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# A Community-Based Participatory Research Training Program for American Indian Students

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## Abstract

American Indians (AI) are under-represented in the health professions and in medical research. Reasons attributed to this include socioeconomic and culture barriers, lack of educational opportunities, lack of AI mentors and role models, and lack of educational counseling. The American Indian Health Research and Education Alliance (AIHREA) developed a summer internship to provide health and medical research experience for AI students based on the principals of community based participatory research (CBPR). The internship supports the academic and career development of high school, undergraduate, and graduate students, and exposes them to opportunities in the health professions and medical research. The AIHREA Summer Internship program provides a unique research experience through its collaborations among an academic medical center, a community college, and tribal communities. Additionally, the internship offers social and cultural support often lacking for AI students, an emphasis on CBPR, and a focus on ethical research with sovereign AI nations.

**Keywords:** American Indians (AI), Alaska Natives (AN), American Indian Health Research and Education Alliance (AIHREA), Community Based Participatory Research (CBPR)

## Introduction

American Indians/Alaska Natives (AI/AN) have some of the poorest health outcomes and lowest educational attainment rates of any racial or ethnic group in the United States. AIs continue to recover from centuries of trauma, including forcible and violent removal from their lands, legally imposed segregation, and cultural, social, and linguistic destruction, all of which have led to these disparities [1-4]. Severely underfunded tribal health and education systems exacerbate the problem [2]. Abysmally high mortality rates exist among American Indians/Alaska Natives (AI/AN). When AI/AN are compared to the U.S. all races death rate, their numbers are significantly higher: alcohol use (520% greater), tuberculosis (450% greater), chronic liver disease and cirrhosis (368% greater), diabetes mellitus (177% greater), suicide (60% greater), and pneumonia and influenza (37% greater) [5]. Though cancer rates remain lower among AI/AN than the majority population, it has now become the leading cause of death for AI/AN [6]. There are also high disparities when it comes to mental health, AI/AN are 59% more likely to experience serious psychological distress within the previous year than their non-White Hispanic peers [6]. Additionally, AI/AN are the least represented racial or ethnic group in health care delivery, making up only 0.6% of the biomedical workforce [8]. In 2016, 0.56% of 727,398 active physicians and 0.48% of 174,570 total full-time faculty members at U.S. medical schools and teaching hospitals identified as AI/AN [9].

Much has been written on the need for increasing the diversity of biomedical professionals and students entering the health sciences and the benefits this would have on AI/AN peoples and communities [10-13]. Greater diversity in biomedical fields, including individuals in leadership positions in academic research and clinical service has a high potential to improve health care delivery and service. For example, service providers and researchers who have the capacity to navigate the cultural beliefs, attitudes, and behaviors that promote greater trust of medical professionals and greater adherence to prescribed treatments can improve health outcomes [14-20]. The National Institutes of Health (NIH) has long recognized the critical need and the challenges to achieve a more Inclusive biomedical and behavioral research workforce [13]. Diversity of thought has been credited with successful scientific research and recognized as a socioeconomic good [21].

AI/AN are also severely underrepresented in health and medical research interventions and services [17]. In studies directly examining attitudes of racial/ethnic minorities, fear and mistrust of medical research has been identified for every group as a deterrent to research participation [18]. Mistrust of the scientific community and medical research may be caused by perceived and overt racial/ethnic discrimination in health care settings [14]. There are documented examples of

unethical medical research involving racial/ethnic minority participants during which researchers failed to obtain informed consent, modified protocols without consulting participants, withheld information, and failed to follow up, and this all has resulted in a lack of trust [15,22-24]. AI/AN health researchers may be able to overcome mistrust and communication issues in Indigenous communities, [25-27] thus potentially encouraging more AIs to participate in research. Health research priorities are influenced by the research interests of established investigators, yet solutions and breakthroughs in research alleviating health problems are more likely to come from members of underrepresented groups who face these disparities [11,25,28,29]. Underrepresented minorities are more familiar with and more motivated to improve health conditions impacting their own demographic groups [30].

AI educational attainment also lacks significantly when compared to other racial/ethnic groups. AI/AN represent a small fraction of students in higher education; only 1% of undergraduate degrees and 0.6% of graduate degrees are awarded to AI/AN in an average year [31]. The disparity is evident starting in high school and extends into graduate and professional degree levels [8]. Approximately 72% of AI high school students finish school, as compared to Black students (76%), Hispanic students (79%), White students (88%), and Asian students (91%) [32]. Only 23% of AI/AN aged 18-24 are enrolled in college, compared to 42% of White students [33]. Between the years 2000-2015, the share of AI/AN enrolled in full-time undergraduate programs in the U.S remained stable at 1%, yet there were increases among Hispanics (10% to 17%) and Blacks (11% to 13%), [34] AI/AN accounted for only 0.6% of undergraduate degrees in all fields in 2015 [35].

The gap widens at the graduate level. Graduate enrollment between the years 2010 and 2016 among AI/AN decreased by 20% (from 17,100 to 13,700) AI/AN graduation rates for master's degrees and doctoral degrees average 32.8% and 43.9%, the lowest of all racial/ethnic groups [36.37]. In comparison, graduation rates for non-Hispanic Whites average 51.9% and 65%, for Blacks 47.1% and 48.1%, for Hispanics 38% and 55.4%, and for Asian/Pacific Islander 48.4% and 72.5%. The number of doctorate degrees awarded fluctuated among AI/AN (790 awarded in 2004 - 05, 950 in 2009 - 10, and 880 in 2014 - 15) [31]; while doctoral degrees awarded to Hispanic students increased by 84%, by 56% for Black students, by 46% among Asian/Pacific Islanders, and by 21% for White students. AI/AN represent only 0.3% of physicians, 0.1% of medical school faculty, and 0.3% of the science and engineering workforce [21,38-40].

One way to meet the challenge of addressing the enormous health inequities AIs face is by providing opportunities that attract, retain, and support the academic success of AI students in undergraduate and graduate programs. Evaluation and assessments of undergraduate research experiences have shown positive outcomes in increased self-efficacy within science and desire to pursue careers in a health or science field [30]. To fill this need, the American Indian Health Research and Education Alliance (AIHREA) has developed an internship program to increase the number of AIs in health professions and health research.

The American Indian Health Research and Education Alliance is an alliance of organizations whose mission is to partner and collaborate with AI peoples, nations, communities, and organizations to improve the physical, mental, emotional, and spiritual well-being of AIs throughout the United States through quality participatory research and educational programs. Until August of 2020, the primary partners were the Center for American Indian Community Health (CAICH) at the University of Kansas Medical Center in Kansas City, Kansas, and the Center for American Indian Studies (CAIS) at Johnson County Community College in Overland Park, Kansas. The two centers have combined and are now the Institute for Indigenous Studies at Lehigh University in Bethlehem, Pennsylvania. AIHREA partners and collaborates with numerous organizations and American Indian tribal communities conducting research with and providing services to AIs in the central and northern Plains, as well as nationally.

At any given time, between 65% and 85% of AIHREA research team members are AI representing numerous tribal nations from all across the United States; it is among the largest AI health research teams in the country. AIHREA researchers have developed culturally tailored health interventions and programming in smoking cessation, weight management, health literacy, cancer education and prevention, environmental health, cultural education, and a culturally-tailored college prep workshop for AI high school students. AIHREA also provides scholarships and educational opportunities for AI undergraduate and graduate students outside of the internship, including the AIHREA Scholarship awarded to undergraduate and graduate students seeking to improve the health and well-being of AI and Alaska Natives, the Lance T'ain Tha-gyah (Good Heart) Cully Memorial Scholarship for AI high school, undergraduate, or graduate students pursuing education in the fine arts, and the Language Acquisition Program (LAP) Preschool Scholarship for AI youth needing speech and language therapies. Scholarship opportunities through CAICH were available for students pursuing graduate study at the University of Kansas Medical Center in biostatistics, health policy and management, or public health at the master's or doctoral level.

The purpose of this paper is to describe a community-based health research training program we have developed to attract AI undergraduate and graduate students. Our design can provide insight to other programs who wish to tailor educational programs for AI students, specifically those seeking to increase the number of AIs in the health professions and health research.

**Development of the AIHREA Summer Research Program**

The AIHREA Summer Internship began in 2010 and was made possible through a National Institute on Minority Health and Health Disparities funded Exploratory Center of Excellence award that established the Center for American Indian Community Health at the University of Kansas Medical Center (KUMC) and the Center for American Indian Studies at Johnson County Community College. Since its inception, AIHREA has provided internships to 91 students (Table 1).

| Year (2010-2018) | Number (%) |
|---|---|
| **Total internships** | 98 |
| **Total students** | 91 |
| High school students | 12 |
| Undergraduate | 68 |
| Graduate | 10 |
| Medical school | 1 |
| **Demographics** | |
| **Gender** | |
| Male<br>Female | 35 (38%)<br>56 (62%) |
| **Race/Ethnicity** | |
| American Indian | 60 (66%) |
| Non-Hispanic White | 19 (21%) |
| Hispanic/Latino | 4 (4%) |
| African American | 3 (3%) |
| Asian American | 5 (6%) |
| **Colleges/universities represented** | 15 |

**Table 1:** Characteristics of AIHREA Interns.

The AIHREA Summer Internship was developed to teach culturally competent interdisciplinary health research and increase the number of AI students entering the health professions. The internship design has provided instruction and hands-on experience in AI focused health research, education, and service projects. The leadership team at AIHREA who first developed the internship program included Native and non-Native faculty and staff from a variety of disciplines and experiences that included community-based participatory research (CBPR), tobacco prevention and control, mixed methodology, epidemiology, clinical research and medicine, American Indian studies, law, anthropology, ethnography, and public health. They recognized that student interns conducting ethical academic research with AI should be instructed across these disciplines within in a CBPR approach. They also wanted the internship to be highly receptive to the issues of American Indian mistrust of the medical establishment and research due to historical injustices and unethical research carried out by academic researchers in the past and not so distant past. Therefore, instruction and sensitivity to this issue became a cornerstone of the internship.

The AIHREA internship is one of the most unique programs in the country for several reasons, including the collaboration between an academic medical center and community college, the social and cultural support available to interns and AIHREA faculty and staff, the emphasis on CBPR, the focus on understanding cultural context, and the focus on conducting ethical research with sovereign American Indian nations. The program also utilizes a community advisory board (CAB) consisting of tribal members from both reservation and urban AI communities. The CAB provides guidance, assuring our program component content and delivery is appropriate for AI students and tribal communities in which we work.

## Methods of Recruitment and Selection

Students throughout the country were recruited through AIHREA, CAICH, and CAIS websites and social media sites where online applications were available and accessed. Academic resources centers serving AI students, particularly at tribal colleges, were also used. A close working relationship with a regional tribal college enabled AIHREA to recruit on campus through flyers, presentations in classes, and at campus events.

Completed applications included demographic information, personal statements related to interest in working with American Indians peoples and communities, two letters of recommendation, transcripts, and a 500-word essay on a topic related to AI health. In the first phase of the selection process, applications were reviewed, evaluated, and ranked by a team of AIHREA faculty and staff. The selection committee was comprised of AIHREA faculty and staff members and was over 50% AI in each year of the internship. The top 10 - 15 applicants were selected for in-person or telephone interviews. AI preference was exercised because it is the mission of the AIHREA Summer Internship to increase the number of AIs in the health professions and conducting health research. Non-AI students were also accepted based on their level of interest in working with AI peoples and communities.

### Curriculum and Structure of the Program

The AIHREA Summer Internship is an eight-week program that provides research experience based on the principals of community-based participatory research (CBPR) (Figure 1 and Table 2). A majority of the time is spent at the CAICH offices on the University of Kansas Medical Center campus in Kansas City, Kansas. Students also spend significant time at the CAIS offices at Johnson County Community College in Overland Park, Kansas and in several AI reservation communities in our region. Immersion in AI communities is a key component to the internship program with interns spending on average one day per week in AI communities working directly with Native community members. Interns also spend an entire week actively engaged in research and outreach, and providing health and educational services to a tribal partner in South Dakota. The experience working with one of the largest AI reservation communities in North America provides a rich experience in health research and service, and exposure to the diverse cultural beliefs and customs of tribes outside of our Central Plains region.

To begin, interns are paired with an AIHREA faculty or and staff mentor who will guide them throughout the internship process. Instruction on the principals of CBPR was provided by AIHREA faculty and staff through presentations and discussions. Interns were also required to complete research compliance trainings through the Collaborative Institutional Training Initiative (CITI) Program, KUMC's research ethics and compliance training management system, provided the initial foundation for students to effectively learn about community-based research. Our internship program includes not only ethical conduct of research training, but also includes numerous trainings specific to conducting research with Native peoples and communities. Interns have opportunities to meet with Native community members, representatives from tribal organizations, departments and programs, tribal councils, and tribal institutional review boards (IRBs) to learn and understand strategies that promote ethical reciprocal relationships between researchers and Native peoples and that foster ethical and quality research with AI peoples and their communities.

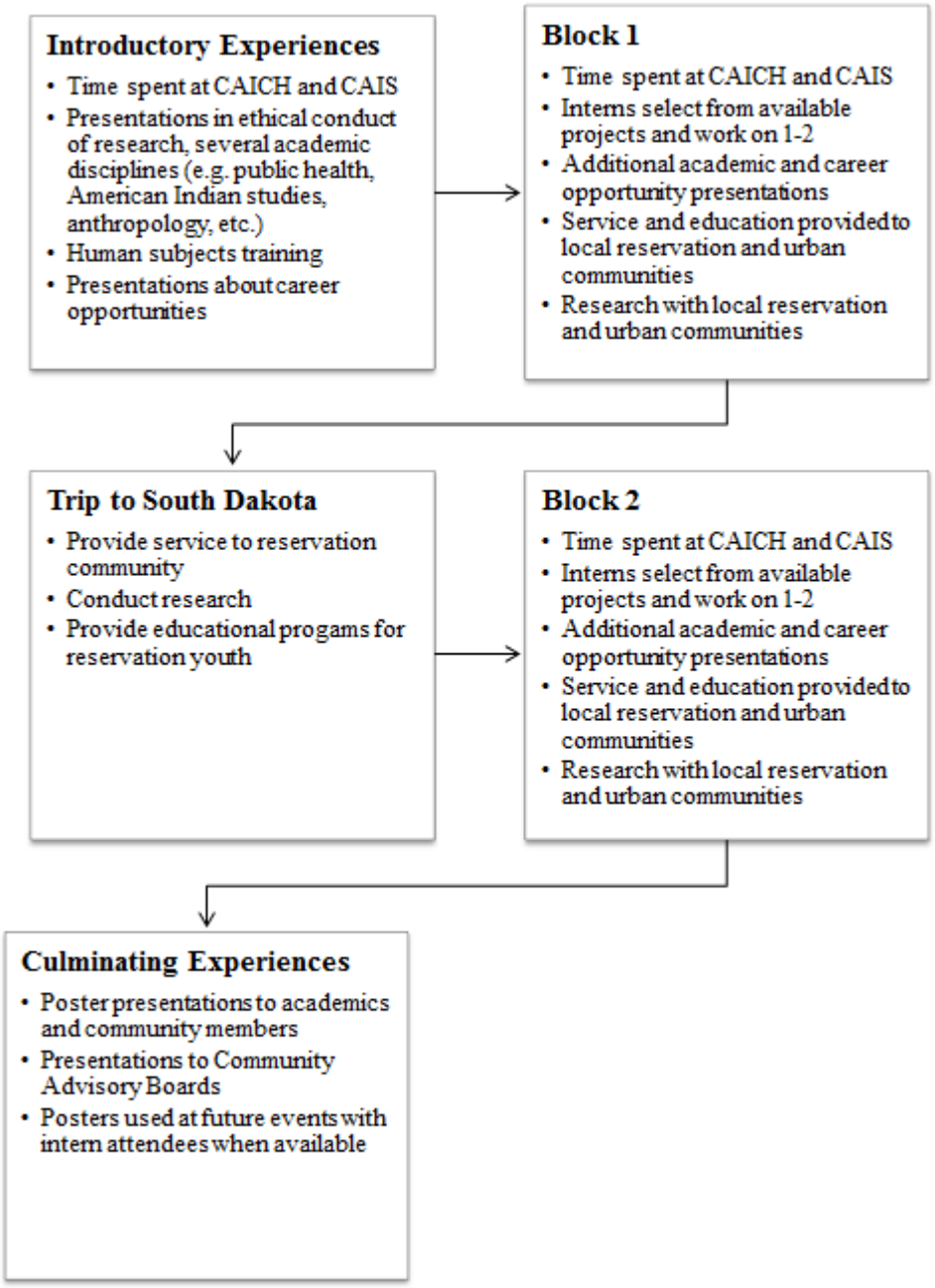


**Figure 1:** AIHREA Internship Program Timeline.

| | |
|---|---|
| Curriculum | • Faculty presentations – Graduate opportunities and careers in health professions<br>• Research poster presentations<br>• CBPR Research<br>• Community Engagement<br>• Culture Experience for non-Native students<br>• Data Management<br>• Public Health, American Indian Studies, Anthropology, Law, Medicine, Statistics<br>• Conducting ethical academic research<br>• Develop scholarly presentations and posters<br>• Writing for community and for academics<br>• Research compliance training – Human subjects training<br>• Health presentations for youth and community members<br>• Cultural competency and humility |
| Community Engagement | • Screening Clinic<br>• Community friendly research write ups<br>• Community Advisory Boards |

| | |
|---|---|
| | • Health Screening Clinic<br>• Research<br>• Outreach to youth and community<br>• Community Service<br>• Cultural education<br>• Health education |
| Research Projects | • GPS Mapping, Weight Management, Tobacco Cessation, Health Literacy, Mental Health, Cancer Education and Prevention, Environmental Health, Native Identity, Native Culture, Education |
| Physician Shadowing | • Interns shadow physicians in their fields of interest |
| College Prep | • Literature reviews<br>• Database research |
| Research Presentations | • Dissemination of research results |
| Regional and Local Presentations | • Present research to tribal communities, KUMC, JCCC |
| Mentorship | • Paired with faculty or staff mentor |

**Table 2:** AIHREA Intern Experiences.

During the internship, interns attend lectures given by AIHREA faculty and Native community members, engage in professional development workshops, and receive instruction and guidance from KUMC and JCCC faculty and staff from diverse academic disciplines including, American Indian Studies, anthropology, law, medicine, public health, and statistics. Student interns also learn how to develop scholarly presentations and academic posters.

Interns also work on a variety of research projects and health and education outreach service activities. Examples include working on the All *Nations Breath of Life* (ANBL) Smoking Cessation Program, a quit smoking program designed specifically for Native peoples, the *Native 24/7 Ethnic Identity Study*, a nationwide study of how Native people define what it means to be "Native" today, or the *Native Research Ambassadors Program* (N-RAP), a research training program and grant writing workshop for Native community organizations and Native academic researchers. Interns have an option to choose one to two projects on which to work during each four-week block. Over the years, interns have assisted and contributed culturally-tailored components to all of our programs. They have recruited for studies, administered surveys, and conducted interviews with study participants at tribal colleges, in urban communities, and on reservations. Interns have also developed community health education materials for tribal communities that have been utilized at pow wows, community research forums, and health screening events, as well as tribal 638 clinics

Interns are challenged to explore the health and education issues prevalent in AI communities while being exposed to the cultural, social, and linguistic diversity of the tribal nations with whom they are working. Student interns gain an understanding of the health disparities that exist in AI communities and the reasons why they exist. Issues to which interns are exposed via academic settings and in the communities include access and barriers to care from both Western and Native points of view, how these barriers can be overcome, and how to go forth and conduct successful research in these communities. Discussions and presentations focused on working with reservation and urban based Native communities, the basics of the Indian Health Service and tribal 638 clinics, historical trauma, and the mistrust of Western medicine and medical practitioners provide students with the basic knowledge needed to begin to actively engage Native communities.

Student interns become an integral part of the AIHREA traveling health screening clinic where they provide primary health screenings and services to Native peoples and communities during at least two screening clinics each summer. Interns are trained to take blood pressure and administer blood glucose and cholesterol screenings. They develop health educational materials about the screenings and interact and provide community participants with prevention strategies to combat chronic disease.

Trips to Native communities to address different topics pertaining to public health and cultural education and preservation are also a part of the internship and provide experiential learning opportunities. Students visit and meet with representatives from tribal health clinics, cultural centers, and language preservation programs.

Poster presentations are a culminating activity to end the internship. Interns develop scholarly posters that discuss the projects with which they were involved during their summer experience. Posters are presented at a half-day event for faculty, staff, and students from both academic institutions. This event is also open to the public and regularly brings in community members from the Native communities with whom the interns have worked. This allows each intern the opportunity to present to both academic and community members, enhancing their CBPR experience. For an additional experience presenting to community members, interns also present to our Community Advisory Boards about their experiences using either their posters or oral presentations. The posters the interns create are used at different AIHREA events throughout the year to highlight each year's interns and to help recruit future interns. After the internship ends, interns are invited to attend future events if they are available.

## Student Outcomes – Results

Since 2010, the AIHREA Summer Internship program has provided internships to 91 students representing 15 colleges and universities throughout the U.S. Nearly two-thirds of student interns (60 of 91 interns) have been AI students. AIHREA interns have been highly successful within

their institutions and early professional careers. Of the interns who have responded to follow up and maintained contact with AIHREA faculty and staff (80% response rate), one has completed a Ph.D., 14 have completed a Master's program, 19 have completed undergraduate degrees, 11 are currently in graduate school, 35 are current undergraduate students, and one is currently in medical school. AIHREA interns who have completed degrees have begun careers at state departments of health, in health research, nursing, the Indian Health Service, in social work and behavioral health services, and in education and coaching athletics at the collegiate level (Table 3).

| **Education Status** | |
|---|---|
| Current undergraduate student | 35 |
| Received an undergraduate degree | 19 |
| Currently in graduate School | 11 |
| Completed a Master's program | 14 |
| Currently in Med School | 1 |
| Accepted to Ph.D/MD program | 2 |
| Completed a Ph.D program | 1 |
| **Careers** | |
| Indian Health Service | 3 |
| Tribal Health Program | 2 |
| Tribal Epidemiology Center | 1 |
| State Health Departments | 2 |
| Private Health Practice | 2 |
| Health Research | 5 |
| Social work/Behavioral health services | 5 |
| Education | 3 |
| Coaching | 1 |

**Table 3:** Intern Outcomes.

## Discussion

The AIHREA Summer Internship addresses key strategies identified by the U.S. Department of Health and Human Service (HHS) Action Plan to Reduce Racial and Ethnic Health Disparities; this includes prioritizing cultural competence to better serve patients with diverse cultural and social backgrounds, increasing diversity in the workforce, and promoting community-based models to improve access and quality of health care for all [10]. It also works to meet the challenges cited by the Working Group on Diversity in the Biomedical Research Workforce 8, to build infrastructure leading to diversity in research through training and mentorship programs that are attractive to underrepresented minorities [13,41,42]. Though summer research programs that target minorities have improved the diversity of the STEM-PhD pipeline [43], a small percentage of AI students participate, because very few programs are culturally-tailored to AI students. Research Centers in Minority Institutions (RCMI) report that between 2008 – 2016, they collectively enrolled 16,731 diverse research participants that included; 70% women, 41% Black, 32% Hispanic, 14% Native Hawaiian, 15% White, 3% Asian, and only 1% were AI. RCMI's also report of 3,570 science doctoral degrees and 18,657 health professions doctoral degrees awarded to Black, Hispanic, Asian, and White students, none were awarded to AIs [13]. Increasing the educational opportunities and number of AIs entering the health professions and health research is crucial to addressing the health disparities suffered by AIs.

As previously noted, AIs also have the lowest level of educational attainment of all racial/ethnic groups in the U.S. The disparity exists at all levels of education and in all types of degrees conferred. Improvement in educational outcomes is a necessary step to prepare students for the health professions and careers in health research. Greater potential exists for innovations in research and culturally responsive health care from a more diverse pool of biomedical professionals. Increasing the number of AI professionals in health research and in the delivery of health services would make greater strides to close the health disparities gap.

There is a glaring need for improvement in both recruitment efforts and programs that lead to and sustain a better educational outcome for AI students. These programs would need to attract AI students by promoting a culturally relevant academic research experience that addresses the issues in their communities. AIHREA interns are encouraged to use their experiences to guide their research, in this way, add culturally tailored aspects to every project. Interns become not only the researcher but by using their experiences, they provide input and become an active participant, all within the concept of CBPR. Barriers to academic achievement must also be overcome through academic counseling and guidance, mentorship, and social and culturally supportive environments within academic institutions. AIHREA interns receive mentorship from AI researchers who have often shared similar experiences as students. The program encourages interns, who come from several tribal nations throughout the U.S. to share their tribal languages and foods with each other. The socially and culturally supportive environment provides a more nurturing and socially supportive experience that is often cited as a deterrent to AI student success. The AIHREA Summer Internship provides and encourages AI students to establish a support network during the internship and beyond. This network of student intern colleagues, faculty, and staff serves as an available support system throughout their academic careers and beyond that can mitigate the cultural isolation barriers AI students may face at their respective institutions [44].

A few culturally relevant health research internships exist for AI students, with some notably success stories that inspire what we do. The University of Utah's Native American Research Internship program began in 2010 and offers a 10-week health science research experience for undergraduate junior and senior students based on community engagement. The internship supports the development of Native America students interested in Health Science careers [45]. The Four Directions Summer Research Program at Harvard Medical School and Brigham and Women's Hospital began in 1994 and provides an opportunity for American Indian undergraduate students to explore careers in the medical professions [46]. Johns Hopkins' Center for American Indian Health provides a training program for AI scholars wishing to pursue careers in health care and public health science [47]. The Colorado School of Public Health's Centers for American Indian and Alaska Native Health at the University of Colorado Anschutz Medical Campus provides research opportunities and training for AI/AN focused projects [48].

AIHREA has developed s successful summer internship program to increase the number of AI students in the health professions and health research for students in the Midwest as well as nationally. Through AI focused research, services, and education projects, students gain research experience working within their own communities, or similar communities facing the same inequalities. The AIHREA Summer Internship has had success recruiting AI students, engaging them in a CBPR experience, and retaining students through an entire summer research internship program. Our program provides a unique blend of academic and cultural experience that values the physical, mental, emotional, and spiritual realms of health many AI tribal nations see as important. Our interns have completed undergraduate degrees and gone on to attain graduate degrees and are working in health care, health care delivery, social and behavioral health, education, and services for AI communities. The development of more programs like this one at institutions of higher education serving AI students that sustain interest in science will continue to be a need. Equally important are programs that pique interest and support students in the STEM disciplines much earlier in the educational pipeline. The AIHREA Summer Internship can help inform other institutions about recruitment and development of a research experience for AI students and students from other underrepresented groups.

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## Conflicts of Interest

The authors declare that there is no conflict of interest.

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