


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




"Native American Cancer Education for Survivors Findings and Use of NACES: All Sites of Cancer and Both Genders" And NEXT STEPS to address the challenges

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This session is dedicated to Eduard Gamito, dear friend and colleague

- 📅 Born 1962
- 📅 Passed January 22, 2008
- 📅 Dear Ed, we miss you and we honor you



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Comments Heard and Possible Next Steps

- 📅 MN and WI Cancer programs have increased, but now there are fewer funding sources
 - 📅 Accurate perceptions
 - 📅 Foundations that existed a few years ago have fewer donations = fewer grants or grants for less money
 - ✳️ Have to tailor the application to be closer to what the funder has for priorities

Who has grant writing skills? How can a grant writer be paid when you have no money?

Comments Heard and Possible Next Steps

- 📅 After we lost our funding, our _____ program actually did better. How can we submit an application and explain that we NEED the funding?
 - 📅 Very challenging. Need to determine how or why the program began to succeed working on less money?

What are some possible reasons why a program may become more successful *after* they lost their funding?

Comments Heard and Possible Next Steps

- ✳️ If due to strong infrastructure, program may continue <18 months before it begins to lose effectiveness
- ✳️ Program based on volunteerism and when the staff need money for grandchildren's shoes, clothing, they accept a paying position and the program crashes

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Comments Heard and Possible Next Steps

- 📅 Saw a lot of statistics and graphs about us having a big problem with cancer, so what do we do about it?
 - 📅 Create "real" partnerships for "win-win" situations
 - 📅 Create and maintain Native survivorship support groups
 - 📅 Recruit and support (pay) local cancer survivors to help with outreach work for early detection programs

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Comments Heard and Possible Next Steps

- 🗨️ It is unethical to educate about screening, when there are no screening services available to the local community.
 - ❖ How to access services?
 - Partnerships? With good organizations or are we “selling our souls”
 - Bartering one-on-one with the screening services

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Comments Heard and Possible Next Steps

- 🗨️ Try to work with individuals or organizations with whom you may had bad experiences previously
 - ❖ Create ground rules that can work for both of you
- 🗨️ Support and/or find ways to support the next generation of public health workers (educators, nurses, social work)
- 🗨️ Train and support (pay) navigators

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What are YOU willing to do?

- 🗨️ Help write grants and know you will receive payment only after the grant is awarded (thus risk of never receiving pay)
- 🗨️ Work on creating and maintaining partnerships with organizations with whom you or your colleagues have had a previously negative experience?

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What are YOU willing to do?

- 🗨️ Help find ways to support the next generation of healthcare and public health professionals from within the AI community?
- 🗨️ Create, maintain, and implement local AI cancer survivorship programs?
- 🗨️ Help increase access to cancer early detection services for AI people?


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Comments Heard and Possible Next Steps


- 🗨️ Avoid re-inventing the wheel and build upon other programs that have worked well in Indian Country
 - <http://www.NativeAmericanPrograms.org>
 - <http://www.NatAmCancer.org>
 - ❖ Online education (shield for risks)
 - ❖ Handouts
 - ❖ Soon to come = Navigator trainings
 - ❖ “Native American Cancer Education for Survivors”

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“Native American Cancer Education for Survivors” (NACES) supported by:



Susan G. Komen for the Cure®
[#POP0503920] and [#POP0202135]



National Cancer Institute
[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. Access and use the QOL NACES surveys and educational modules.
3. Identify ways the modules can be tailored for use with an individual cancer patient.


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

Examples of Preliminary Findings

June 2008 320 Native Cancer Survivors -- All Cancers Sites (as of September, there are 400 Native Survivors from all sites of cancer)


 NOTE: National Cancer Institute Survival = ~63% of AIANs diagnosed with cancer are alive five years after diagnosis




 Within NACES, 85% of AIAN patients are alive five years after diagnosis!



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June 2008 320 Native Cancer Survivors -- All Cancers Sites

 Demographics and Logistics of AIAN Cancer Care

-  15.5% move back and forth between the Reservation and an urban (city) area
-  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 320 Native Cancer Survivors -- All Cancers Sites


-  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 Patients who also have Co-Morbidities

-  Less than 10% recall ever being told about any clinical trial opportunities
-  Co-morbidities:
 -  Diabetes = 50.6%
 -  High Blood Pressure = 45.4%
 -  Habitual Tobacco Use = 36%
 -  Obesity / Overweight = 30.7%
 -  Arthritis = 25.1%

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



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

June 2008 320 Native Cancer Survivors -- All Cancers Sites

- 📖 About 1/3 have insurance (IHS is not now and never has been health insurance)
 - 📌 Almost half (45.6%) had difficulties accessing cancer care
 - 📌 IHS infrequently (18%) able to provide **TIMELY** referral to quality care (due to Congressional cuts to Contract Health Services)

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June 2008 320 Native Cancer Survivors -- All Cancers Sites

- 📖 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

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June 2008 320 Native Cancer Survivors -- All Cancers Sites

- 📖 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 = 23.1%
 - 📌 Dx between 1-4 years ago = 44.6%
 - 📌 Dx 5 or more years ago = 51.0% (p=.000)

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June 2008 320 Native Cancer Survivors -- All Cancers Sites

- 📖 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

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📖 For Example (Fatigue)

Side Effect	Frequency	Length Since Cancer Diagnosis			Average Total
		Diagnosed within Last Year	Diagnosed Between 1-4 Years Ago	Diagnosed 5 or More Years Ago	
Fatigue	Not a Problem or only a Problem a Few Days Each week	28.8%	46.5%	71.1%	55.8%
	A Problem At Least Once a Week	19.2%	16.9%	11.1%	14.3%
	A Problem a Few Days Each Week or Every Day	51.9%	36.6%	17.8%	29.8%

Notice the TREND →

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- 📖 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**

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What is NACES?

"quality of life" (QOL) – how well you are able to do everything you want to do: physically, mentally, emotionally, and spiritually

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




Dorcas Bloom
Siberian Yupik
Dx breast cancer 1998

My doctor talked to me about what I had and I talked to my husband and then we decided what we wanted to do

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

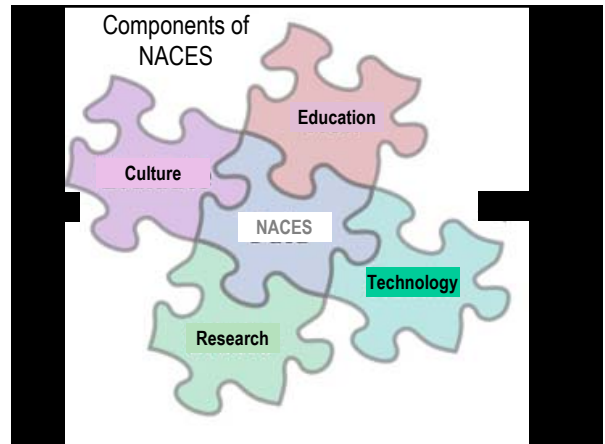
- 📁 Resource for those needing information
- 📁 Research study
- 📁 Culturally specific
- 📁 Inter-tribal
- 📁 Uses the Medicine Wheel



Rosanne Wynnan
Mohawk
Diagnosed 1987, breast / cervical cancer

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.

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

2002		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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Overview of NACES Components

NACES Native Survivors' Advisory Committee

 Dorcas Bloom Siberian Yupik Dx breast cancer 1998	 Dennis Whiterock Navajo Dx 2001 Multiple Myeloma	 Rosanne Wynan Mehawk Diagnosed 1987 uterine / cervix 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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Layout of the Quality of Life Tree Information




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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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Go LIVE online to show how some parts of the online NACES works
<http://www.NatAmCancer.org>

- Code Name
- Survey
- Side Effects Limb
- Side bar:
 - 🌳 Videovignettes
 - 🌳 Story Tellers
 - 🌳 Visitors’ Questions

