



Patrik Johansson

ANNOUNCEMENT

UPCOMING INVITATION FOR TRIBAL LEADERS AND HEALTH DIRECTORS TO PARTICIPATE IN A RESEARCH STUDY



Cole Allick

WHY IS THIS STUDY IMPORTANT?

Alzheimer's disease is the third leading cause of death among older adults in the U.S. The number of cases will triple between 2010 and 2050, largely because life expectancy is increasing. Today, about 500,000 Native elders live in the U.S. This number will double by 2050, and the number of Native elders over 85 will increase 7-fold. As the population of Native elders grows, Alzheimer's disease and cognitive impairment such as difficulties with memory and concentration will increase in parallel. These trends raise potential concerns about the capacity of Tribal health systems to meet the health care needs of aging Tribal members. Without representation of American Indian and Alaska Native people in Alzheimer's disease research, results may not benefit Tribal communities.

WHO IS LEADING THIS STUDY?

Washington State University's Institute for Research and Education to Advance Community Health (IREACH) engages in community-centered research, training, education, and outreach with Tribal communities to improve the health of American Indian and Alaska Native people. Dr. Patrik Johansson (Cherokee ancestry) is the lead investigator.

WHAT WILL TRIBAL LEADERS AND HEALTH DIRECTORS BE ASKED?

We will be inviting Tribal leaders and health directors to participate in Zoom interviews to learn about the impact of the growing population of older American Indian and Alaska Native adults and to offer their opinions about:

- Why so few American Indians and Alaska Natives participate in research on Alzheimer's disease and cognitive impairment
- Data sharing between Tribal organizations that control access to health data and academic medical centers relevant to data collected in Alzheimer's disease research. For example, under what conditions, if any, could study information be shared? If information could be shared, what type of information would be permitted to be shared?
- Acceptability of an existing Alzheimer's disease clinical research protocol

WHAT IS THE OUTCOME OF PARTICIPATION?

Based on feedback from the interviews and from other stakeholders including Tribal elders, we will develop and test a protocol tailored to American Indian and Alaska Native people that will both encourage and compensate them to participate in a large, ongoing clinical research study on Alzheimer's disease and cognitive impairment.

WHEN WILL THESE INTERVIEWS TAKE PLACE?

We expect to start interviews in December 2020. Participants will be compensated.

QUESTIONS?

For questions or further information on this upcoming study or for free educational materials on Alzheimer's disease and cognitive impairment, please contact Cole Allick, MHA, (Turtle Mountain Band of Chippewa Indians), Tribal Liaison, Partnerships for Native Health, Washington State University, at cole.allick@wsu.edu.

