


# How to Use “Native American Cancer Education for Survivors” to help Survivors



**Ways to Use “Native American Cancer Education for Survivors” to Help Cancer Patients**

Supported by:  
National Center for Minority Health and Health Disparities

Native Navigators and the Cancer Continuum (NNACC) [NCMHD R24MD002811]


**OBJECTIVES**

By the end of this segment, the community 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.
4. Interact with at least one QOL module in real-time.

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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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**What is NACES?**

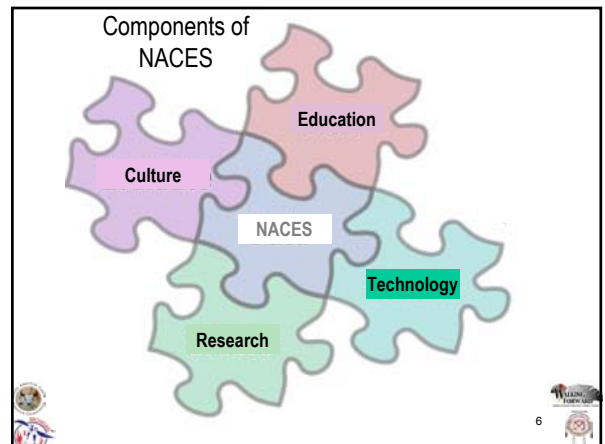
**How can it Help with Local AIAN Cancer Patients**

**What is “Native American Cancer Education for Survivors”?**

- Web-based
- FREE!!
- Quality of life surveys
- Designed for breast cancer patients
  - But has information relevant to patients who have other types of cancer
  - Includes both genders
- Tailored to the individual
- Resource for those needing information
- Research study
- Culturally specific
- Inter-tribal
- Uses the Medicine Wheel and Circle of Life

**“quality of life” – how well you are able to do everything you want to do: physically, mentally, emotionally, and spiritually**

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# How to Use “Native American Cancer Education for Survivors” to help Survivors

How moved to the Internet

## Question asked of community members:

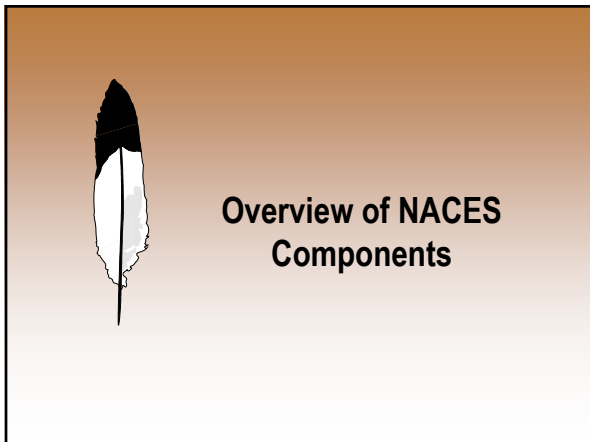
2002	If this information was available on the Internet, would you be able to use it?	2006
15%	1. Yes, I could download the information myself	35%
30%	2. Yes, I could get someone to help me download the information	40%
30%	3. No, I'm not certain if I could get the information	15%
25%	4. No, I do not have access to the Internet	10%

## 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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## 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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# How to Use “Native American Cancer Education for Survivors” to help Survivors

## Denver’s Native Sister 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

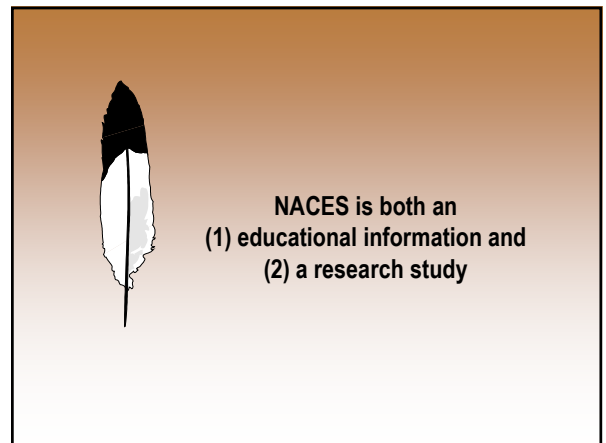
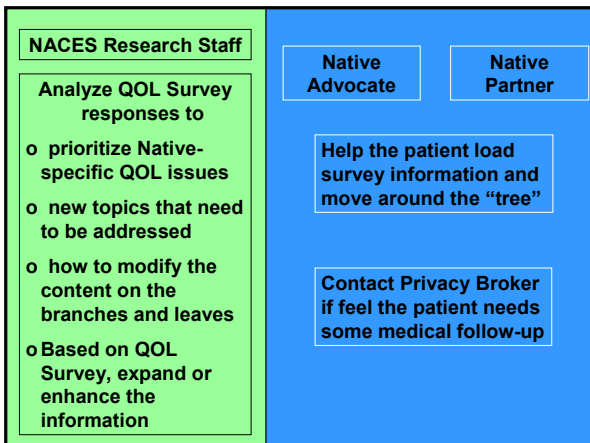
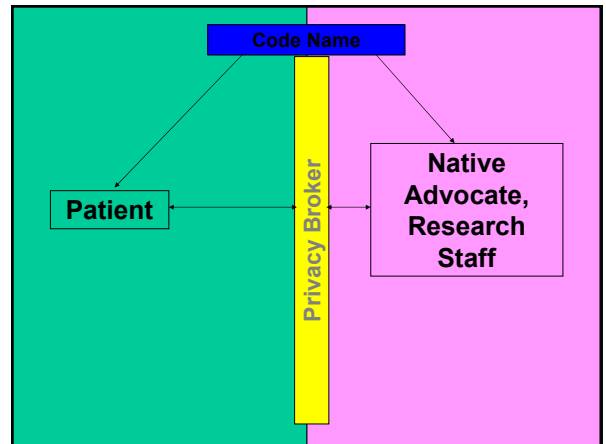
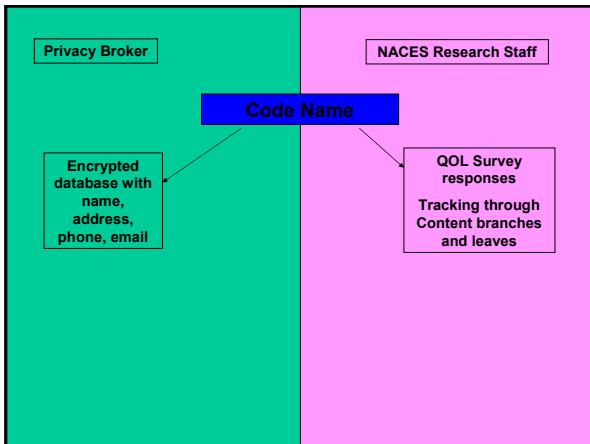


Alice Bradley, MA  
Colorado Springs, CO  
**1-877-838-9359**

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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# How to Use “Native American Cancer Education for Survivors” to help Survivors



## Example of Findings

Anonymous Information

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Overall, do you feel you are \_\_\_\_\_ able to do everything you want to do on a daily basis?

	Phys	Spirit	Soc	Ment
I am never able to do everything I want to do	7.7%	4.1%	4.3%	Ext poor 2.2%
I'm not able to do most things I want to do	27.5%	8.2%	21.5%	Poor 7.5%
I am able to do most things I want to do	41.8%	38.4%	34.4%	Okay 43%
I am able to do everything I want to do	23.1%	49.3%	39.8%	Good 36.6%
				Excellent 10.8%

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## Characteristics

- Diagnosed with breast cancer
  - 34% - not diagnosed (family members)
  - 6.4% - diagnosed with last year
  - 14.9% - diagnosed between 1-4 years ago
  - 44.7% diagnosed more than 5 years ago

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## Characteristics

- Blood Quantum
  - Full blood = 44.4%
  - 75-99% = 12.2%
  - 50-75% = 17.8%
  - 25-49% = 11.1%
  - Less than 25%=14.4%

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## Characteristics

- Education
  - No education / schooling = 9.7%
  - Grade school / elementary = 7.5%
  - Middle / Junior high = 9.7%
  - High School / GED = 24.7%
  - Technical / Apprentice = 7.5%
  - Some college = 24.7%
  - College AA degree = 2.2%
  - College BA, BS degree = 10.8%
  - Masters, Doctorate or more= 3.2%

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## Characteristics

- Told by Health Provider You have Problem:
  - High blood pressure = 45.6%
  - Diabetes =45.6%
  - Arthritis / Rheumatism = 30%
  - Obesity = 33.3%
  - Thyroid = 21.1%
  - Habitual Tobacco Use = 26.2% (not to be confused with ceremonial use)

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# How to Use “Native American Cancer Education for Survivors” to help Survivors

## Characteristics

- 📖 Close blood relative (parent, sibling, children) diagnosed with cancer = 81.6%
- 🗣️ NOTE: BRCA1, BRCA2, her2/neu do not explain this pattern
- 🗣️ Where genetic markers identified in AIANs = none in full-bloods and only 2 in mixed bloods

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## Characteristics

- 📖 How many close blood relative(s) have / had cancer:
  - 🗣️ 1 relative = 32.1%
  - 🗣️ 2 relatives = 21.4%
  - 🗣️ 3 relatives = 16.7%
  - 🗣️ 4 relatives = 7.1%
  - 🗣️ 5 or more relatives = 9.5%
- 📖 Of these blood relatives with cancer
  - 🗣️ 42.4% of the relatives had BREAST cancer
  - 🗣️ 70% diagnosed younger than age 50

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## Characteristics

- 📖 Where do you live?
  - 🗣️ On the reservation = 38.9%
  - 🗣️ In a rural setting, but not on reservation = 18.9%
  - 🗣️ In a city, town, village = 26.3%
  - 🗣️ I move back & forth among city, rez, rural = 15.8%

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## Characteristics

- 📖 How far from your home (one way) did you travel for cancer treatment
  - 🗣️ 0-25 miles = 16.7%
  - 🗣️ 26-50 miles = 11.7%
  - 🗣️ 51-75 miles = 8.3%
  - 🗣️ 76-100 miles = 16.7%
  - 🗣️ 101-200 miles = 20%
  - 🗣️ 201-300 miles = 15%
  - 🗣️ 301-400 miles = 11.7%

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## New Symptoms since Diagnosis

Symptoms	Fatigue	Pain	Memory Problems	Insomnia
Yes	32.6	26.1	16.3	14.1
No	67.4	73.9	87.7	85.9

Body aches = 35.9%  
Changes in concentration = 6.6% (4.4% of overall total – unable to concentrate at all)  
Feeling Moody = 22.8%

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## Symptoms Today

Symptoms	Fatigue	Pain	Concentration	Neuropathy
Not a problem	25.3	52.8	5.5	56.5
Few days a month	30.8	19.1	13.2	27.7
Once a week	11.0	5.6	24.2	5/4
Few days a week	17.6	10.1	49.9	5.4
Every day	15.4	12.4	14.3	12.0

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# How to Use “Native American Cancer Education for Survivors” to help Survivors

## How useful do you feel?

	Overall%
Not at all	14.3
A little useful	19.8
Useful	24.2
Very useful	24.2
Extremely useful	17.6

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## Positive Changes from Having Cancer

	Overall%
Not at all	2.3
A few good changes	6.8
Good changes	21.6
A lot of good changes	33.0
A great deal of positive changes	36.4

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## Feeling Isolated Since Diagnosis

	Overall%
Very isolated/alone	7.8
Occasionally isolated/alone	18.9
Rarely isolated/alone	15.6
Feel okay (not isolated/alone)	35.6
Feel well supported and not isolated /alone	22.2

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<http://www.NatAmCancer.org>



- Code Name
- Survey
- Survivorship Info on the Tree Limbs
- Side bar:
  - Videovignettes
  - Story Tellers
  - Visitors’ Questions
  - Sample Patient Questions
  - Glossary