Tribal Consultation on the National Institute on Minority Health and Health Disparities (NIMHD) Initiative for Improving American Indian and Alaska Native Cancer Outcomes

May 22, 2024 | 2:00 p.m. – 3:00 p.m. ET (1:00 p.m. CT, 12:00 p.m. MT, 11:00 a.m. PT)

This document provides an overview for Tribal leaders and community members as background for participation in the upcoming National Institutes of Health (NIH) **Tribal**Consultation on the National Institute on Minority Health and Health Disparities

(NIMHD) Initiative for Improving American Indian and Alaska Native Cancer Outcomes.

NIH Mission

The NIH mission is to seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability.

- NIH invests most of its \$48 billion budget¹ in medical research for the American people.
- NIH invested \$7.22 billion in cancer research in fiscal year 2024.²
- More than 80%³ of NIH's funding awarded through almost 50,000 competitive grants to more than 300,000 researchers greater than 2,500 universities, medical schools, and research institutions in every state.
- About 10% of the NIH's budget supports projects conducted by approximately 6,000 scientists in its own laboratories, most of which are on the NIH campus in Bethesda, Maryland.
- Located in Bethesda, Maryland, the NIH is a component of the U.S. Department of Health and Human Services and is composed of the Office of the Director and 27 Institutes and Centers, many of which have an organ- or disease-specific focus. The Office of the Director is the central office at NIH responsible for setting policy for NIH and for planning, managing, and coordinating the programs and activities of all NIH components.

¹ Based on historical distribution of actual FY 2022 obligations across extramural and intramural mechanisms that comprise the annual NIH budget.

² NCI Budget and Appropriations: <a href="https://www.cancer.gov/about-nci/budget#:~:text=NCI's%20budget%20history%3F-ywhat%20is%20NCI's%20current%20fiscal%20year%202024%20(FY24)%20budget%3F,provided%20under%20the%20Continuing%20Resolution.

³ Reflects the sum of enacted discretionary budget authority of slightly over \$46.1 billion received under the Consolidated Appropriations Act, 2023 (P.L. 117-328). The budget total of \$47.7 billion also includes \$1.412 billion derived from PHS Evaluation financing, \$141.5 million mandatory funding for the Special type 1 diabetes account, and \$1.085 billion received from 21st Century Cures Act allocations. Appropriations received by the recently established Advanced Research Projects Agency for Health (ARPA-H) are excluded as is unobligated carryover related to emergency pandemic supplemental appropriations enacted prior to FY 2022 and resources from the HHS Nonrecurring Expenses Fund (NEF).

NIMHD Mission

• NIMHD's mission is to lead scientific research to improve minority health and reduce health disparities. Please visit our <u>website</u> for more information.

NCI Mission

 NCI leads, conducts, and supports cancer research across the nation to advance scientific knowledge and help all people live longer, healthier lives. Please visit our website for more information.

Purpose of Consultation

The FY 2024 Federal appropriations provided funding to NIMHD for the creation of an "Initiative for Improving Native American Cancer Outcomes." The purpose of this consultation is to foster ongoing collaboration and seek input from Tribal Nations and organizations in the creation of a funding opportunity that supports the research priorities and cultural approaches important to American Indian and Alaska Native communities, with the goal of making findings applicable and impactful in improving Cancer outcomes American Indian and Alaska Native patients and their families.

Cancer in Native American Communities

American Indians and Alaska Natives experience overall cancer incidence and mortality rates that are strikingly higher than non-Native populations. While there is considerable variation in certain types of cancers by region, compared with non-Hispanic whites, American Indians and Alaska Natives had higher incidence rates of liver, stomach, kidney, lung, colorectal and female breast cancers across most regions of the United States. NCI-designated cancer centers are uniquely positioned to collaborate with Tribal Nations, Tribal organizations, and urban Indian organizations to lead innovative and impactful efforts to improve the screening, diagnosis, and treatment of cancers.

Initiative for Improving American Indian and Alaska Native Cancer Outcomes

The Initiative for Improving American Indian and Alaska Native Cancer Outcomes will support efforts including research, education, outreach, and clinical access to improve the screening, diagnosis, and treatment of cancers in culturally respectful and practical ways among American Indians and Alaska Natives, particularly those living in rural communities. Potential areas of focus may include, but not be limited to:

 Interventions with outreach strategies for cancer survivors related to challenges with adherence to treatment, diagnostic tests or follow-up visits such as financial hardships, caregiver availability, or access to treatment facilities.

- Testing health care delivery approaches that are culturally appropriate but strengthen self-management of clinical outcomes, appropriate surveillance of any concerns or that improve comorbidities such as anxiety and depression.
- Impact of behavior change, survivorship and quality of life, resilience, positive assets, long term side effects and pain management among cancer survivors.
- Interventions including innovative approaches to cancer screening and early detection.
- Cancers related to carcinogens including environmental exposures across various regions (e.g., radioactive areas, arsenic levels in water on the Great Plains, uranium mines in the Southwest).
- Research on treatments grounded in Indigenous Knowledges (e.g., including traditional medicines or other holistic healing approaches for mind, body and spirit).
- Cancer control plans driven by Tribal Nations including surveillance, screening, navigation, survivorship, workforce, policy, research, and evaluation.

NIMHD will work with the NCI to locate this initiative at NCI-designated cancer centers demonstrating partnerships with Tribal Nations, Tribal organizations, and urban Indian organizations.

Suggested questions for representatives of various AI/AN populations to consider:

- Are there research priorities or types/areas of research that should be included?
- What concepts are important for the initiative to support efforts that are culturally appropriate and supportive of Tribal sovereignty and Tribal data sovereignty?
- What guidance would you provide for NCI Cancer Centers to partner with Tribal Nations on how they can expand efforts to improve Cancer outcomes and sustain meaningful relationships with the Tribes?

Additional Resources

- Cancer and American Indians/Alaska Natives:
 https://minorityhealth.hhs.gov/cancer-and-american-indiansalaska-natives#:~:text=American%20Indian%2FAlaska%20Native%20women,than%20non%2DHispanic%20white%20women.
- A Seat at the Table: Culturally based Cancer Research Among American Indians and Alaska Natives: https://www.youtube.com/watch?v=mcCMprOdZvU
- NIMHD: https://www.nimhd.nih.gov/
- NCI-Designated Cancer Centers: https://www.cancer.gov/research/infrastructure/cancer-centers
- Addressing Cancer Disparities Among American Indian and Alaska Native Populations: https://www.youtube.com/watch?v=JLRCh8tWwzY