



A NATIONAL ACTION PLAN  
FOR CANCER SURVIVORSHIP:  
**Native American Priorities**



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Cory Frisby

Leslie Greene

Mary Lovato

Mary Nance

Ellen Pagano

Blanche Thomas

May Thomas

Arlene Wahwasuck

Walter Woods

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## INTRODUCTION

There are currently more than 10 million people living with, through or beyond cancer in the United States today.<sup>1</sup> One in three people will be diagnosed with cancer during their lifetime, and three in four families will care for a family member with cancer.<sup>1</sup> More people diagnosed with cancer are surviving each year as a result of improvements in screening, early detection and treatment for many cancers. However, survivors often face numerous physical, psychological, social, spiritual and financial issues during their diagnosis and treatment and throughout their lives.

Cancer survivors are defined as those who have been diagnosed with cancer as well as the people in their lives who are affected by the diagnosis, including family members, friends and caregivers. Survivorship begins at the moment of diagnosis and continues through the balance of life.<sup>2</sup>

While cancer affects all segments of the population, there are wide disparities in cancer survival rates and quality-of-life issues by race, ethnicity and geography. American Indians and Alaska Natives have the poorest five-year survival rates of any other racial group from all cancer sites combined.<sup>3</sup> Furthermore, cancer rates in American Indians and Alaska Natives have been shown to be increasing in the past 20 years.<sup>4</sup> However, cancer rates in American Indian/Alaska Native (AI/AN) survivors may be underrepresented due to data limitations, such as racial misclassification, condensing of categories to “other” and a lack of a comprehensive database for AI/AN cancer.<sup>5,7</sup>

In Census 2000, 4.3 million people reported that they were American Indian or Alaska Native. This number included 2.4 million people who reported only American Indian or Alaska Native as their race. There are currently more than 560 federally recognized tribes and 100 state tribes in the United States today.<sup>6</sup> *A National Action Plan for Cancer Survivorship: Native American Priorities* provides a framework for actively addressing the needs of this diverse group of cancer survivors.

## BACKGROUND

In 2002, the Centers for Disease Control and Prevention (CDC) and the Lance Armstrong Foundation (LAF) collaborated to chart a course for comprehensively addressing cancer survivorship. This collaboration involved a series of meetings among key partners and experts, including numerous organizations, health advocates, cancer survivors and researchers from a variety of ethnic and racial backgrounds across the United States. The goal was to identify public health issues that would serve as a framework from which to mobilize cancer survivorship.

The needs of cancer survivorship for all racial and ethnic groups were prioritized across four core areas:

- Surveillance and applied research
- Communication, education and training
- Programs, policies and infrastructure
- Access to quality care and services

In addition, five other issues or needs were identified that cut across the four issues above. These were a need to support:

- Infrastructure for a comprehensive database on cancer survivorship
- Patient navigation systems that facilitate optimum care for cancer survivors
- Clinical practice guidelines for each stage of cancer survivorship
- Public education programs that promote informed decisions
- Comprehensive evaluation programs to measure outcomes and ensure service quality

The result of these efforts is [\*A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies\*](#). This national action plan provides a framework for addressing the problems faced by cancer survivors in our nation.

## PURPOSE

*A National Action Plan for Cancer Survivorship: Native American Priorities* prioritizes the cancer survivorship needs of the Native American community to ultimately lead to improved quality of life and survival from cancer. State agencies, organizations and individuals can use the identified priorities to increase awareness among the general public, policy makers, researchers, advocates, survivors and others of the needs of Native American cancer survivors and to stimulate organizations to take direct and focused action to meet those needs.

Using *A National Action Plan for Cancer Survivorship*, a number of AI/AN stakeholders in cancer survivorship participated in prioritizing the needs and topics contained in the original action plan. Through an Internet-based survey process, 129 respondents ranked each need in five topic areas of cancer survivorship. Respondents also provided comments on the survey process and cancer survivorship in general. Overall, access to care was identified as the top area of need and patient navigation was the top cross-cutting issue that affected all of the topic areas. Many respondents admitted that it was difficult to prioritize when there is so much that needs to be done. Comments ranged from improved access to services, increased patient education and more culturally competent training and communication for providers to expanding community infrastructure to better support cancer survivors. All survey responses were confidential and reported in the aggregate. The following report summarizes the ranked priorities as identified by Native Americans regarding cancer survivorship issues.

# PRIORITIZED RANKING AND COMMENTS

Stakeholders in the AI/AN community prioritized the survivorship needs identified in *A National Action Plan for Cancer Survivorship* across the various topic areas. Each section below contains a description of the survivorship topics prioritized, a list of the needs in the order they were ranked (one being the most important and five being the least), and finally, a summary of the comments made by participants on that particular topic area.

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## OVERVIEW

### MAIN CANCER SURVIVORSHIP TOPICS:

These are listed in the order of importance.

1. **Access to quality care and services** means ensuring that survivors are able to obtain high quality treatment and services in a timely, competent manner. This approach must also promote good, culturally appropriate communication and shared decision making between the cancer survivor and healthcare providers.
2. **Education, training and communication** include efforts to communicate with the general public as well as policy and decision makers, to educate survivors and their families and to train healthcare providers to meet informational needs of all those affected by cancer survivorship.
3. **Infrastructure, programs and policies** are the means by which change can be made in public health.
4. **Applied research and surveillance** are the scientific tools of public health and can be used to establish a solid, systematic knowledge base in cancer survivorship.

*“You wait six months for that Medicaid to get placed. If you have to go through surgery and...chemo and radiation sometimes it takes longer and it is that much more days that the cancer is spreading.”<sup>8</sup>*

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### CROSSCUTTING ISSUES:

A set of five core issues ‘cut across’, or affected, all of the main topic areas. These were prioritized and are listed below.

1. **Develop and promote patient navigation systems for cancer survivors.** Patient navigation can be used to ensure that survivors understand their care and to enhance the delivery of optimum care. Navigators can ensure timely delivery of care, connect survivors with appropriate resources, provide educational information on cancer survivorship and provide general oversight to the delivery and payment of services for each survivor.
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2. **Develop and disseminate public education programs on informal decision making for cancer survivors.** Cancer survivors are faced with extremely difficult medical decisions at each stage of living with, through and beyond cancer. Survivors need to thoroughly understand their options for care. When patients are well-informed and participate in deciding how to manage their health, the results are more positive and survivors are more likely to follow their providers' recommendations.
3. **Develop and disseminate clinical practice guidelines for each stage of cancer survivorship.** Clinical practice guidelines summarize research on outcomes pertaining to one disease. Physicians select guideline recommendations according to the individual's healthcare needs. Guidelines have been developed for the treatment of particular cancers, but not enough for cancer survivors at each stage of cancer survivorship (e.g., monitoring survivors after treatment is completed, monitoring long-term health care and end-of-life care).
4. **Develop comprehensive evaluation systems that monitor cancer survivorship issues and services.** The goal of evaluation is to increase program efficiency and its impact over time. Effective evaluation requires high quality indicators that are comprehensively monitored during all steps in program implementation.



5. **Develop a comprehensive database on cancer survivorship.** Increasing the capacity of surveillance systems to capture information on health topics can lead to a better understanding of diseases and the people affected by them. A comprehensive database system could provide information on the ongoing health and other issues facing survivors.

**COMMENTS: CROSSCUTTING NEEDS**

- There is a need for culturally appropriate information and education for patients on all stages of cancer.



- Medical providers need cultural competency training to better serve patients.
- More attention should be paid to the spiritual, emotional and psychological needs of cancer patients and their families.
- Rural environments present many economic, time and educational challenges for survivors.
- A patient navigation system would greatly benefit many cancer patients.

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*“Public education and clinical practice guidelines work hand-in-hand. The people need the best information to make the best decisions, however providers need to be giving the best current information to be able to do so.”<sup>9</sup>*

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## DETAIL

### MAIN CANCER SURVIVORSHIP TOPICS:

#### ACCESS TO QUALITY CARE AND SERVICES:

Access to quality care and services means ensuring that survivors have access to high quality treatment and services delivered in a timely, competent manner. This approach must also promote good, culturally appropriate communication and shared decision making between the cancer survivor and healthcare providers.

1. **Access to quality treatment:** The AI/AN communities face unique challenges related to access to treatment. Many complex factors including health care funding, geography, cultural issues and the relationship between tribal and U.S. governments can affect a survivor’s ability to access quality care. All cancer patients should have timely access to the latest and most effective treatments available, including clinical trials.
2. **Pain and symptom management:** The goal of pain and symptom management is to provide relief so that survivors can tolerate the diagnostic and therapeutic procedures needed to treat their cancer and live comfortably throughout each stage of cancer survivorship.
3. **End-of-life care:** Appropriate end-of-life care affirms life and regards dying as a natural process, neither hastening nor postponing death. The goal of end-of-life care is to achieve the best possible quality of life for cancer survivors.

#### NEEDS:

The following access to quality care and services needs are ranked in their order of importance.

1. Establish integrated multidisciplinary teams of healthcare providers that support cancer survivors.
2. Develop and promote a patient navigation system for cancer survivors.
3. Develop and disseminate guidelines that promote quality and timely service provision to cancer survivors.
4. Educate decision makers about economic healthcare barriers related to cancer survivors.
5. Assess and enhance palliative services for cancer survivors.

**COMMENTS: ACCESS TO QUALITY CARE AND SERVICE**

- Promote the use of integrated, multidisciplinary teams to help survivors navigate through the system.
- More training should be given to providers on the long-term effects of treatment on personal health.

**EDUCATION, TRAINING AND COMMUNICATION:**

Education, training and communication include efforts to educate survivors and their families, as well as to train healthcare providers to meet informational needs of all those affected by cancer survivorship. This category also includes communication with the general public and policy and decision makers.

1. **Survivor education:** Education of cancer survivors includes information tailored to the particular stage of survivorship. Educational interventions may be most appropriate during the first five years after diagnosis as this is the time when many of the challenges associated with the adjustment to survivorship occur.
2. **Provider training:** Healthcare provider training aims to ensure that providers are aware of the medical and special needs of cancer survivors. Training should cover all services necessary to enhance quality of life throughout survivorship.

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*“It is my experience that the best care comes through advocacy and being armed with high quality information. Both public education and navigators would strengthen the advocacy and support for individual patients.”<sup>9</sup>*

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3. **Public Communication:** Communication about the issues surrounding cancer survivorship aims to create a societal understanding and acceptance of the growing population of cancer survivors and the issues they face.
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Communication strategies will need to target the general public as well as policy or decision makers.



#### NEEDS:

The following education, training and communication needs are ranked in their order of importance.

1. Educate healthcare providers about cancer survivorship issues.
2. Teach survivors to access and evaluate cancer survivorship information.
3. Develop and promote patient navigation systems for cancer survivors.
4. Educate decision makers on the value of follow-up care and clinical trials.
5. Train survivors in advocacy skills.
6. Educate the public about cancer survivorship.

#### COMMENTS: EDUCATION, TRAINING AND COMMUNICATION

- More patient navigation and patient education is necessary.
- More cultural competence training for providers is needed.
- More patient navigation systems are needed and cancer survivors should be part of the navigation team.

#### INFRASTRUCTURE, PROGRAMS AND POLICIES:

Infrastructure, programs and policies are the means by which change can be made in public health.

1. **Infrastructure:** Infrastructure refers to basic resources and facilities to address survivorship, such as staff, partnerships, equipment, public outreach materials, clinics, privacy in the clinic setting, data management and administration. Effective infrastructure and good relationships with public and private sectors are required to operate and manage effective programs.
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2. **Programs:** Programs are specific activities that aim to improve the quality of life of cancer survivors. These programs may address medical, psychosocial, cultural, spiritual and/or financial issues associated with cancer survivorship.
3. **Policies:** Policies include legislation, regulations, ordinances, guidelines and norms that establish an environment conducive to program implementation and other changes specific to survivorship. Policies may be implemented at the national, state, organizational and community levels in an effort to advance public health.

## NEEDS:

The following infrastructure, programs and policies needs are ranked in their order of importance.

1. Identify and implement programs proven to be effective.
2. Develop and disseminate education programs that empower survivors to make informed decisions.
3. Develop and promote patient navigation programs that facilitate optimum care.
4. Implement evidence-based cancer plans that include all stages of cancer survivorship.
5. Establish clinical practice guidelines for each stage of cancer survivorship.
6. Promote policy changes that support addressing cancer as a chronic disease.
7. Develop infrastructure to obtain quality data on all cancer management activities.

## COMMENTS: INFRASTRUCTURE, PROGRAMS AND POLICIES

- Patient navigation systems are needed to help individuals and family members to better understand the healthcare system.
  - Better patient education is needed.
  - Providers need training on how to communicate with Native American cancer survivors.
  - Providers need more training in palliative care.
  - Accelerate the translation of evidence-based programs into the community.
  - Multidisciplinary teams are needed to provide the best treatment. Cancer survivors can benefit most when teams of both medical and non-medical professionals work together to provide care and support.
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## APPLIED RESEARCH AND SURVEILLANCE:

Applied research and surveillance are the scientific tools of public health and can be used to establish a solid, systematic knowledge base in cancer survivorship.

1. **Applied research:** Cancer survivorship research focuses on applying our knowledge of cancer and issues survivors face to the development of solutions and appropriate interventions. Applied research investigates health systems, public policy and effects on individuals to address survivor needs.
2. **Surveillance:** Cancer surveillance is the collection, analysis and use of cancer data. Surveillance data is critical for directing effective cancer prevention and control programs. Data comes from cancer registries that collect information on each cancer patient. National surveys collect data on health attitudes, beliefs and behaviors that are used to help understand issues related to all stages of cancer survivorship.

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*“Currently, I believe that Indian country does not have a handle on the cancer burden specific to their tribe. I believe this is the first step in identifying which cancers are most relevant to tribes so funds can be sought to help in those areas.”<sup>9</sup>*

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## NEEDS:

The following applied research and surveillance needs are ranked in their order of importance.

1. Identify programs/services that best meet cancer survivorship needs.
2. Identify factors associated with health concerns of cancer survivors.
3. Research preventive interventions to evaluate their impact on survivorship.
4. Translate applied research into practice.
5. Enhance existing surveillance and applied research infrastructure.

## COMMENTS: APPLIED RESEARCH AND SURVEILLANCE

- More patient education is needed.
- In rural areas, more attention needs to focus on providing child care and transportation between the patient’s home and clinics.
- Indian Health Service/Tribal, Urban Indian leaders need to know more about the prevalence and impact of cancer within their tribes.
- Accelerate the translation of evidence-based programs that have been found to be effective in American Indian/Alaska Native communities.

## COMMENTS: GENERAL SURVEY

- All the issues presented in the survey were important; therefore it was difficult to prioritize the needs of cancer patients in the Native American community.
- Respondents were grateful for the opportunity to participate in the survey.
- Additional funding for cancer research is needed to increase education and improve cancer care in Native American communities.
- Patient/survivorship navigation supported by the healthcare system needs to be improved.
- The most recent advances in cancer treatment should be better promoted and should be made available to all cancer survivors.
- More spiritual and emotional support is needed for cancer survivors.

## IMPLEMENTATION

As cancer rates continue to rise in the AI/AN population, it is important that the public health community mobilizes to address the needs in these communities. By using *A National Action Plan for Cancer Survivorship: Native American Priorities* as a guide, the public health community can better respond to this disparity and effectively address the needs of AI/AN cancer survivors.

This report has identified the areas of greater access to care and better availability of culturally appropriate care as priorities for improving the survivorship infrastructure. Organizations and individuals representing healthcare personnel and the public may use this report to focus their current and future cancer survivorship activities along the lines proposed below:

- Local organizations will find the report useful as a starting point or as a source for strategic planning goals for local activities. This report can also be used as a guide for prioritization or justification of organizational infrastructure development, such as in the determination of which projects to invest in, especially when resources are limited and/or access to local or regional opinion leaders is difficult or not feasible to obtain in a timely manner.
- These recommendations could act as a basis for the design of local programs, especially at the early stages of planning when there is a need to prioritize objectives for cancer survivorship.
- Another core event for many organizations is the development of grant applications for organizational support. These recommendations will

serve as a credible reference source for establishing needs (i.e., literature review) as well as for describing operational goals and objectives or culturally supported methods, which are clearly delineated in the action plan.

- Local cancer survivors can help relay culturally acceptable and powerful messages about cancer survivorship. These recommendations can contribute to talking points for cancer survivorship representatives.
- Similarly, political advocacy could benefit from the credibility of recommendations in the action plan supporting specific policy points to local funding agencies, local government decision makers and even regional and state politicians responsible for healthcare legislation.
- The recommendations could be used as content for public educational purposes, whether through mass media channels (e.g., public affairs or news broadcasting) or via group education to the public.
- Healthcare professionals could also find these recommendations useful in formal or informal presentations on a variety of issues, such as cultural competence training, treatment and palliative care, and/or for clinical trial recruitment and retention.

By focusing programmatic and advocacy activities on the identified priorities, organizations and individuals can work collaboratively toward addressing the needs that will ultimately lead to improved quality of life for Native American cancer survivors, their families, friends and caregivers.



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9. Quotations are derived from the survey respondents’ comments.



## NATIVE AMERICAN WORKGROUP MEMBERS

1. **Judith S. Kaur, MD** (Chair)  
Choctaw/Cherokee  
Medical Oncologist  
Director, Native American Programs, Spirit of EAGLES  
Mayo Clinic Comprehensive Cancer Center  
Rochester, MN
2. **Linda Burhansstipanov, MSPH, DrPH**  
Cherokee Nation of Oklahoma  
Executive Director  
Native American Cancer Research, Inc.  
Pine, CO
3. **Dorcias Bloom**  
Siberian Yupik  
NACES Native Survivors Advisory Board  
Nome, AK
4. **Patricia Canfield**  
Seneca Nation of Indians  
Health Department
5. **Michael George, Sr.**  
Coeur d'Alene Tribe  
Training/Safety Officer  
Plummer, ID
6. **Ralaine "Rae" Hinton**  
Liverpool, NY
7. **Gerald L. Ignace, MD**  
Milwaukee, WI
8. **Mary Reiner**  
Santee Sioux  
John T. Vucurevich Cancer Care Institute  
Rapid City, SD
9. **Doug Six-Killers St. Clair, PhD**  
Shoshone Cherokee Nation of Oklahoma  
Vice President of Institutional Development and Research  
Tohono O'odham Community College  
Sells, AZ

10. **Arlene Wahwasuck, RN** (retired)  
Prairie Band Potawatomi  
Horton, KS
11. **Celeste Whitewolf**  
Confederated Tribes of Umatilla  
Tigard, OR

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*“Thank you for the opportunity to hear from a perspective of one who works with the tribal community and Indian Health Services. We are a very much unheard voice in mainstream America.”<sup>9</sup>*

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