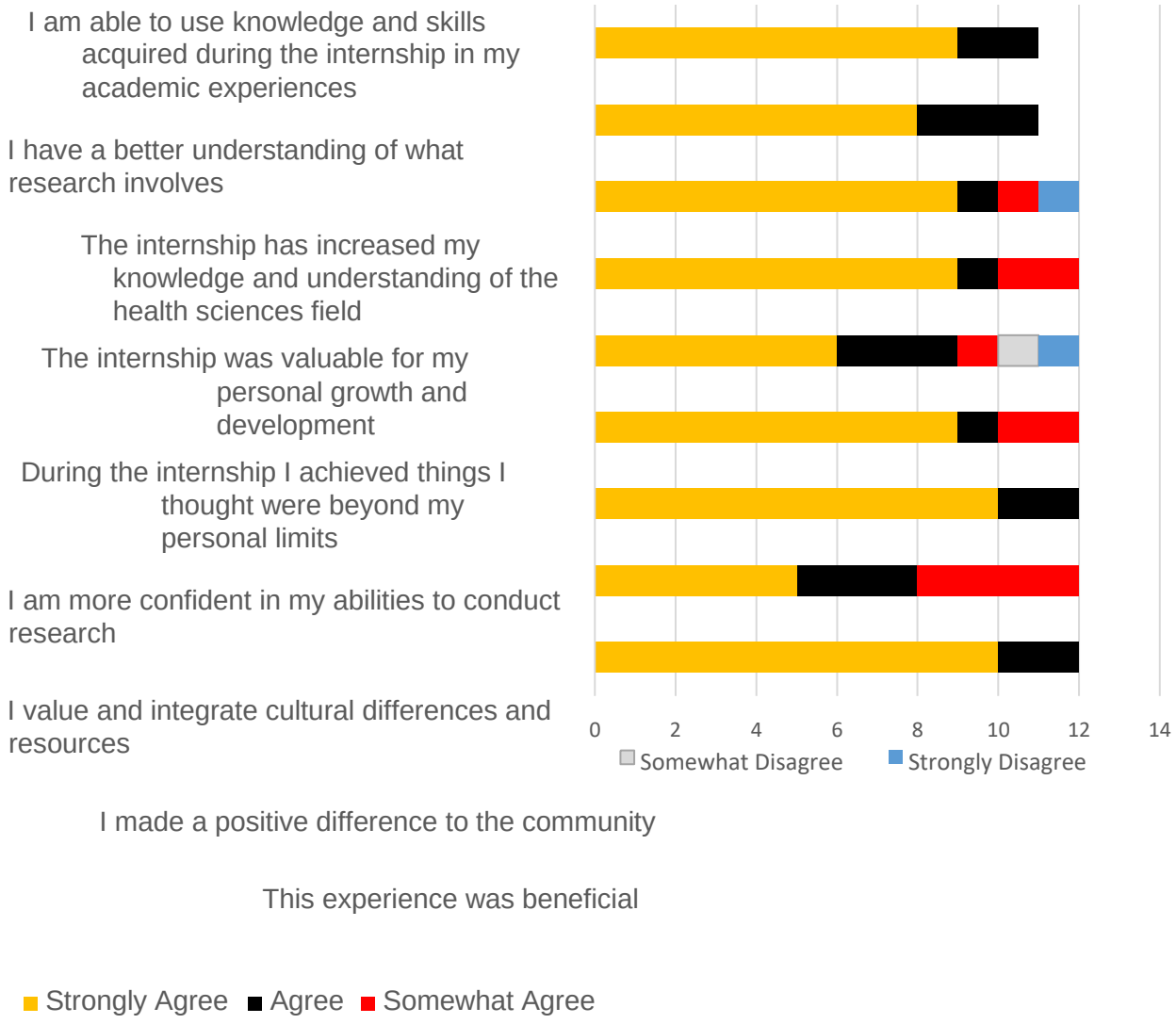

Figure 5: Strengths of Student Career Enhancement Programming through Student Evaluation of Internships, 2014-2017 (n=12)

Pilot Evaluation for Wellness and Culture

The wellness survey was conducted on a subset of GLNARCH participants starting in Spring of 2019 (n= 24). Wellness surveys were distributed at cultural events (i.e., powwows), TCU visits, health fairs, and to participants in other GLNARCH programming (i.e., internship) when they interfaced with GLNARCH personnel in-person. The results and analysis of that pilot survey are being prepared for publication. Preliminary results suggest that culture is viewed as a

crucial component of wellness and the perpetuation of culture is an important concern for these community stakeholders.

Broadly, the results of the pilot suggest positive sentiments regarding cultural matters. Many respondents reported that they feel healthy. Health is often reported as a difficult term to define for different cultures and many participants reported a culturally specific term for health and wellness. The most common terms were “minobimaadaziiwin” and “Ni Mino Ayaa” which translate roughly to “living in a good way.” This highlights the prominence of holistic conceptions of health and wellness. Most participants in the pilot reported habitually giving thanks. “Giving thanks” was developed by the Anishnaabe members of the survey development team to reflect the level of respect for cultural and spiritual traditions.

Question	Scale
I feel connected to the land around me	Likert (5)
I feel connected to my community	Likert (5)
My culture is respected by members of my community	Likert (5)
My culture is respected by individuals outside of my community	Likert (5)
I feel healthy	Likert (5)
My community participates in cultural activities that promote well-being	Likert (5)
I am optimistic when I think about passing on our culture to the next generation	Likert (5)
I am in the habit of giving thanks	Likert (5)
My community has the ability to support and provide for the next generation in a monetary sense (clothing, housing, etc.)	Likert (5)
My community has the ability to support the next generation culturally (language, stories, etc.)	Likert (5)
Would you say that, in general, your health is	Excellent - Poor

Table 2: Specific questions and scales used to assess wellness, sentiments toward cultural resilience, or health status

DISCUSSION

The GLNARCH evaluation outcomes align with the four core components: 1) the administrative core, 2) research projects; 3) the student career enhancement component that exposes tribal students to academic opportunities, and 4) capacity building to extend research opportunities for projects that focus on the priorities of Bemidji tribes. Many respondents to the

culture and wellness pilot reported that they feel healthy, but this metric yielded less agreement than those relating to the importance of culture (i.e., giving thanks and connection to land). Respondents were less sure of their ability to pass on cultural teachings to the next generation. The data suggest that many were concerned about the perpetuation of culture. It was clear from discussions with these participants that sustaining the culture was a priority.

The GLNARCH program is still evolving, building on strengths, and seeking areas of improvement and expansion. The data presented here as well as feedback from community engagement activities guides expansion of the program. GLNARCH is therefore responsive to conditions in the communities it serves. Ideally, GLNARCH also adapts to the positive changes brought on by its own activities. All aspects of the grant, ranging from student enhancement, research, to capacity building offer unique opportunities for prospective and current partners at any stage of education or professional development. GLNARCH therefore offers flexible options to get involved with research, education, and scientific infrastructure. This broad mandate, including the goal of partnering with AI/AN communities and organizations, presents unique challenges to program evaluation.

The wellness pilot supported assumptions that culture and spirituality are central to Anishinaabe health and wellness and need to be further integrated into the program. This observation is consistent with other work across North America that has recently emphasized cultural values as central to understanding health in the AI/AN context (Donatuto et al., 2019; Donatuto et al., 2014; Finn et al., 2017; Isaac et al., 2018; Tobias & Richmond, 2014). Although those values may differ from culture to culture, the need to consider wellness and spirituality in health queries to improve relevance within the community is a common theme. The importance of connection to the land and its people has also been reported from these national works and past GLNARCH program evaluation (M. Dellinger et al., 2015; M. J. Dellinger et al., 2016; Jackson et al., 2015). Despite this growing consensus regarding the importance of culture in

assessing tribal health and wellness, little guidance exists on how to report programmatic progress on the matter. Confirmation of these sentiments suggests that the wellness pilot questionnaire is building a foundation to further explore the challenges of applying rigorous evaluation of important, health variables and concepts.

Telecommunication has been an important part of GLNARCH coordination across the tristate area. In the wake of COVID-19, the team has been able to continue weekly teleconference meetings with minimal disruptions. The flexibility this mode of operations offers, and established remote co-working, have enabled the team to continue their capacity building and student career enhancement pursuits. It seems likely that teleworking and virtual meetings will become more commonplace throughout the post-COVID-19 world. Recognizing this, the team is prioritizing enhanced online engagement with students, cultivating remote internship opportunities, and developing internet-based networking.

Limitations

The pilot project data were collected via convenience sampling and are not intended to generalize the sentiments of any given population. The sample size was small and provided preliminary data. However, these results provide key insights for program evaluation and planning. Furthermore, tribal membership and participation in tribal culture create overlap that challenges our ability to distinguish between cultural insider's vs outsiders. Many individuals are full participants of the culture as well as the community yet, do not or cannot identify as tribal members. This is a unique challenge to interpreting this data. A worthwhile standard to consider for interpreting cultural affinity is to adopt a more inclusive view for the program evaluation context. The context in which the questions were asked may have produced a favorability bias towards answering positively to questions regarding culture. Therefore, the noted ambivalence is further indicative of anxiety towards promoting culture in an uncertain future.

Broad Wellness Initiatives: NARCH and Sustainable Development

In addition to aligning with NIH strategic goals on Native American research, GLNARCH activities share best practices with global health and wellness efforts. The United Nations has set forth ambitious goals to pursue a unified vision of peace and prosperity throughout the world. From 2000-2015, health as a central development outcome was strongly emphasized in the Millennium Development Goals (MDGs). Three of the eight MDGs explicitly featured health and much progress in population health has occurred globally. However, many health and development challenges persist including chronic disease, child/maternal health, and socio-economic issues (Dietler et al., 2019). Similarly, AI/AN health in the U.S. and Bemidji area has improved since the 1950s (e.g., precipitous drops in infant mortality due to treatments for infectious diseases like tuberculosis) (HHS, 1999).

Holistic concepts of health are suggested to reduce health disparities across broad domains as more technically advanced, but conceptually simple disease etiologies are addressed (i.e. vaccinations and sanitation). Holistic health initiatives leverage models such as One Health, (Sinclair, 2019) or the Social Ecological Model (Cramer & Kapusta, 2017), or the "Exposome" (Isaac et al., 2018) to address multifactorial causes of disease. These models contain unique strengths and are tailored to slightly different contexts, but they hold the common value of providing best practices to coordinate research, development, scholarship, infrastructure, and public service into a unified front.

The culture and wellness survey development and preliminary responses provide intriguing insights. Participants from both community and partnership events appear to respond favorably to questions regarding culture and resilience. However, certain questionnaire items suggested a lack of confidence in perpetuating wellness through culture. This is coupled with

consistent affirmation that culture represents an important conduit for promoting wellness, and by extension, health. A manuscript is in preparation to explore this further.

CONCLUSIONS

The strengths of established GLNARCH initiatives and the adaptations to obstacles were described by the ongoing program evaluation methods presented here. The new culture and wellness findings address persistent challenges while also expanding the horizons of the program. Overall, GLNARCH has presented participants with high quality opportunities. Satisfaction across all metrics are largely positive. The longstanding evaluation metrics for students and mentors continue to affirm positive experiences while the recently implemented digital storytelling program provides further context and affirmation that these metrics target valuable concepts. By producing rich qualitative data, the digital stories afford the program staff an opportunity to interpret feedback on programmatic strengths as well as areas for improvement.

These preliminary results provide encouragement that culture and wellness questionnaires can provide important insights for GLNARCH programmatic development. Given the long-term mission of NIH funded NARCH programs, much work remains despite ongoing progress. The team will continue to develop and validate evaluation tools. Items on culture and wellness will be included in future questionnaires and digital story interviews. A mixed method analysis of qualitative and quantitative data is planned to further refine the GLNARCH program evaluation, which will move the program closer to demonstrating a strong connection between GLNARCH activities, wellness, and health.

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