# A Culture and Wellness Pilot to Guide Community Engaged Public Health Research in Native American Populations

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## ABSTRACT

**Background:** Alaskan Native/American Indian (AI/AN) participation in biomedical sciences is often hindered by cultural miscommunication regarding concepts and definitions of health. Identifying culturally contextualized health priorities is crucial to building research collaborations between academic institutions and AI/AN consortia.

**Methods:** This article describes pilot data from the development of a culture and wellness questionnaire deployed by the Great Lakes Native American Research Center for Health at cultural events and community engagement meetings. The questionnaire was designed in collaboration with AI/AN members to assess performance indicators of public health promotion in AI/AN populations who are culturally inclined to interpret health holistically.

**Results:** There were 25 completed questionnaires. Connection to the land (88%) and "giving thanks" (96%) were the most prominently affirmed health and wellness concepts. Participants were least confident (33%) in the ability to support the next generation culturally (language, stories, etc).

**Discussion:** These results comport with anecdotal data that AI/AN concepts of health and wellness should be co-developed with AI/AN cultural leaders and community members. Future implications for academic partnerships are discussed.

## INTRODUCTION

This paper reports the findings of a novel assessment of health and wellness contextualized to American Indian/Alaska Native (AI/AN) culture in the service area of the Great Lakes Native American Research Center for Health (GLNARCH). The NARCH centers pursue a mandate to improve Native American participation in biomedical sciences, broadly defined for our purposes as any research initiative that addresses a health issue in these communities, including clinical, applied, and community-engaged research. NARCH also supports AI/AN (sometimes referred to as tribal) health priorities via training, public health promotion, and education. The National Institute of General Medical Sciences and several other National Institutes of Health (NIH) institutes and centers partner with the Indian Health Service to support the NARCH program. A detailed description of GLNARCH, the founding principles, and its development was reviewed by Jackson et al.[1] These programs are responsive to the NIH Tribal Research Office stated goal "to promote an authentic, inclusive, and equitable partnership with American Indian and Alaska Native communities by improving cultural awareness and respect across the NIH and its intramural and extramural research."[2]

As alluded to by the NIH Tribal Research Office priorities, academic partners must interface with AI/AN culture and traditions to pursue community-engaged research. An equitable, inclusive, and authentic health research interface will require cultural contextualization of health outcomes and indicators. All NARCH centers throughout the United States face challenges interpreting their health-related initiatives across cultural contexts. The unique circumstances of AI/AN health promotion have been discussed by our GLNARCH team[1,3,4] and others extensively.[5] Specifically, we recently postulated that complex public health challenges, such as inadequate access to health care, can be addressed by interpreting health research and information in the context of traditional knowledge (sometimes referred to as "Tribal Ways of Knowing").[6]

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**Table 1.** Current GLNARCH Program Evaluation Metrics

| Metric Topic | Data Source |
|---|---|
| 1. Is GLNARCH operating with fidelity? counts, event counts | Participant satisfaction questionnaires, attendance |
| 2. Is GLNARCH fostering partnerships? | Number of partnerships initiated and maintained |
| 3. Are GLNARCH research activities contributing to health science fields? | Yearly counts of academic outputs (abstracts, reports, publication, grants, presentations, etc) |
| 4. Is GLNARCH fostering community-based participatory research? | Yearly counts of community-engaged academic outputs; mentor and student satisfaction questionnaires |
| 5. Is GLNARCH research serving the community and addressing health disparities? | Mentor and student satisfaction questionnaires, key informant interviews |
| 6. Are AI/AN students successfully mentored and supported through each phase and progressing through phases? | Mentor and student satisfaction questionnaires, student progress tracking (degrees, job attainment, program completion, etc) |

Abbreviations: GLNARCH, Great Lakes Native American Research Centers for Health; AI/AN, American Indian, Alaska Native.
Examples of specific metrics and outcomes from recent reports can be viewed at the GLITC.org website.[1,7]

**Table 2.** Specific Questions and Scales Used to Assess Either Wellness, Sentiments Towards Cultural Resilience, or Health Status

| 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 |

For example, our community partners, colleagues, and Elders teach that the key to promoting wellness is by democratizing health capacity. This can be accomplished through cultural vectors of community, education, and inclusivity.

We summarized some main cultural themes for improving tribal health as follows: (1) helping my people, (2) honoring our elders, (3) self-determination, (4) living in a good way.[6] The latter is of particular relevance to the current pilot. This work is unique as a health research topic since the starting point is traditional knowledge that was accumulated over generations and codified in culture. Thus, we report here the beginning of a formalized process to translate this information into a format that can interface with biomedical research. The best practices for meeting these challenges may overlap with other ambitious health- and wellness-promoting efforts. This article describes pilot data from the development of a culture and wellness questionnaire deployed by the GLNARCH staff at cultural events and community engagement meetings.

GLNARCH currently provides a Community Scientific Advisory Committee with established performance indicators (Table 1)[7] focused on the experiences, accomplishments, and satisfaction of students, community advisors, researchers, and mentors. This has provided valuable data to track the Center's progress towards stated goals. However, these historical program evaluation priorities were noted to lack key insights regarding health status, wellness, and concepts of health based in local culture. A new metric category is in development for future reports: Do GLNARCH activities promote health and wellness as defined by the culture of the community? This new metric category—and the broader implications for NARCH initiatives—is the focus of this report.

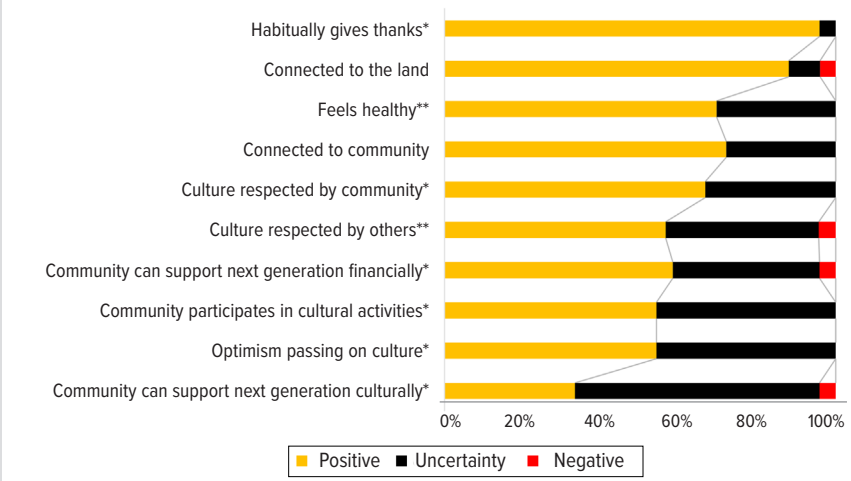
## METHODS

### Study Participants and Recruitment

GLNARCH personnel piloted a new culture and wellness questionnaire at 2 events in 2019: (1) an "open house" center grant meeting to report out progress and future directions in dialogue with educational, community, and research partners, and (2) the Bear River Powwow, in which the team engaged directly with tribal community members. Both events were held onsite in Lac du Flambeau, Wisconsin. Participants were from the Bemidji area, and most participants were AI/AN, though non-Native event participants 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. Questionnaires were conducted in English since that is an in-common language among AI/AN populations in the region.

GLNARCH coordinators conducted site visits to tribes, tribal colleges, universities, and tribal health fairs as part of normal center grant activities. This included meetings, booths at events, etc. During this time, subjects were asked to participate in questionnaires and/or on-camera interviews (digital stories). Individuals also were 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 if being interviewed on camera. Participants at the powwow were incentivized to complete questionnaires and interviews with various gift items, such as Medical College of Wisconsin (MCW) and Great Lakes Inter-Tribal Council (GLITC) water bottles, shirts,

**Figure.** Wellness Pilot Survey Results




Likert scale responses are compiled to reflect positive, negative, or ambivalent responses. n = 25, *n = 24, **n = 23.

or bags. All participants provided written and verbal informed consent, and all protocols were reviewed and approved by the MCW Institutional Review Board. Digital stories are posted on the GLITC website (https://www.glitc.org/programs/education-health-and-research/native-american-research-center-for-health-narch/publications-and-media/). These stories provide further context for the questionnaire development but are not the focus of this report.

### Wellness and Culture Questionnaire Development

To explore health and wellness, contextualized broadly to Bemidji region culture, questions were developed in consultation with members of the GLNARCH team (current co-authors) who themselves are Anishinaabe and/or work and live at the Salish Kootenai or Lac du Flambeau reservations. The questionnaire was developed iteratively with team discussions, based on decades of stakeholder feedback from GLNARCH programs ranging from elder teachings to student interviews. Much of that information also appears in previous publications and reports covering 18 years of GLNARCH programming.[1,3,7,8] Though somewhat informal, this served as an efficient way to synthesize decades of experience, advisory committee feedback, and stakeholder engagement into an emerging pilot assessment of important health phenomena. Critiques of the questionnaire items were collected and reviewed for common and conflicting viewpoints, and best practices for questionnaire development were followed.[9]

The final questionnaire consisted of 18 questions, four of which focused on basic demographic information, including tribal affinity. Ten questions concerning wellness and culture used a Likert-type scale to rate level of agreement, while 1 question asked about general health status (Table 2). Participants also were asked about traditional words or phrases to describe wellness. The wellness questionnaire pilot was conducted on a subset of GLNARCH participants starting in spring 2019 (n = 25).

## RESULTS

The Figure summarizes the findings from the wellness and culture pilot. Respondents most frequently reported feeling connected to the land and habitually giving thanks. Broadly, the responses illustrate the importance of culture when interpreting concepts of health and wellness. Findings aligned with perspectives espoused in digital storytelling sessions, which can be viewed in the aforementioned link for further context.

Many respondents reported that they feel healthy. Many participants reported a culturally specific term for health and wellness. "Minobimaadaziiwin" and "Ni Mino Ayaa" were commonly reported and translate from Ojibwe roughly to "living in a good way." This highlights the prominence of holistic conceptions of health and wellness. The most prominently affirmed statements were: "I feel connected to the land around me" (88%) and "I am in the habit of giving thanks" (96%). In the context of Ojibwe culture, these both present spiritual implications of wellness. The Anishinaabe members of the questionnaire development team developed the wording of the item on giving thanks to assess the level of respect for cultural and spiritual traditions.

Despite positive sentiments regarding the importance of culture and spirituality, a pattern of uncertainty towards the future of cultural practices emerged. Respondents seemed less confident that their culture could be perpetuated and passed on to the next generation (Figure). The respondents also expressed less certainty that their culture was respected by others. Among the wellness pilot metrics, GLNARCH and powwow participants expressed the least confidence in response to the question: "My community has the ability to support the next generation culturally (language, stories, etc)." Only 33% of respondents expressed confidence in this item.

## DISCUSSION

Health can be a difficult term to define for different cultures, since it can often refer to more than simply the presence or absence of disease. Concepts of "health" have evolved throughout history and remain a topic of bioethical and philosophical discussion.[10] Many respondents reported that they feel healthy but 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 longevity of the culture was a priority. This theme also

was identified in digital storytelling sessions with GLNARCH participants over the years.[3]

Questionnaire 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 pilot data. Furthermore, tribal membership and participation in tribal culture create overlap that challenges our ability to distinguish between cultural insiders vs outsiders. Many individuals are full participants of the culture and the community, yet do not or cannot identify as tribal members. Nevertheless, these experiences demonstrate important candidate phenomena for conceptualizing health for the purpose of improving research inclusivity for underrepresented populations,[11] such as AI/AN. These phenomena include connectedness to land, routine spiritual customs, and Minobimaadaziiwin. The importance of "living in a good way" has been emphasized throughout our affiliated research efforts—particularly as important context for understanding environmental research in Anishinaabe territories.[6]

These questionnaire results provide an outline for the prominent perceptions regarding Anishinaabe concepts of health. The highly affirmative responses demonstrate agreement between the concepts identified by key informants when developing the questionnaire and the surveyed community members. The context in which the questions were asked may have produced a favorability bias towards answering positively to questions regarding culture. Despite a potential favorability bias, the noted ambivalence indicates anxiety towards promoting culture in an uncertain future.

It seems likely that all human beings feel a desire to maintain their traditions and cultures as an important component of their wellness. The AI/AN communities present an instructive example of how the organism (humans) cannot be fully removed from the environment (culture). The GLNARCH culture and wellness pilot data are intriguing because the trends affirm the a priori insights of the GLNARCH advisory committee and culturally AI/AN staff: environmental health is tribal health, tracking morbidity and mortality data alone misses the bigger picture, and health encompasses how a life is lived ("living in a good way"). The concept of health is active and dynamic in the minds of these participants, as opposed to a passive state represented by a morbidity prevalence or rate.

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