

## Lessons from a Research Collaboration with the Oneida Nation of Wisconsin

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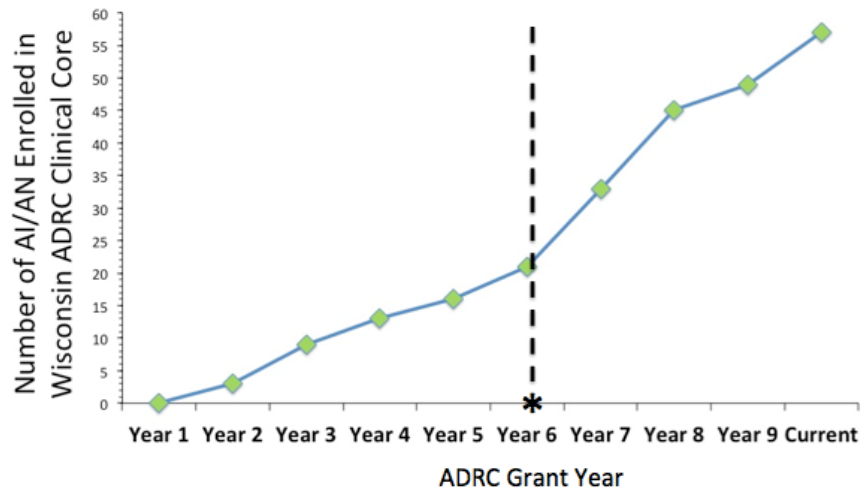
**Background:** As Alzheimer's disease and related dementias prevalence (ADRD) increases it will disproportionately burden racial and ethnic minority communities. Recent population-based evidence suggests that American Indians and Alaska Natives (AI/AN) are at increased risk for dementia relative to non-Hispanic Whites and Asians. Despite evidence that 1 of every 3 AI/AN elders will develop dementia, they remain substantially underrepresented in ADRD research. As of March 2019, only 248 of the 40,000+ individuals enrolled at Alzheimer's Disease Centers (ADC) were AI/AN. Subsequently, little is known about dementia etiology, progression, and care in AI/AN communities. We describe an ongoing partnership between the Oneida Nation of Wisconsin and the Wisconsin Alzheimer's Disease Research Center (ADRC) that seeks to address this knowledge gap and respond to the ADRD-related concerns in Wisconsin's Indian Country.

**Methods:** We implemented an NIA-funded, community-based, culturally-relevant approach to address barriers to participation in ADRD research and access to services for persons with dementia. This approach is comprised of four aims: (1) Establish a Community Advisory Board (CAB) to guide culturally-tailored outreach programs to increase research enrollment and retention of AI/AN participants, (2) Improve access to culturally appropriate dementia diagnostic services, (3) Survey of Oneida caregivers of persons with dementia to understand caregiving experiences, and (4) Initiate liaisons with ten other Wisconsin tribes.

**Results:** Project leaders and Oneida CAB members meet monthly on Oneida lands, and ADRC staff attend quarterly meetings with an Inter-Tribal Elders Association. In 2018, project leaders held an inaugural National Conference on Dementia in Native American Communities. Preliminary results for Aim 1 are promising. Following establishment of the partnership, the number of AI/AN participants enrolled in the ADRC has increased tremendously (see Figure 1), and rises at a rate of two new participants per month. 77% of AI/AN participants also participate in an imaging sub-study.

**Conclusions:** The Wisconsin ADRC has enrolled nearly a quarter of all AI/AN participants included in the combined ADC dataset. Actively prioritizing a collaborative partnership and investing in community-based relationships was essential to our inclusion efforts with AI/AN communities. These elements are fundamental for establishing research and clinical efforts that effectively respond to the needs of AI/AN populations.

Figure 1. American Indian Recruitment Over Time



\* Dashed line represents beginning of ADRC-Oneida partnership. In just over four years, AI/AN participant enrollment has increased by nearly 200%.