



Northwest Native American  
Research Center for Health

# Cancer Prevention Resource Guide

Second Edition

for

AMERICAN  
INDIAN &  
ALASKA NATIVE  
CANCER  
RESEARCHERS

# USING THIS GUIDE

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The Cancer Resource Guide is intended to provide helpful resources for Native cancer researchers. It is not an exhaustive list. This guide was originally developed to support the efforts of NW NARCH fellows in the Tribal Researchers' Cancer Control Fellowship program.

The Second Edition contains updated resources. We will continue to update the guide for your use. We welcome our suggestions. Please share your favorite resources with us.

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# FOREWARD

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I am sometimes shocked when I realize how long the Native Researchers' Cancer Control Research Training program has been going on, and how it has evolved over that period. The first cohort of ten trainees came to the University of New Mexico in 1995 for a three-week marathon that involved development of a skill set needed to succeed as an investigator or investigative team member in cancer prevention studies in Native communities. All of those trainees returned home looking pretty exhausted, but they all made headway in their careers in this arena. Subsequent cohorts over the following decades were of similar size...up to 15 per year...and were similarly successful as the first group.

Our program's faculty and staff share the commitment of our fellows. A substantial number of our faculty have been with us since the early days, including Linda Burhansstipanov, Jennie Joe, Jodi Lapidus, John Stull, and others. They remain current with new techniques and approaches to cancer prevention and control, and to statistical and study design methods used in cancer studies. The program staff commitment remains equally high, as evidenced by the lovely job that Grazia Cunningham did in preparing this resource guide. It is not meant to be comprehensive; rather, to point the reader in the direction of key resources that may be useful to design new community-based studies.

While the National Cancer Institute directly provided funding to universities for each of the four-year grant cycles, they now funnel institute funds through the Native American Research Centers for Health (NARCH) program. We at the Indian Health Board are part of that network. As a result of this funding stream moving through the NARCH program, we have not been able to include Native Hawaiian, Samoan, Chamorro, or other Polynesian trainees in our mix of students. I continue to stay in contact with many of them, and am amazed at the enormous success that many of them have demonstrated in cancer prevention research and project implementation in Polynesian communities. The Pacific Island fellows had great commitment to improving the picture of cancer incidence and survival among people at home and we hope that parts of this document will be useful to them as well.

In addition to thanking Grazia, I wish to thank all of the impressive trainees who have joined us in this endeavor, and the future trainees whom we will enroll and support in our cancer prevention fellowships. Our program faculty and staff have been terrific, and fun to work with in this program. Ashley Thomas is the NARCH senior program manager and is very vigilant about opportunities to further careers of young tribal researchers. We appreciate the Indian Health Board's sponsorship of the program and of this document, the support of the NIGMS and NCI, of the NARCH program, and of the universities that have helped in various ways to move our program forward. The challenges of reducing cancer incidence and improving cancer mortality have not gone away, although we have seen clear progress for some cancer sites in Native communities. Thanks go to those who have been 'fighting the good fight', and to you for your willingness to join in the effort.

A presto,

Tom Becker

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CANCER  
SURVEILLANCE

### **Alaska Native Tumor Registry (ANTR)**

Created in 1974 by NCI, CDC and Alaska Tribal leaders, ANTR is a cancer surveillance system focused on Alaska Native people.

### **CDC Behavioral Risk Factor Surveillance System**

Behavioral risk factor data collected at state and local data via telephone survey.

### **CDC Cancer Data & Statistics Tools**

A list of cancer databases for public use and researchers

### **CDC USCS Data Visualization Tool**

The United States Cancer Statistics Data Visualization Tool provides incidence and death counts, rates, and trend data; survival and prevalence estimates; and state-, county-, and congressional district data. Includes a module of AI/AN living in Indian Health Service purchased/referred care delivery areas.

### **Cherokee Nation Cancer Registry**

Developed by Cherokee Nation Tribal Council and the State of Oklahoma and supported by SEER, this cancer registry collects high quality and up-to-date cancer data for cancer control and research efforts.

### **Division of Cancer Control & Population Sciences**

National cancer surveillance system featuring analytical tools and methods for collecting, analyzing, and interpreting cancer data.

### **National Cancer Database (NCDB)**

A joint program between the American Cancer Society and Commission on Cancer (COC) hospital registries. Requires log in info.

### **National Cancer Institute - Health Disparities**

NCI's Division of Cancer Control & Population Health Sciences monitors the burden of cancer among Americans to assess, understand, and improve the disparities of cancer in the US.

### **National Program of Cancer Registries**

Compilation of data on cancer incidence, type, and treatment outcomes.

### **New Mexico Tumor Registry**

A founding member of SEER, the New Mexico Tumor Registry provides population-based cancer surveillance for Native populations in New Mexico and Arizona.

### **North American Association of Central Cancer Registries**

NAACR strives to develop and promote uniform data standards for cancer registries.

## **State Cancer Profiles**

Collection of cancer data from public health surveillance systems intended for health planners, policy makers, and information professionals. Focused on cancer sites for which there are evidence-based intervention programs.

## **Surveillance, Epidemiology, and End Results Program (SEER)**

SEER is a collection of cancer incidence and survival data from population-based cancer registries.

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AI/AN  
PROGRAMS



## **Alaska Native Health Tribal Health Consortium**

Information on the ANTHC Cancer Program, Alaska Native Epidemiology Center, and ANTHC's Clinical and Research Services.

## **CDC Cancer in American Indians and Alaska Natives**

Brief summary of cancer in AI/AN communities with links to relevant research among tribal communities.

## **Johns Hopkins Center for American Indian Health - Addressing Disparities in Cancer Education, Care, and Outcomes in Native American Communities**

This program works with Navajo Nation and White Mountain Apache Tribe to reduce disparities in cancer education, care, and outcomes for Native American communities.

## **Native Cancer Information Resource Center and Learning Exchange (CIRCLE)**

Resource center of culturally-appropriate cancer information (and non-cancer information) to health care professionals and people involved in the treatment and care of American Indian and Alaska Native individuals.

## **Native American Cancer Research Initiatives, Inc. (NACI)**

Tribally-owned organization that provides culturally appropriate cancer education, evaluation and survivorship navigation.

## **Native American Cancer Data**

A collaboration between University of New Mexico, Spirit of Eagles, and the Mayo Clinic, this website provides scientifically reviewed and region specific cancer data in American Indian/Alaska Native populations.

## **NW Tribal Comprehensive Cancer Project**

A program of the Northwest Portland Area Indian Health Board, the NTCCP provides technical assistance to Northwest tribes. Website includes access to cancer data and reports.

## **NAU Native American Cancer Prevention (NACP)**

NACP offers research programs to support entry-level Native Americans in biomedical research who are dedicated to improving the lives of SW tribal communities. Projects include laboratory-based and community-based participatory research.

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COMPREHENSIVE  
CANCER  
WEBSITES

## **CDC National Comprehensive Cancer Control Program**

NCCP provides funding, guidance, and technical assistance to cancer prevention & control programs.

## **George Washington University Cancer Center Cancer Control Technical Assistance Portal (TAP)**

Cancer Control TAP provides technical assistance and training resources for cancer control professionals.

## **National Cancer Institute Division of Cancer Control and Population Sciences (formerly Cancer Control Planet)**

Data and resources available to assist program planners and researchers develop, implement, and evaluate successful cancer control programs and research.

## **National Cancer Institute Resources for Cancer Researchers**

Researchers can sort through tools, databases and resources in various areas.

## **NIH Oncology Guide**

This guide provides access to biomedical, interdisciplinary, and clinical trial databases.

## **Oncology Nursing Society**

Educational resources, publications, tools, and practical resources can be found here.

## **Physician Data Query (PDQ)**

PDQ contains information for providers and patients, including drug information summaries, cancer treatment, and cancer therapies.

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PROFESSIONAL  
ORGANIZATIONS

## **Academy of Oncology Nurse & Patient Navigators**

Largest national organization focused on improving patient care and quality of life by supporting and developing nurse and patient navigators.

## **American Association for Cancer Research**

This website provides information to cancer researchers, healthcare professionals, and patients or survivors. Includes information on training and career development.

## **American Cancer Society**

National cancer organization with information on site-specific cancer, treatment, support, prevention, and research. Note: this is not AI/AN specific.

## **American Cancer Society Cancer Action Network (ACS-CAN)**

Excellent resource for lobbying and legislative information.

## **American Indian Cancer Foundation**

National non-profit established to address cancer inequities. Resources include toolkits, webinars, infographics, and more. The ACIF Research Program works with communities to conduct research.

## **American Institute for Cancer Research (AICR)**

The mission of AICR is to drive cutting edge research on cancer risks and prevention, funding research specifically focused on lifestyle and diet.

## **American Lung Association**

Information for patients, caregivers, and health professionalson on various lung diseases, including lung cancer. Research reports and clinical trial information available.

## **American Society of Clinical Oncology**

This organization maintains a database that approved organizations and individuals can access for research.

## **Association of Community Cancer Centers**

National, multi-disciplinary organization that helps define quality care along the continuum. Information on various cancer types, pharmacological treatments, and research

## **Cancer Atlas (ACS)**

Created by the American Cancer Society, this website provides reliable and evidence-based data on global cancer burden, risk factors, and interventions for cancer advocates, policy makers, public health professionals, patients, and survivors.

## **Cancer Statistics Center at ACS**

An American Cancer Society comprehensive and interactive website to learn about the burden of disease in the U.S.

## **Susan G. Komen Foundation**

National and local breast cancer organizations offering funding to researchers as well as information to patients and caregivers.

## **Commission on Cancer**

This is a consortium of professional organizations dedicated to improving survival and quality of life for cancer patients and promoting cancer prevention, research, education, and monitoring of comprehensive quality care.

## **Livestrong Foundation**

Nationwide organization focused on cancer survivorship. Website includes a comprehensive research library.

## **National Comprehensive Cancer Network**

Not-for-profit alliance of 31 cancer centers fostering research to improve cancer care.

## **National Coalition for Cancer Survivorship**

Organization dedicated to cancer survivorship and improving the experience of those living with cancer.

## **Oncolink**

Established in 1994, Oncolink was the first cancer website created by healthcare professionals. Find presentations, information on cancer sites, and continuing education.

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DEMOGRAPHIC  
DATA

## **Census.gov**

Search Census data on a variety of parameters, including race/ethnicity and health, and peruse data briefs on American Indian/Alaska Natives.

## **Census Intergovernmental affairs: Tribal Affairs - American Indian and Alaska Native**

This website highlights the Census Bureau's provides access to AI/AN data tools and datasets.

## **Tribal Epidemiology Centers**

IHS-funded organizations that provide public health research, surveillance, training, technical assistance, and program support to tribal communities.



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IMPLEMENTATION  
RESOURCES

## **CDC Comprehensive Cancer Control Program**

Provides funding, guidance, and technical assistance to states, tribal organizations, and states to implement cancer control programs.

## **The Community Guide**

Resource of evidence-based programs and interventions to guide your cancer prevention planning.

## **National Association of County Health Officials (NACCHO)**

With funding from the American Lung Association, NACCHO and CDC collaborated to develop implementation resources for cancer researchers. Access to toolkits and implementation guides on this webpage.

## **NCI Evidence-Based Cancer Control Programs (EBCCP)**

The Evidence-Based Cancer Control Programs website is a searchable database to provide program planners and public health practitioners with immediate access to program materials.

## **RePORT**

RePORT provides access to data, reports, and analyses of NIH-funded research. Users can also access research results and spending information.

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PUBLISHING  
RESOURCES

## **CDC Grant Writing Guidance and Tips**

Grant writing resources for public health professionals seeking CDC funding.

## **Evidence-Based Cancer Control Programs**

EBCCP is a repository of evidence-based cancer control program materials to assist program planners.

## **Elsevier Research Academy**

Free resources to a number of online resources to help researchers publish their manuscripts.

## **Freedom of Information Act Office (FOIA)**

Public information can be requested and accessed through the FOIA office.

## **Journal Name Author Estimator (JANE)**

Need help finding a journal for your paper? Enter keywords in JANE for some suggestions.

## **National Institute on Drug Abuse Grant Writing Tools**

Learn how to plan and write successful NIH grant proposals.

## **National Institutes of Health Grant Information**

A summary of types of NIH funds available to cancer researchers.

## **National Institutes of Health Library - Office of Management**

A number of writing resources are offered to biomedical researchers.

## **Native American Cancer Control Literature Database**

Part of the NCI's Intervention Research to Improve Native Health, this database is a compilation of published scientific literature on cancer-related topics within Native American communities, including American Indian, Alaska Native, Native Hawaiian, and First Nations.

## **SciENVcv: Science Experts Network Curriculum Vitae**

NIH resource for researchers to generate and store a biosketch.

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RESEARCH IN  
AI/AN  
COMMUNITIES

## **American Indian Cancer Fund (AICF) Research Program**

Program that works with communities to identify research questions, methods, and funding to conduct cancer research.

## **Guidelines for Researchers - NACP**

This guide outlines methods for establishing effective research partnerships with American Indian tribal communities.

## **How to Build and Sustain a Tribal IRB**

Developed by The Partnership for Native American Cancer Prevention, this guides AI/AN communities on how to create a Tribal research review board or Institutional Review Board, conduct a review, and register an IRB.

## **IHS Human Subjects Research**

Information on conducting research involving AI/AN people, including submitting for IRB approval, via Indian Health Service.

## **Yakama Nation President's Cancer Panel Report**

Report to the President on cancer in Yakama Nation.

## **Johns Hopkins Center for American Indian Health - Cancer Care & Prevention Program**

This program works with Navajo Nation and White Mountain Apache Tribe to reduce disparities in cancer education, care, and outreach.

## **NAU Native American Cancer Prevention (NACP)**

NACP offers research programs to support entry-level Native Americans in biomedical research who are dedicated to improving the lives of SW tribal communities. Projects include laboratory-based and community-based participatory research.

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TEXTBOOKS &  
BOOK CHAPTERS

# TEXTBOOKS

Armstrong BK. **Cancer Epidemiology and Prevention** Oxford University Press; 2018 Dec 1. ISBN:9780190238667

Burhansstipanov L, Braun KL, editors. **Indigenous Public Health: Improvement through Community-Engaged Interventions.** University Press of Kentucky; 2022 Sep 6. ISBN:978-0-8131-9584-1 (hardcover); 978-0-8131-9587-2 (epub).

Greenwald P, Kramer, BS, Weed DL. **Cancer Control and Prevention.** 1995. ISBN: 0824792580

Henrikson NB, Ivlev I, Blasi PR, et al. **Screening for Skin Cancer: An Evidence Update for the U.S. Preventive Services Task Force** [Internet]. Rockville (MD): Agency for Healthcare Research and Quality (US). 2023 Apr. (Evidence Synthesis, No. 225.)

Institute of Medicine (US) Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care; Smedley BD, Stith AY, Nelson AR, editors. **Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care.** Washington (DC): National Academies Press (US). 2003.

Institute of Medicine (US) and National Research Council (US) National Cancer Policy Board; Curry SJ, Byers T, Hewitt M, editors. **Fulfilling the Potential of Cancer Prevention and Early Detection.** Washington (DC): National Academies Press (US). 2003.

Institute of Medicine (US) Committee on the Review and Assessment of the NIH's Strategic Research Plan and Budget to Reduce and Ultimately Eliminate Health Disparities; Thomson GE, Mitchell F, Williams MB, editors. **Examining the Health Disparities Research Plan of the National Institutes of Health: Unfinished Business.** Washington (DC): National Academies Press (US). 2006.

Institute of Medicine (US) Committee on Women's Health Research. **Women's Health Research: Progress, Pitfalls, and Promise.** Washington (DC): National Academies Press (US). 2010.

Loscalzo J, Fauci AS, Kasper DL, Hauser SL, Longo DL, Jameson JL. **Harrison's Principles of Internal Medicine.** 2022 May.

**Note: Links to free books or books for purchase.**



# TEXTBOOKS

National Academies of Sciences, Engineering, and Medicine; Health and Medicine Division; Board on Population Health and Public Health Practice; Committee on the Review of Federal **Policies that Contribute to Racial and Ethnic Health Inequities**; Geller AB, Polsky DE, Burke SP, editors. Federal Policy to Advance Racial, Ethnic, and Tribal Health Equity. Washington (DC): National Academies Press (US); 2023 Jul 27.

National Research Council (US) Panel on Race, Ethnicity, and Health in Later Life; Anderson NB, Bulatao RA, Cohen B, editors. **Critical Perspectives on Racial and Ethnic Differences in Health in Late Life**. Washington (DC): National Academies Press (US). 2004. doi: 10.17226/11086

National Research Council, Committee on Population. **Changing numbers, changing needs: American Indian demography and public health**. 1996.

Nelson HD, Cantor A, Wagner J, et al. **Achieving Health Equity in Preventive Services** [Internet]. Rockville (MD): Agency for Healthcare Research and Quality (US); 2019 Dec. (Comparative Effectiveness Review, No. 222.)

**PDQ Cancer Information Summaries**  
Bethesda (MD): National Cancer Institute (US); 2002.

Roundtable on the Promotion of Health Equity and the Elimination of Health Disparities; Board on Population Health and Public Health Practice; Institute of Medicine. **Leveraging Culture to Address Health Inequalities: Examples from Native Communities: Workshop Summary**. Washington (DC): National Academies Press (US). 2013 Dec 19. doi: 10.17226/18496

Smedley BD, Haynes MA, editors. **The unequal burden of cancer: an assessment of NIH research and programs for ethnic minorities and the medically underserved**. 1999

**StatPearls**. Treasure Island (FL): StatPearls Publishing. 2023 Jan.

United States Public Health Service Office of the Surgeon General; National Center for Chronic Disease Prevention and Health Promotion (US) Office on Smoking and Health. **Smoking Cessation: A Report of the Surgeon General**. Washington (DC): US Department of Health and Human Services. 2020.

Wallace RB and Koahatsu N. Eds. **Public Health & Preventive Medicine**. 15th edition. 2008. ISBN: 978007144198-8

**Note: Links to free books or books for purchase.**

# BOOK CHAPTERS

Around Him DM, Gachupin FC, Freeman WL. **Research with American Indian and Alaska Native Individuals, Tribes, and Communities.** Institutional Review Board Management and Function, 3rd ed.; Bankert EA, Gordon BG, Hurley EA, Shriver SP, Eds. 2021.

Credo J, Ingram JC, Briehl M, Gachupin FC. **Utilizing Environmental Analytical Chemistry to Establish Culturally Appropriate Community Partnerships.** In *Indigenous Populations-Perspectives From Scholars and Practitioners in Contemporary Times* 2022 Aug 2. IntechOpen.

Freeman WL, Romero FC. **Community consultation to evaluate group risk.** *Institutional Review Board: Management and Function*. Sudbury, MA: Jones & Bartlett. 2002:160-4.

Freeman WL, Romero FC, Kanade S. **Community consultation to assess and minimize group harms.** *Institutional Review Board: Management and Function*. 2nd ed. Sudbury, MA: Jones and Bartlett Publishers. 2006:4-134.

Gachupin, FC. **Protections to consider when engaging American Indians/Alaska Natives in human subjects research.** Health and social issues of Native American women (pp. 237–264).; In Joe, J., Gachupin, F., Eds. 2012.

Gachupin, FC & Freeman, WL. **Ethics of biospecimen research.** Conducting health research with Native American communities (pp. 197–210). Solomon, T & Randall, L. Eds. 2015.

Held S, McCormick AK, Simonds V, Braun KL, Burhansstipanov L, Haozous E, Rangel V, Chung-Do JJ, Ho-Lastimoso I, Novotny R, Revilla MK. **Using Community-Based Participatory Research to Address Indigenous Health.** *Indigenous Public Health: Improvement through Community-Engaged Interventions*. 2022 Sep 6:80.

**Note: Links to book chapters may not exist. Links to books for purchase have been provided.**

Citations in Vancouver style.

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NCI WEBSITES

## **NCI Cancer Research Data Commons (CDRC)**

A cloud-based resource that provides access to an expanding collection of cancer research data.

## **NCI Cloud Resources**

Part of Cancer Research Data Commons (CDRC), these are cloud-based resources for cancer researchers.

## **NCI-Designated Cancer Centers**

This provides a list of cancer centers in the US.

## **NCI Intervention Research to Improve Native American Health (IRINAH)**

Program dedicated to improving health of Native American communities. Website provides information on funded projects, grant preparation, agency contacts, literature database, and other helpful resources.

## **NCI Oncology Resources**

A guide to databases, pharmaceutical resources, e-books, professional societies and patient education resources.

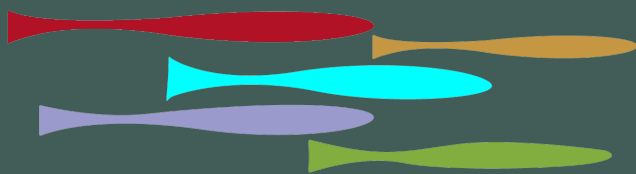
## **NCI Resources for Researchers**

A searchable list of useful resources for cancer researchers, including cancer biology sites, public health resources, and clinical research tools.

## **The Cancer Genome Atlas Program**

Access information about NCI's cancer genomics program, including data visualization, computational tools, and information on cancer sites.

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