



“Native American Cancer Education for Survivors” NACES Preliminary Findings and Uses




“Native American Breast Cancer Education for Survivors Findings and Use of NACES”

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[NCI R25 CA 101938]




Mayo Clinic's Spirit of Eagles Community Network Programs
[NCI U01 CA 114609]

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Objective: By the end of this segment, the workshop participant will be able to:

1. Identify selected findings from the NACES.
2. Identify ways the NACES information may be accessed and used by cancer patients, loved ones and Patient Advocates (Navigators)

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AIAN Breast Cancer Patterns

NOTE: data from “National Native American Cancer Survivors’ Support Network” (1997 through 2005)

AIAN Patterns of Breast Cancer

- 📄 Average age of AIAN population is younger in comparison to US All Races and our people are diagnosed at younger ages
- 🕒 ½ of AIAN breast patients younger than 50
- 📄 Hereditary forms of Breast Cancer (e.g., BRCA1 / BRCA2)
- 🕒 Less than 1% among full bloods
- 🕒 Most Natives are of mixed blood, but BRCA1 / BRCA2 only documented in ONE family throughout Turtle Island

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AIAN Patterns of Breast Cancer

- 📄 Access to cancer resources outside of IHS / Tribal / Urban clinical settings insufficient or non-existent
- 🕒 ½ of AIAN cancer patients fight for Medicaid (young at time of dx) or Medicare)

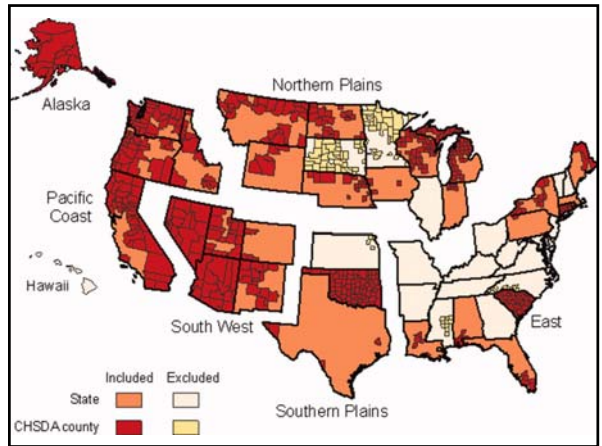
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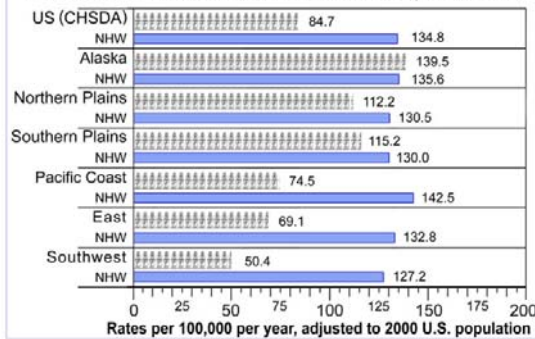
AIAN Patterns of Breast Cancer

- Access to cancer resources (continued)
- 64+% of AIANs live in urban areas of which there are only two I/T/U cities that provides cancer care:
 - Anchorage
 - Fairbanks



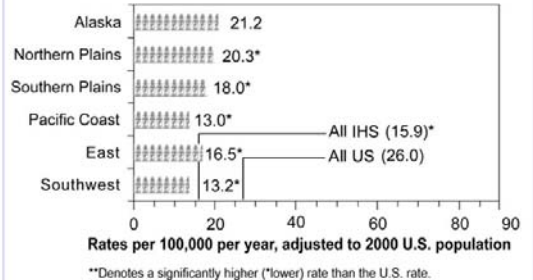
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Breast Cancer Incidence Rates - Females, 1999-2004



Espey, David K; Wu, Xiao-Chen; Swan Judith; Wiggins, Charles; Jim, Melissa A.; Ward, Elizabeth; Howe, Holly L.; Rice, Lynn A.G.; Miller, Barry A.; Jamal, Ahmed; Ahmed, Farooq; Cobb, Nathaniel; Kilar, Judith S.; and Edwards, Brenda K. Annual Report to the Nation on the Status of Cancer, 1973-2004. Featuring Cancer in American Indians and Alaska Natives. Cancer (American Cancer Society), 2007[11-1547], Volume 110, No. 10. GRAPH MODIFIED BY Rick Clark, Native American Cancer Research

Breast Cancer Mortality Rates Females, 1999-2003



Haverkamp D, Espey D, Paisano R, Cobb N. Cancer Mortality Among American Indians and Alaska Natives: Regional Differences, 1999-2003. Indian Health Service, Rockville, MD, February 2008. GRAPH MODIFIED BY: Rick Clark, Native American Cancer Research (note horizontal grid)

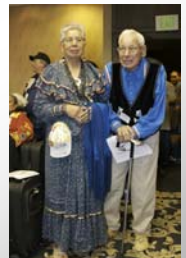


Approaching NACES "backwards"
(excerpts of findings before NACES is described):

Examples of Preliminary Findings

June 2008 140 Native Breast Cancer Survivors
(as of September, there are 200 Native BC Survivors)

- NOTE: National Cancer Institute Survival = ~63% of AIAN women diagnosed with breast cancer are alive five years after diagnosis
- Within NACES, 83% of AIAN women are alive five years after diagnosis!



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June 2008 140 Native Breast Cancer Survivors

- 📖 Demographics and Logistics of BC Care
 - 👤 Almost all of the BC patients are women (only 3 males)
 - 👤 More than ¼ (26.5%) had less than high school education
 - 👤 40% currently live on the Reservation
 - 👤 40% travel between 101 to 300 miles ONE WAY to obtain cancer care
 - 👤 12.4% traveled more than 300 miles

ONE WAY to obtain cancer care



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June 2008 140 Native Breast Cancer Survivors

- 📖 About younger than age 50 at the time of their diagnosis
- 📖 More than half diagnosed stages 3 or 4 (advanced stages)
 - 👤 Survival related to stage of cancer at the time of diagnosis, yet NACES is documenting good long-term survival!



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Excerpts of Percentage of Native BC Patients who also have Co-Morbidities

- 📖 Less than 10% recall ever being told about any clinical trial opportunities (co-morbidities):
 - 👤 High Blood Pressure = 51.9%
 - 👤 Diabetes = 44.2%
 - 👤 Arthritis = 32.7%
 - 👤 Obesity / Overweight = 32.7%
 - 👤 Thyroid = 22.1%

***HBP = ineligible for clinical trials, unless one-on-one negotiation with CT supporter**



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June 2008 140 Native Breast Cancer Survivors

- 📖 About 1/3 have insurance (IHS is not now and never has been health insurance)
- 📖 45.6% had significant problems accessing cancer care
 - 👤 IHS rarely (17.5%) able to provide TIMELY referral to quality care (due to Congressional cuts to Contract Health Services)



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June 2008 140 Native Breast Cancer Survivors

- 📖 No differences in physical, spiritual, emotional, mental or social QOL when comparing:
 - 👤 Natives who have 1 cancer in comparison to those Natives who have 2 or more cancer diagnoses
 - 👤 Native men and women
 - 👤 but for **breast**, only 3 of the 140 were male;
 - 👤 of all cancer sites, 1/3 are males and they do just as well as do the women



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June 2008 140 Native Breast Cancer Survivors

- 📖 For almost all physical side effects associated with cancer or cancer treatments:
 - 👤 There are *statistically significant* improvements when comparing QOL for Natives for physical health as “good to excellent”:
 - 👤 Dx w/in last year = 30%
 - 👤 Dx between 1-4 years ago = 42.4%
 - 👤 Dx 5 or more years ago = 54.2% (p=.044)



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June 2008 140 Native Breast Cancer Survivors

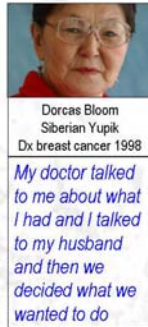
- 📖 Most physical side effects problem multiple days each week in 1st year, then drop (statistically significant (i.e., not "chance") for:
 - 🌐 Fatigue
 - 🌐 Pain
 - 🌐 Neuropathy
 - 🌐 Radiation skin reactions

June 2008 140 Native Breast Cancer Survivors

- 📖 Physical Side Effects (continued)
 - 🌐 HOPE!!!! However badly you feel within first year of the cancer experience is very likely to be TEMPORARY.
 - 🌐 You are likely to feel BETTER
- 📖 Almost all Native patients rated their spiritual health as HIGH

What is "Native American Cancer Education for Survivors"?

- 📖 FREE!!
- 📖 Web-based, Quality of life survivorship education
- 📖 Designed for breast cancer patients
 - 🌐 But has information relevant to patients who have other types of cancer
 - 🌐 Includes both genders
- 📖 Tailored to the individual



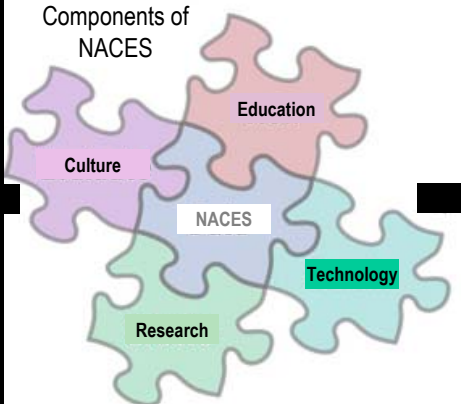
What is "Native American Cancer Education for Survivors"? (continued)

- 📖 Resource for those needing information
- 📖 Research study
- 📖 Culturally specific
- 📖 Inter-tribal
- 📖 Uses the Medicine Wheel



We save our hair and when we die a silk pillow is made and filled with our saved hair. This is the pillow that we finally rest our head on in the casket.

Components of NACES



Question asked of community members: (Explains why NACES moved to the Internet)

2002	If this information was available on the Internet, would you be able to use it?	2007
15%	1. Yes, I could download the information myself	65.2%
30%	2. Yes, I could get someone to help me download the information	17%
30%	3. No, I'm not certain if I could get the information	10.7%
25%	4. No, I do not have access to the Internet	4.5%

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Internet Issues

- ☞ Lack of access and comfort among many community members.
- ☞ Addresses costs issues (mailing, returns, printing, printing errors)
- ☞ Addresses updating issues (allows for rapid update ... sort of) and correction of errors
- ☞ Addresses access issues by providing Native Partners with laptops and training to help other survivors use the Page



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NACES Native Survivors' Advisory Committee

 Dorcas Bloom Siberian Yupik Dx breast cancer 1998	 Dennis Whiterock Navajo Dx 2001 Multiple Myeloma	 Rosanne Wynan Mohawk Diagnosed 1997 uterine / cervical cancer	 Michael T. George, Sr. Coeur d'Alene Dx 2001 Throat Cancer
 CeCe Whitewolf Confederated Tribes of Umatilla Dx 1998 Breast	 Frankie White Dress Oglala Lakota Dx 2001 Breast	 DeAnna Finlrock Fond du Lac Dx 1998 Breast	 Arlene Wahwasuck Prairie Band Potawatomi Dx 2002 Breast

Purpose of NACES

Improve the **QUALITY OF LIFE** for American Indian, Alaska Native, North American Indian (AI/AN/NAI) women and men who are breast cancer survivors by:

1. Developing and testing culturally specific cancer education materials
2. Making the materials easily available through the internet
3. Helping survivors find resources to help them with their cancer issues



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NACES is designed:

- ☞ For Native American breast cancer patients, Advocates and family and others who care about them.
- ☞ To give information that may help improve the patient's quality of life.
- ☞ To include information that may be useful for those with other types of cancer.



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Native Patient Advocates



Available by toll free phone (1-800-537-8295) to help patients obtain the information on the web site (e.g., uncomfortable or don't know how to use the web, prefer to talk with live person)



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The Privacy Broker



Alice Bradley, MA
Colorado Springs, CO
1-877-838-9359

The *only* person who can access private information (e.g., when patient forgets her code name or needs some additional help or something mailed to her)



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"Native American Cancer Education for Survivors" NACES Preliminary Findings and Uses

NACES includes:

- 📖 Both broad and specific educational information arranged by topics
- 📖 Surveys to help you find information of most interest and use to you
- 📖 Storytellers (real life examples but combined from different Native patients)
- 📖 Native vignettes (real survivors sharing their stories)
- 📖 Examples of questions that you may want to ask your provider



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Layout of the Quality of Life Tree Information



Patients click on leaves in the site

The hummingbird appears next to the current leaf being viewed



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Code Name and Online Survey



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Joining the Study

- 📖 Going to the Internet Web site or calling **PRIVACY BROKER**
- 📖 Selecting your code name
- 📖 Filling out the survey(s)
- 📖 Using information on the branches
- 📖 Side bar:
 - 📖 Video vignettes
 - 📖 Story Tellers
 - 📖 Visitors' Questions
 - 📖 Sample Patient Questions for Providers



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