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)

AIAN Breast Cancer Patterns

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

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

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

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

Breast Cancer Incidence Rates - Females, 1999-2004

Breast Cancer Mortality Rates - Females, 1999-2003

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!
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

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

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!

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

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)

Burhansstipanov, Native American Cancer Research 1-800-537-8295; http://www.NatAmCancer.org; NCI R25 CA 101938; Susan G. Komen for the Cure® #POP0503920; Mayo [NCI U01 CA 114609]
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

Components of NACES

Education

Culture

Research

Technology

Question asked of community members:

(Explains why NACES moved to the Internet)

<table>
<thead>
<tr>
<th>Year</th>
<th>Answer 1</th>
<th>Answer 2</th>
<th>Answer 3</th>
<th>Answer 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>2002</td>
<td>15%</td>
<td>30%</td>
<td>30%</td>
<td>25%</td>
</tr>
<tr>
<td>2007</td>
<td>65.2%</td>
<td>17%</td>
<td>10.7%</td>
<td>4.5%</td>
</tr>
</tbody>
</table>

If this information was available on the Internet, would you be able to use it?

1. Yes, I could download the information myself
2. Yes, I could get someone to help me download the information
3. No, I’m not certain if I could get the information
4. No, I do not have access to the Internet

Burhansstipanov, Native American Cancer Research 1-800-537-8295; http://www.NatAmCancer.org; NCI R25 CA 101938; Susan G. Komen for the Cure® #POP0503920; Mayo [NCI U01 CA 114609]
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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 ... so sort it) and correction of errors
- Addresses access issues by providing Native Partners with laptops and training to help other survivors use the Page

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

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.

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

The Privacy Broker
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)

“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

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.

Code Name and Online Survey

Patients click on leaves in the site. The hummingbird appears next to the current leaf being viewed.

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