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

1. Describe how the NACES (Native American Cancer Education for Survivors), a web based public health education program, can be adapted to improve the cancer survivors quality of life, particularly in those populations who are underserved or live with disparities.

What is NACES?

- 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
- FREE!!

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

Born 1962
Passed January 22, 2008
Dear Ed, we miss you and we honor you
**What is “Native American Cancer Education for Survivors”?**

- Resource for those needing information
- Research study
- Culturally specific
- Inter-tribal
- Uses the Medicine Wheel and Circle of Life

**Research Question**

Does a culturally relevant cancer intervention that can be adapted by the individual Native American cancer patient to address personal needs, increase access to and utilization of resources that improve the Native American survivor’s quality of life (QOL)?

**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:**

- Originally for Native American breast cancer patients, Advocates and families
- To give information that may help improve the patient’s quality of life.
- Expanded in 2007 to include:
  - Indigenous peoples from all Nations
  - Information that may be useful for those with other types of cancer

**Layout of the Quality of Life Tree Information**
“Native American Cancer Education for Survivors” (NACES)

NACES Native Survivors’ Advisory Committee

NACES 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)

NACES Data

318 surveys (taken offline June 2nd for updates/refinements until July 1st)

Most implemented with a “Native Advocate”

Question: How much of an impact does the Native Advocate have on data collection?

Most of the surveys are from OK and AZ = two dynamic Advocates

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

<table>
<thead>
<tr>
<th></th>
<th>Phys</th>
<th>Spirit</th>
<th>Soc</th>
<th>Ment</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am never able to do everything I want to do</td>
<td>7.7%</td>
<td>4.1%</td>
<td>4.3%</td>
<td>Ext poor 2.2%</td>
</tr>
<tr>
<td>I’m not able to do most things I want to do</td>
<td>27.5%</td>
<td>8.2%</td>
<td>21.5%</td>
<td>Poor 7.5%</td>
</tr>
<tr>
<td>I am able to do most things I want to do</td>
<td>41.8%</td>
<td>38.4%</td>
<td>34.4%</td>
<td>Okay 43%</td>
</tr>
<tr>
<td>I am able to do everything I want to do</td>
<td>23.1%</td>
<td>49.3%</td>
<td>39.8%</td>
<td>Good 36.6%</td>
</tr>
<tr>
<td></td>
<td>4.3%</td>
<td>8.2%</td>
<td>4.1%</td>
<td>Ext poor 2.2%</td>
</tr>
</tbody>
</table>

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

Characteristics

Age

- 1910-1919 = 2.2%
- 1920-1929 = 1.1%
- 1930-1939 = 9.8%
- 1940-1949 = 32.6%
- 1950-1959 = 41.3%
- 1960-1969 = 8.7%
- 1970-1979 = 1.1%
- 1980-1989 = 3.3%
Characteristics

Blood Quantum

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

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%

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)

Characteristics

Close blood relative (parent, sibling, children) diagnosed with cancer = 81.6%

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%

Characteristics

Of these blood relatives with cancer

- 42.4% of the relatives had BREAST cancer
- 70% diagnosed younger than age 50

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%
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%
- Move back & forth among city, rez, rural = 15.8%

New Symptoms since Diagnosis

<table>
<thead>
<tr>
<th>Symptoms</th>
<th>Fatigue</th>
<th>Pain</th>
<th>Memory Problems</th>
<th>Insomnia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>32.6</td>
<td>26.1</td>
<td>16.3</td>
<td>14.1</td>
</tr>
<tr>
<td>No</td>
<td>67.4</td>
<td>73.9</td>
<td>87.7</td>
<td>85.9</td>
</tr>
</tbody>
</table>

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

Symptoms Today

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

To what degree do you feel non-Native providers control your cancer?

<table>
<thead>
<tr>
<th>Level of Control</th>
<th>Overall %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all</td>
<td>18.2</td>
</tr>
<tr>
<td>Little</td>
<td>8</td>
</tr>
<tr>
<td>Fair</td>
<td>18.2</td>
</tr>
<tr>
<td>Good</td>
<td>35.2</td>
</tr>
<tr>
<td>Completely</td>
<td>18.9</td>
</tr>
</tbody>
</table>

How useful do you feel?

<table>
<thead>
<tr>
<th>Overall%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all</td>
</tr>
<tr>
<td>A little useful</td>
</tr>
<tr>
<td>useful</td>
</tr>
<tr>
<td>Very useful</td>
</tr>
<tr>
<td>Extremely useful</td>
</tr>
</tbody>
</table>

Positive Changes from Having Cancer

<table>
<thead>
<tr>
<th>Overall%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all</td>
</tr>
<tr>
<td>A few good changes</td>
</tr>
<tr>
<td>Good changes</td>
</tr>
<tr>
<td>A lot of good changes</td>
</tr>
<tr>
<td>A great deal of positive changes</td>
</tr>
</tbody>
</table>

“Native American Cancer Education for Survivors” (NACES)
“Native American Cancer Education for Survivors” (NACES)

Feeling Isolated Since Diagnosis

<table>
<thead>
<tr>
<th>Feeling</th>
<th>Overall%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very isolated/alone</td>
<td>7.8</td>
</tr>
<tr>
<td>Occasionally isolated/alone</td>
<td>18.9</td>
</tr>
<tr>
<td>Rarely isolated/alone</td>
<td>15.6</td>
</tr>
<tr>
<td>Feel okay (not isolated/alone)</td>
<td>35.6</td>
</tr>
<tr>
<td>Feel well supported and not isolated</td>
<td>22.2</td>
</tr>
</tbody>
</table>

To Join the Study, go to http://www.NatAmCancer.org and click on tree

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

Native American Cancer Research 303-838-9359; http://NatAmCancer.org