



The American Indian Cancer Collaborative for Women's Health [U57 DP001138]
Demographics, Historical Trauma, Racial Misclassification, Cancer Data, Barriers

Building Relationships with Native American Populations

American Indian / Alaska Native (AIAN) Cultural Workshop for Public Health Professionals [CDC U57 DP001138]

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Native American Cancer Research 303-838-9359 <http://www.NatAmCancer.org>

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Objective 1: by the end of this session, the participant will be able to:

- Summarize the need for culturally appropriate actions based on the historical perspective of Native American populations



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Introduction



What is "an Indian" and how do we differ from other medically under-served communities?

American Indian = AI
Alaska Native = AN

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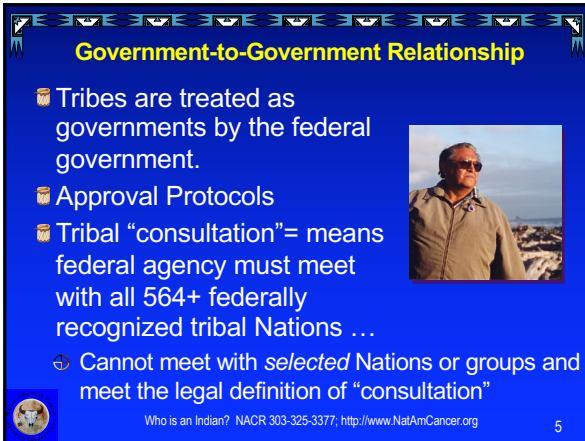


Tribal Sovereignty

- Tribes are governments that have authority with regard to their members
- Tribes existed prior to the U.S.
- Tribal Nations made treaties with colonial powers, states, and the U.S.
- Nations within a nation

Who is an Indian? NACR 303-325-3377; <http://www.NatAmCancer.org>

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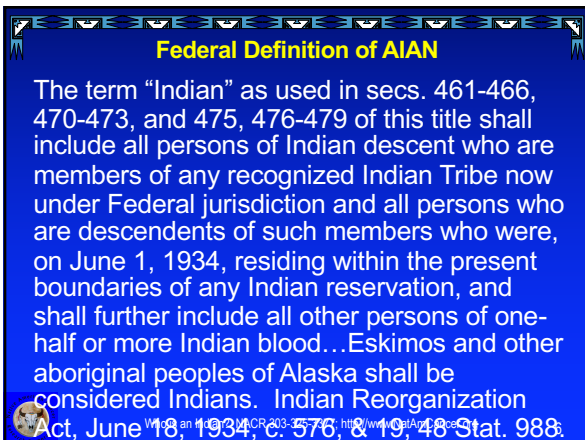


Government-to-Government Relationship

- Tribes are treated as governments by the federal government.
- Approval Protocols
- Tribal "consultation"= means federal agency must meet with all 564+ federally recognized tribal Nations ...
- Cannot meet with *selected* Nations or groups and meet the legal definition of "consultation"

Who is an Indian? NACR 303-325-3377; <http://www.NatAmCancer.org>

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Federal Definition of AIAN

The term "Indian" as used in secs. 461-466, 470-473, and 475, 476-479 of this title shall include all persons of Indian descent who are members of any recognized Indian Tribe now under Federal jurisdiction and all persons who are descendents of such members who were, on June 1, 1934, residing within the present boundaries of any Indian reservation, and shall further include all other persons of one-half or more Indian blood...Eskimos and other aboriginal peoples of Alaska shall be considered Indians. Indian Reorganization Act, June 18, 1934, c. 576, & 49, 48 Stat. 988.

Who is an Indian? NACR 303-325-3377; <http://www.NatAmCancer.org>

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How does the Federal Government Identify AIANs?

- Tribes establish criteria for membership
 - 1/4 tribal blood is the Bureau of Indian Affairs (BIA) Standard
 - A descendant of a tribal member
 - Or a person recognized by the tribal members as a member.
- Alaska Native: The term collectively refers to Eskimos, Aleuts, and American Indians who are indigenous to Alaska.

Who is an Indian? NACR 303-325-3377; <http://www.NatAmCancer.org>

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Self-Identified Data Sources

"American Indian" This includes enrolled members of Federal and/or State recognized tribes as well as people who identify themselves as "American Indian". Includes surveys such as:

- U.S. Census
- Behavioral Risk Factor Surveillance Survey (BRFSS) and Youth Risk Behavior Survey (YRBS)
- National Health Interview Survey

Who is an Indian? NACR 303-325-3377; <http://www.NatAmCancer.org>

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What are the differences in the American Indians history?

- Since the formation of the union, the U.S. has recognized Tribal governments as sovereign nations
- The federal government has enacted numerous statutes and regulations that establish and define who an Indian is and their relationship to the federal government

Thank you, Lauren Tancona, CDC for the use of the slide

Who is an Indian? NACR 303-325-3377; <http://www.NatAmCancer.org>

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Indians are not just . . .


. . . a minority

. . . a special interest group

. . . a political party

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Who is an Indian? NACR 303-325-3377; <http://www.NatAmCancer.org>

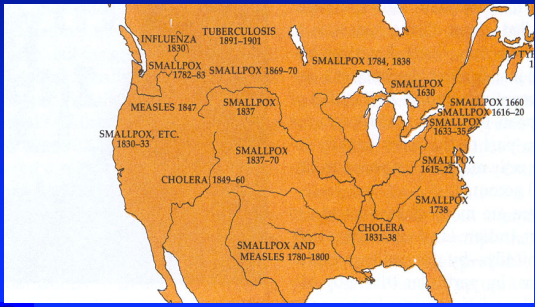
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**Brief overview of AIAN
Historical Events as Basis
of Distrust of Government
and its Programs**

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**Early Diseases
After European Contact**




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Manifest Destiny Adopted as Federal Policy


".... It is the right of our manifest destiny to over spread and to possess the whole of the continent which Providence has given us for the development of the great experiment of liberty and federative development of self government entrusted to us. It is right such as that of the tree to the space of air and the earth suitable for the full expansion of its principle and destiny of growth."

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Federal Indian Policy

- 1608-1830 Treaty Making
- 1830-1850 Removal Policy
- 1850-1871 Establishment of Reservations
- 1871-1928 Assimilation and Allotment Era
- Indian Reorganization Act of 1934
- 1943 – 1968 Termination
- 1968 – Present – Self Determination

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Removal Policy: Eastern Tribes

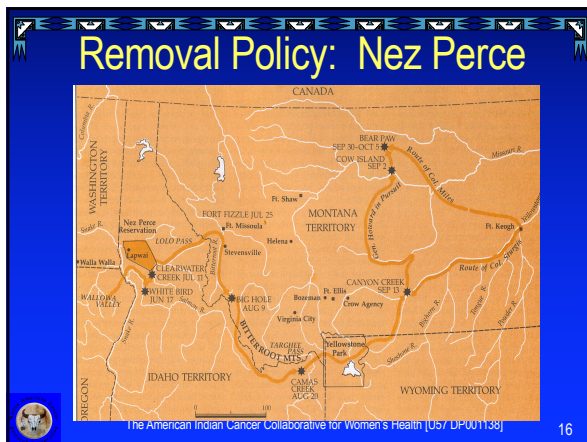


How many tribal Nations were included in the "Trail of Tears"?

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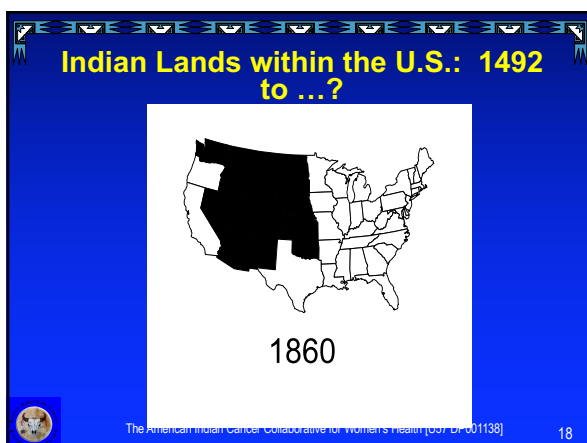
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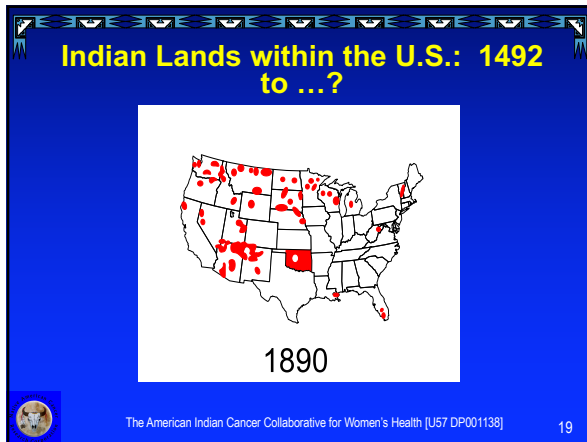


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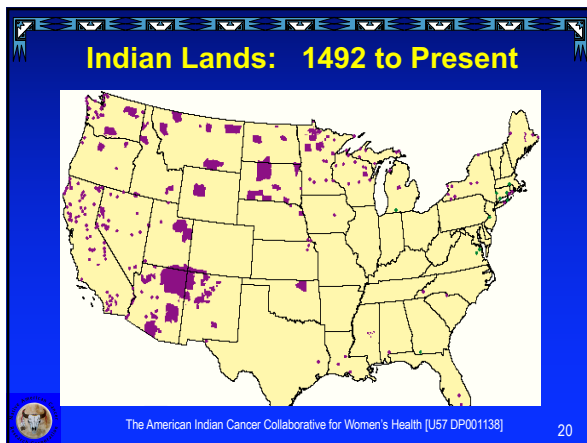


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Indian Boarding School System

- Existed between 1870 - PRESENT
- Movement attributed to Manifest Destiny philosophy
- Mission:** to educate Indian children and assimilate them into the European language and culture.

Thank you, Dean Seneca, MPH, MCURP, Office of Tribal Affairs ATSDR, CDC, for sharing this slide
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Apache Children at Carlisle Indian School

PHOTOGRAPH BY U.S. ARMY SIGNAL CORPS. COURTESY OF THE ARIZONA HISTORICAL FOUNDATION

PHOTOGRAPH BY U.S. ARMY SIGNAL CORPS. COURTESY OF THE ARIZONA HISTORICAL FOUNDATION

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Characteristics of the Boarding School Experience

- Forced separation of children from communities
- Physical, sexual, emotional abuse by caretakers
- Exposure to infectious diseases, resulting in illness and death


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Characteristics of the Boarding School Experience (cont.)

- Extreme diet changes.
- Children who didn't go home, took on the characteristics of their caretakers.



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Key Points In Indian History

- 1802 - War Department
- 1824 - Bureau of Indian Affairs (BIA)
- 1849 - BIA moved under Department of Interior
- 1887-The General Allotment or Dawes Act
- 1924 - Indian Citizenship Act of 1924 (41 Stat. 408)
- 1934 - Indian Reorganization Act
- 1940's – 1980's Indians fought for the right to vote
- 1953 - Termination Act
- 1968 – Self-Determination (PL 93 -638)

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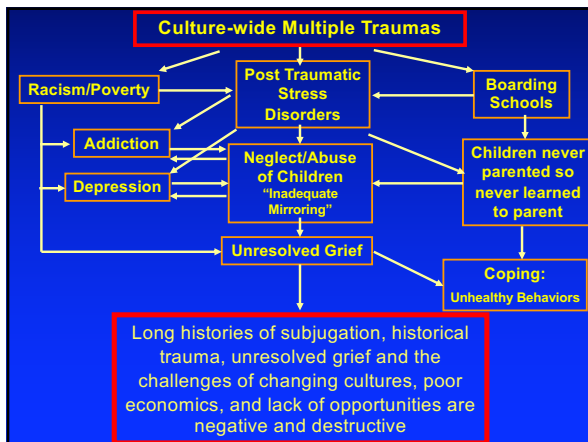
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Many Contemporary (within last 35 years) Events

- 1968 American Indian Movement and Alcatraz Island – reclaiming disserted federal lands as per federal law
- 1970's sterilization of American Indian women without informed consent
- Many other events (NY / Canada Mohawk siege; Rosebud; Wounded Knee (recent event, not the original event)

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How May Historical Trauma Affect AIANs Use Of The Healthcare System?

- Example: distrust = avoid Western medicine
- What are specific examples related to cancer?
- Cancer clinical trials (especially treatment trials)
- Cancer genetic studies

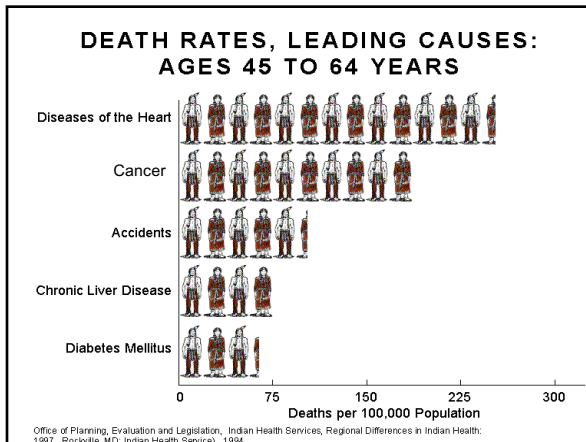
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Sub-Objective:
Distinguish among factors affecting AIAN racial misclassification.

[Note: Results in under-counting of AIAN health / cancer issues that subsequently results in under-funding of AIAN programs]

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"Statistics are merely aggregations of numbers with the tears wiped away."

Dr. Irving Selikoff

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Cancer Data Issues

- Collapsing the diverse smaller population groups into an "other" racial category ... "Other" racial data
 - Lose all racially specific information and cultural relevance
 - "Are of no use when attempting to develop, assess, and monitor public health programs and services" LB

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Most Common Reasons for Racial Misclassification

The Department of Finance Racial Definition is based on Spanish surnames. This results in statistically significant under-counting of AIANs.

medical records (e.g., hospital, health clinic)

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Most Common Reasons for Racial Misclassification


4. Imprecise and inconsistent definitions of AI
5. Changing self-identification
6. Tribe formerly "unrecognized"

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Most Common Reasons for Racial Misclassification

7. Tribal enrollment blood % ordinances changing
8. Tribal enrollment ordinances re: Paternal or Maternal lineage

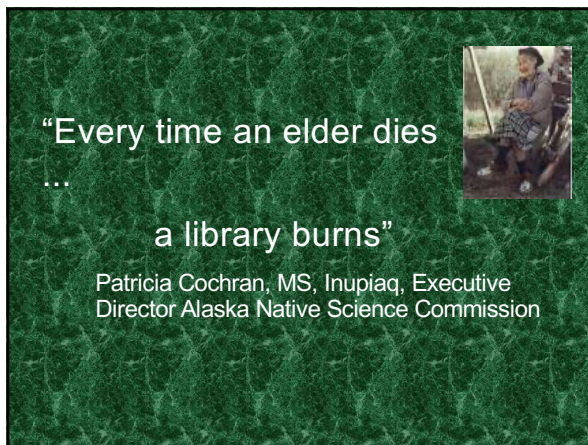
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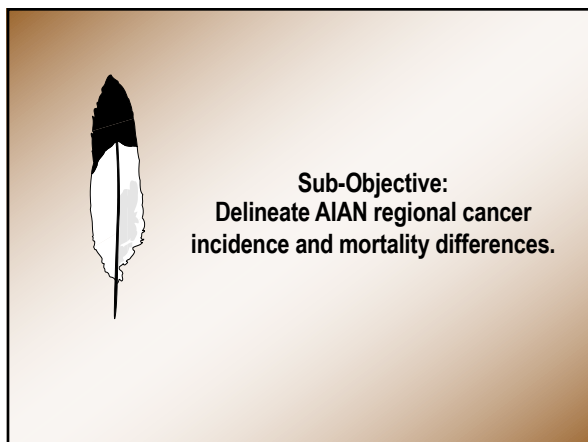
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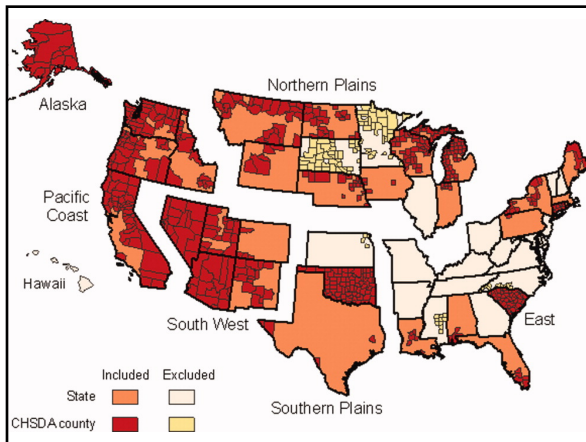


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AIAN Cancer Incidence Data (finally) THANK YOU!

CHSDA Counties = IHS Contract Health Service Deliver Areas

COMMENTARY

Annual Report to the Nation on the Status of Cancer, 1975-2004, Featuring Cancer in American Indians and Alaska Natives

David K. Henry, *ed.*¹
 David Cheng, *ed.*²
 Judith S. Davis, *ed.*³
 Elizabeth W. Holly, *ed.*⁴
 Elizabeth W. Holly, *ed.*⁵
 Philip A. Reilly, *ed.*⁶
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 Barry A. Wilos, *ed.*⁹
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 Richard Wilos, *ed.*¹¹
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⁷ Division of Cancer Prevention and Control, National Cancer Institute, Bethesda, Maryland
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¹³ Division of Cancer Prevention and Control, National Cancer Institute, Bethesda, Maryland

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	US		So. Plains		No Plains	
	AIAN	NHW	AIAN	NHW	AIAN	NHW
All	368.4	475.9	492.6	461.2	538.1	464.8
Breast	85.3	134.4	115.7	129.6	115.9	130.3
Cervix	9.4	7.4	14.1	9.1	12.5	7.4
Colon	46.3	50.8	60.2	51.8	72.5	52.3
Kidney	17.9	11.8	21.3	12.4	23.7	12.1
Lung	48.5	58.6	87.1	82.2	104.3	65.5
Prostate	105.4	154.4	156.7	146.5	174.5	162.2

Source: Cancer registries in Centers for Disease Control and Prevention's (CDC) National Program of Cancer Registries (NPCR) and National Cancer Institute's (NCI) Surveillance, Epidemiology, and End Results Program (SEER). D. Espey, Monograph Group.

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i-3377; Native American Cancer Research
w.NatAmCancer.org

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2007 Annual Report to the Nation

- Cancer incidence among AI/AN's, though generally lower than for the Non-Hispanic White (NHW) population, is rising rapidly
- In 3 of the twelve regions of the Indian Health Service, cancer incidence rates are equal to that of the dominant white population
 - Alaska
 - Northern Plains (IL, IN, IA, MI, MN, MT, NE, ND, SD, WI, WY)

Steele CB, Cardinez CJ, Richardson LC, Tom-Orme L, Shaw K. Surveillance for Health Behaviors of American Indians and Alaska Natives—Findings from the Behavioral Risk Factor Surveillance System, 2000-2006. *CANCER* 2008, in press. The American Indian Cancer Collaborative for Women's Health [U57 DP001138]

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IHS Health Risk Factor Data (BRFSS, 2000-2006)

- Current Smoker
 - US
 - 22.8% NHW
 - 31% AIAN
 - Southern Plains Region
 - 33.2%
 - Northern Plains Region
 - 40.1%

Steele CB, Cardinez CJ, Richardson LC, Tom-Orme L, Shaw K. Surveillance for Health Behaviors of American Indians and Alaska Natives—Findings from the Behavioral Risk Factor Surveillance System, 2000-2006. *CANCER* 2008, in press. The American Indian Cancer Collaborative for Women's Health [U57 DP001138]

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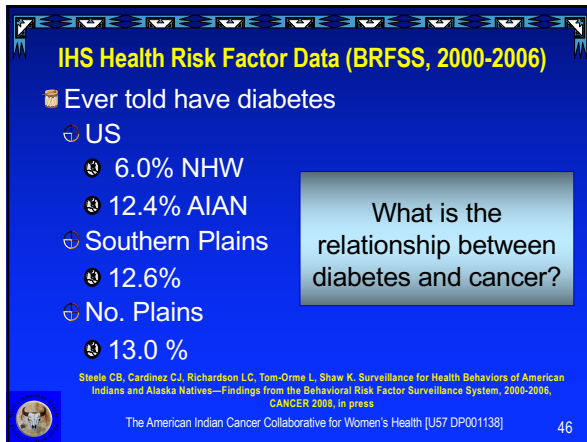
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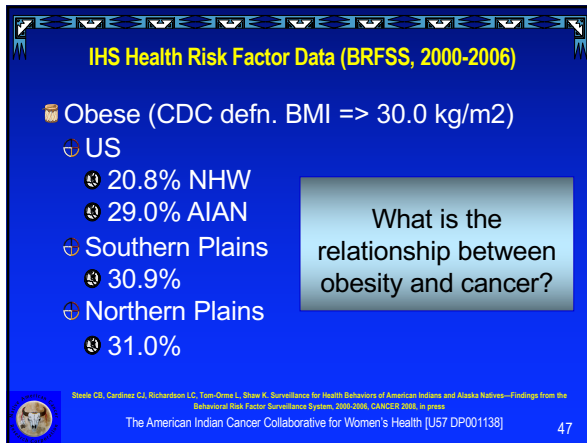
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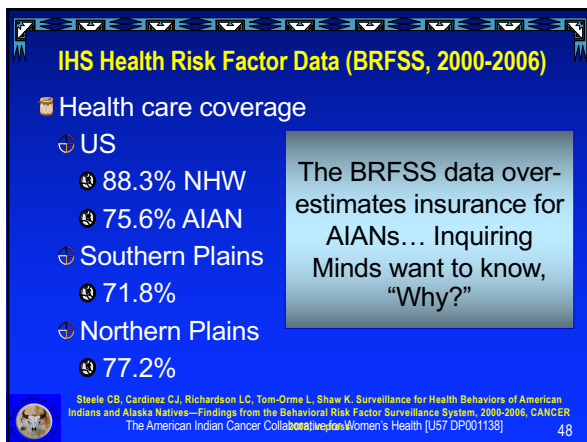
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IHS Health Risk Factor Data (BRFSS, 2000-2006)

 Pap Screening with past 3 years, All women 18+ (w/o hysterectomy):

-  US
 -  84% NHW
 -  78% AIAN
-  S. Plains 74%
-  N. Plains 80.4%


What was the Pap percentage prior to the screening guidelines changing?






Steele CB, Cardinez CJ, Richardson LG, Tom-Orme L, Shaw K. Surveillance for Health Behaviors of American Indians and Alaska Natives—Findings from the Behavioral Risk Factor Surveillance System, 2000-2006. *CANCER* 2008, in press

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IHS Health Risk Factor Data (BRFSS, 2000-2006)

 Mammogram within past 2 years among women aged 40+:


-  US
 -  76% NHW
 -  69.4% AIAN
-  S. Plains 66.4%
-  N. Plains 67.9%


Steele CB, Cardinez CJ, Richardson LG, Tom-Orme L, Shaw K. Surveillance for Health Behaviors of American Indians and Alaska Natives—Findings from the Behavioral Risk Factor Surveillance System, 2000-2006. *CANCER* 2008, in press

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IHS Cancer Mortality

 Note cancers other than breast, cervix, colon, lung and prostate

 This is why AIAN comprehensive cancer plans cannot be limited to only those sites!

Cancer Mortality among American Indians and Alaska Natives: Regional Differences, 1999-2003

Donald Hoverkamp, MPH*
David Espey, MD**
Roberta Paisano, MHSA***
Nathaniel Cobb, MD***

* Mr. Hoverkamp is assigned to the IHS Division of Epidemiology and Disease Prevention from the Public Health Prevention Service, Office of Workforce and Career Development, Centers for Disease Control and Prevention, DHHS.
** Dr. Espey is assigned to the IHS Division of Epidemiology and Disease Prevention from the Division of Cancer Prevention and Control, National Cancer Institute, Centers for Disease Control and Prevention, DHHS.
*** Ms. Paisano and Dr. Cobb work for the IHS Division of Epidemiology and Disease Prevention.

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Table 1: Definition of geographic regions, corresponding IHS service population, total AI/AN population of states included in regions, and service population percentage for the period 1999-2003.

Geographic Region	IHS Service Population estimates*	Total AI/AN population estimates	Serv. Pop. % of total AI/AN	States (IHS Administrative Areas)
Alaska	108,462	108,462	100%	AK (Alaska)
East	103,149	682,523	15.1 %	AL, AR, CT, DE, FL, GA, KY, LA, ME, MD, MA, MS, MO, NH, NJ, NY, NC, OH, PA, RI, SC, TN, VT, VA, WV, DC (Nashville)
Southwest	520,437	597,299	87.1 %	AZ, CO, NV, NM, UT (Albuquerque, Navajo, Phoenix, Tucson)
All Regions Combined	1,694,439	3,007,510	56.3 %	

* All population figures are derived from intercensal estimates and annualized for the period 1999-2003 (updated 2/06).

Haverkamp et al, Cancer Mortality among AIAN: Regional Differences, 199-2003, IHS, Rockville, MD 2008

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IHS Mortality Data (best of any federal database, but still has limitations)

- Note the % of AIANs summarized in report is extreme overestimate
 - 64+% live in urban areas and those data are not included in the reports
 - limited to AIANs WHO USE IHS CLINICAL FACILITIES WITH PREVIOUS 3 YEARS
- Note the horizontal scale fluctuates for each cancer site and can be misleading

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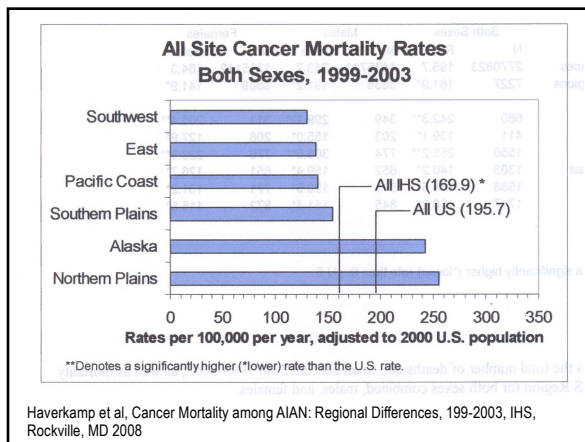
Omissions

- Note: both childhood and adult leukemia increasing among AIAN
 - Childhood under-reported due to children not admitted to a Children's Hospital and symptoms misdiagnosed as diabetes
 - Brain cancer increasing among all races

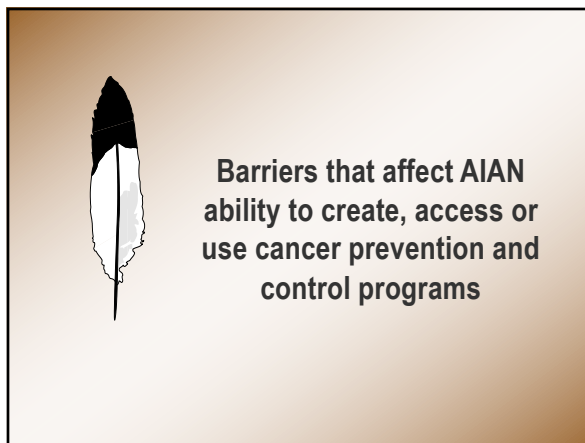
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Which of the following cancer outreach and screening barriers with AIAN communities is one of the only issues that has changed significantly in the last 20 years?


1. Transportation issues
2. Language issues
3. Healthcare system
4. Provider issues
5. Data issues

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Which of the following cancer outreach and screening barriers with AIAN communities is one of the only issues that has changed significantly in the last 20 years?


1. Transportation issues
2. Language issues
3. Healthcare system issues
4. Provider issues
5. Don't know / not sure

 Cancer Program Barriers – Native American Cancer Research <http://NatAmCancer.org> 58


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Linda B's Barriers' Research Tirade

 LB Pet Peeve: wasting limited cancer monies on creating yet another study to list barriers that are documented in more than 100 reports and studies


 The only barriers that have changed in last 20 years are:


- Internet (access to info and resources)
- Healthcare System (or lack of insurance)

 Cancer Program Barriers – Native American Cancer Research <http://NatAmCancer.org> 59


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Linda B's Barriers Tirade

 Public Health Professionals AND COMMUNITY MEMBERS *KNOW* the barriers

 We do NOT know how to address the barriers in culturally respectful strategies

- The strategies vary for each local community and require local tailoring of the interventions to address the barriers

 Please do not waste limited tax dollars to fund any more studies of barriers that are already well documented

 Cancer Program Barriers – Native American Cancer Research <http://NatAmCancer.org> 60

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Linda B's Barriers Tirade (continued)

- For those who feel the need to see SOME of the barriers' research findings, they are listed on the NACR website.
- Because these findings are incredibly old and over-reported, we will not spend any time discussing these unless a participant needs clarification of what the finding means related in Indian Country issues


 Cancer Program Barriers – Native American Cancer Research <http://NatAmCancer.org> 61

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Objective 2: by the end of this session, the participant will be able to:

- Identify health service systems and delivery methods available to Native American populations (includes patterns, IHS CHS, effective messaging, materials development, and literacy issues)

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Examples of Different Cancer Patterns

Disparities

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Examples of Different Patterns of Cancer Sites and Access


- More cancers among AIANs who live in Alaska, Northern Plains and Southern Plains
- BUT, even in Southwest, selected types of cancer continuing to increase
- Burden of disease is extreme
- Average interval from biopsy (diagnosis) to initiation of cancer care is 6 months for AIAN women and 9 months for AIAN males

 AIAN Cancer Misconceptions 64

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Examples of Different Patterns of Cancer Sites and Access (cont.)


- Average age of AIAN population is younger in comparison to US All Races and our people are diagnosed at younger ages
 - 1/2 of AIAN breast patients younger than 50
- Co-morbidity
 - 15%-25% of AIAN cancer patients are diabetic

 AIAN Cancer Misconceptions 65

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Examples of Different Patterns of Cancer Sites and Access (cont.)


- Access to cancer resources outside of IHS / Tribal / Urban clinical settings insufficient or non-existent
 - 1/2 of AIAN cancer patients fight for Medicaid (young at time of dx) or Medicare

 AIAN Cancer Misconceptions 66

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Examples of Different Patterns of Cancer Sites and Access (cont.)


- 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

 AIAN Cancer Misconceptions 67


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Examples of Different Patterns of Cancer Sites and Access (cont.)

- Different Types of Cancer by Geographic Region and Tribal Nation; such as:
 - More stomach, kidney and gallbladder among southwestern tribal nations
 - More CRC, breast and lung among AK, northern plains and southern plains
 - Prostate cancer among northern plains comparable to african americans and whites

 AIAN Cancer Misconceptions 68

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Examples of Issues that Directly Affect AIAN Cancer Programs

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Distrust of IHS

I've always had private insurance, because I don't trust some of the stuff that comes from IHS, and I didn't want to fall into contract care.




Doug Six Killers St. Clair
[Cherokee / Shoshone]
Dx 1990 Lymphoma

AIAN Cancer Misconceptions 70

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Need to Understand "Cancer" Before We Can Understand "Treatments"

She told her husband but the husband didn't quite understand what cancer was all about.




Dominga Rosetta
[Santo Domingo Pueblo]
Dx 1991 Breast

AIAN Cancer Misconceptions 71

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Good Patient-doctor Relationships

Well, Dr. Palmer wanted to make sure and the family fell in love with him because he was so good to me. That we adopted him, and so he likes the idea of being adopted.



Rosa L. Miller
[Tlingit / Auk Kwan]
Dx 1984 Breast

AIAN Cancer Misconceptions 72

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Demographics, Historical Trauma, Racial Misclassification, Cancer Data, Barriers

Mutually Respectful Relationship

I interviewed my doctors, and he put that down in my notes, she's looking for a doctor and is interviewing the doctor... I wanted to be on the same level with them spiritually and for them to respect what I want it and to give him the same respect and accepting what I expected of him... I was just pretty blunt; I said do you believe in God because he is




Mary Nance
[Kickapoo / Hispanic]
Dx 2000 Breast

AIAN Cancer Misconceptions 73

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Need Social Support

So I went through my treatment alone, and that was the hardest thing... thing to do. I think for someone to go through chemo treatment and radiation. It would be very good if they had... have somebody there with them... to help talk to the doctors especially




Dilly Adsuna
[Alaska Native]
Dx 2003 Breast

AIAN Cancer Misconceptions 74

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Decision Makers

I'm a little bit more traditional than a lot of other people, and I don't make the decisions that impact my life. I always look to the oldest female that's there, and the doctors were getting very, very frustrated with me, because I'd always look to my mother, and they would tell my mother to leave the room. So we had a little pow wow with the doctors, and I told the doctors that they needed to talk to my mother, and then my mother would talk to me and then she would tell me and she would advise me. So we were able to educate the doctors a little bit to be a little bit more culturally appropriate.



Doug Six Killers St. Clair
[Cherokee / Shoshone]
Dx 1990 Lymphoma


AIAN Cancer Misconceptions 75

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Demographics, Historical Trauma, Racial Misclassification, Cancer Data, Barriers

Distrust Issues / Historical Trauma

There is mistrust of the medical community historical trauma associated with federal programs including medical. For example, the genocidal policies of the 16th 17th and 18th hundredths included but not limited to intentional smallpox release for the harm and destruction of many induced indigenous




Lorraine "Punkin" Shanaguet
[Pottawatomie / Ojibwe]
Advocate

76

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Doctors Need To Listen

[my husband] took me back to the doctor and... and the doctor said, "you're having a stroke were going to send you to a stroke doctor". We tried to tell him I was not having a stroke... my husband tried to tell them my... her... body is just over drugged from all these medications that they're giving her with... with an empty stomach. But they




Dorcas Bloom
[Siberian Yupik]
Dx 1998 Breast

77

77

Doctor Misdiagnosed Condition And Fought With Oncologists About Treatments

I said I got one question for you, did you um, put radiation on three and that you know the three-inch tumor or did you radiate my entire right pelvis, and he told me "I didn't know."




Dennis Whiterock
[Navajo]
Dx 2001 Multiple Myeloma

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Lack of Access to Quality Care

At that time I thought I had excellent care, the best I could possibly get. When I look back in another time frame of how things happen and my family physician for example, I had complete faith in him, but two years ago I had to quit him. It turned out that he wasn't the best that I thought. There were little things that fell through the cracks




Rosanne Wyman
[Mohawk]
Dx 1987 Cervix

AIAN Cancer Misconceptions 79

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Well-Educated AIANs May Not Have Insurance

"I don't have money to pay the co-pay for my insurance"




CeCe Whitewolf
[Confederated Tribes of Umatilla]
Dx 1998 Breast

AIAN Cancer Misconceptions 80

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Long Delays to Access Care

I saw him and he told me he wouldn't be available to do the needle biopsy until 4 weeks ... I waited for 6 weeks. It was a very stressful 6 weeks. So the day of my surgery... as I arrived they told me "didn't anyone tell you, the surgery was canceled." I broke down and cried because no one could tell me what was going on. I didn't ask and that was my problem. I want to tell



Arlene Wahwasuck
[Prairie Band Potawatomi]
Dx 2002 Breast

AIAN Cancer Misconceptions 81

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Less than 5% AIAN Patients Recall Ever Hearing The Phrase, "Clinical Trial"

- Providers need to DISCUSS clinical trials with patients
- Cannot assume that we will not be compliant
- We do need hospital to pay for medications and transportation for us to participate
- Need variations in some protocols




Maxine Brings
Him Back Janis
[Oglala Lakota]
Dx 1978 Cervix
Dx 2002 Breast

AIAN Cancer Misconceptions 82

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Humor vs. "Stoic" Stereotype

Your muscles are all achy. So my mother told me she'd give me a back rub. She brought this tube in and she opened it and she started to put it on my back. It was toothpaste.



Martha J. Red Willow
[Oglala Sioux]
Dx 1989 Breast

AIAN Cancer Misconceptions 83

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National Indian Gaming Association

Contrary to common misinformation, Indian Gaming provides little to no money to AIAN communities for cancer care

84
Native
Assoc.

Sovereignty and Gaming



- Only a small percent of tribes having gaming.
- Of those who do, many have successfully used resources to build community infrastructure.

AIAN Cancer Misconceptions 85

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Sovereignty and Gaming




- Most tribes are still
 - Small, rural,
 - Greatly lacking in having resources or capacity to meet the health and public health needs of their people

AIAN Cancer Misconceptions 86

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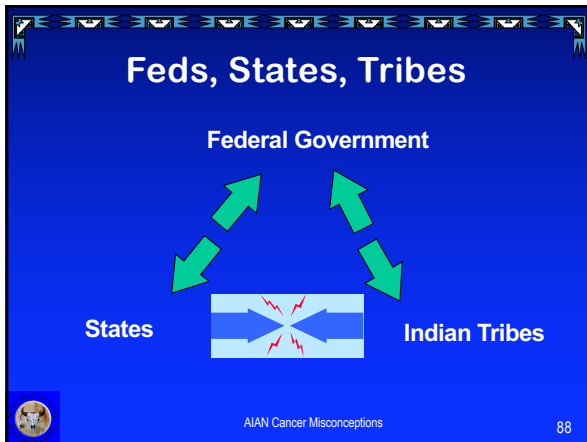
State and AIAN Tribal and Urban Program Relationships



- Varies greatly from state to state and from tribe to tribe within the same state;
- Basically, the tribal Nations are totally independent of one another.
- Same is true for urban Indian clinics

87
Native
Assoc.

The American Indian Cancer Collaborative for Women's Health [U57 DP001138]
 Demographics, Historical Trauma, Racial Misclassification, Cancer Data, Barriers



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Tribal – State Relationships

Many challenges and barriers:

- ⊕ Jurisdictional and legal authority issues
- ⊕ Data ownership and transfer barriers
- ⊕ Revenue base
- ⊕ Gaming myths/realities/controversies
- ⊕ AIANs pay income taxes and state taxes; state roads run through Indian lands


AIAN Cancer Misconceptions 89

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 Native
 Assoc.

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Indian Health Service Today

The mission of Indian Health Services is to, "provide a comprehensive health services delivery system for American Indians and Alaska Natives with opportunity for maximum Tribal involvement in developing and managing programs to meet their health needs. . .and act as the principal Federal health advocate for AI/AN people. . ."

AIAN Cancer Misconceptions

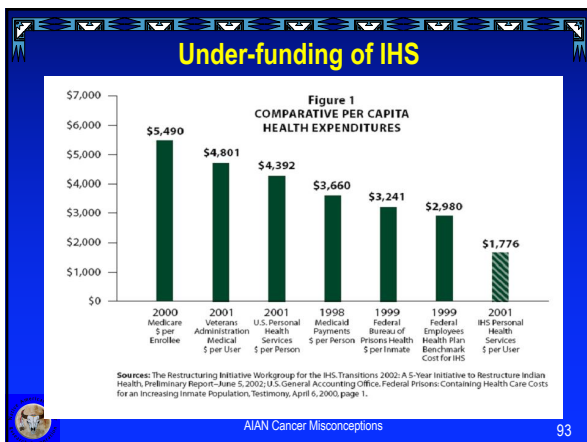
91

91

Which has the lowest per capita health benefits?

1. Medicare
2. Veterans Administration
3. IHS
4. Federal Bureau of Prisons
5. Don't know / not sure

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Demographics, Historical Trauma, Racial Misclassification, Cancer Data, Barriers

Indian Health Service Today


NOTE: When working with AIAN breast cancer patient, have to negotiate with Medicaid / Medicare and IHS regarding *who* is the payer of last resource. Both Agencies claim to be the "last payer".

 AIAN Cancer Misconceptions 94

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Benefits of Indian Health Service, Tribal / Urban Systems


- Health delivery system/Healthcare – *no fee*
- IHS- emphasizes "public health" and not limited to medical care- ex. Mental health
- CDC tribal funded programs (ranged from 9 to 17 since 1995)
- Community Health Representative (CHR) is a precursor to contemporary Navigator programs

 AIAN Cancer Misconceptions 95

95

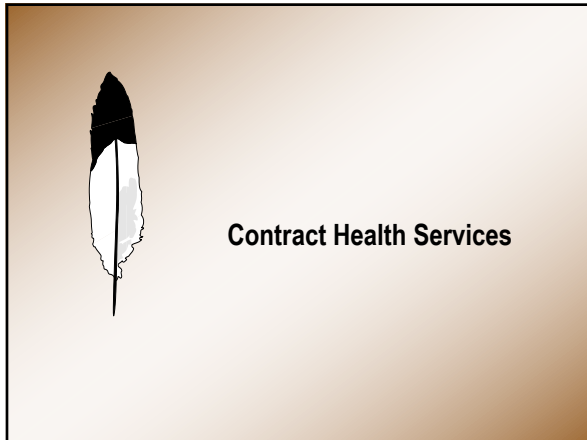
Urban Indian Behaviors

- Inter-tribal (e.g., L.A., Natives from 250 different tribal affiliations served by urban Indian clinic)
- Migration to and from reservations:
 - ceremony **Affects health projects**
 - jobs **because more challenging to**
 - healthcare **find people and keep their**
 - family crises **info current**

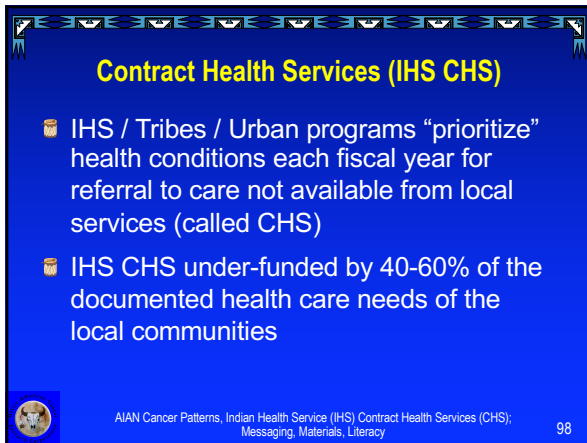
 AIAN Cancer Misconceptions 96

96

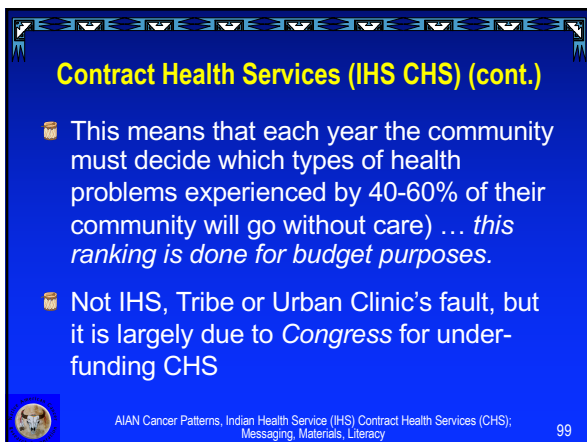
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Demographics, Historical Trauma, Racial Misclassification, Cancer Data, Barriers

Contract Health Services (IHS CHS) (cont.)

- Fiscal year begins October 1
- During federal freezes, IHS CHS monies are also "frozen" except for life and death emergencies
- Most tribes run out of CHS monies by early summer

AIAN Cancer Patterns, Indian Health Service (IHS) Contract Health Services (CHS);
Messaging, Materials, Literacy 100

100

Contract Health Services (IHS CHS) (cont.)

- Because of the under-funding, if a health problem is listing lower than "5" *for most tribes*, the patient is not referred out for care
- Of the 564+ federally recognized tribes, "cancer" was ranked among the top 5 in less than 10 Nations up until 2006.

AIAN Cancer Patterns, Indian Health Service (IHS) Contract Health Services (CHS);
Messaging, Materials, Literacy 101

101


FY 2009 IHS Health Priorities -- By Area -- Scored for Ranking			11 of the IHS Areas		Scoring
Health / Problem	Aberdeen	Omaha	Frequency	Score	
Alcohol / Substance Abuse		60	9	630	For scoring purposes, each Area's priorities were given the following point values: #1 priority = 100 points #2 = 90 pts #3 = 80 pts #4 = 70 pts #5 = 60 pts #6 = 50 pts #7 = 40 pts #8 = 30 pts #9 = 20 pts #10 = 10 pts
Diabetes	100	100	10	890	
Cancer	80	70	11	750	
Heart Disease	70	80	10	740	
Maternal / Child Health	40	20	7	220	
Elder Health	10		6	180	
Mental Health		30	8	450	
Injuries / Prevention	50		9	380	
CHS			0	0	
Dental	60	40	10	400	
Respiratory / Pulmonary	30		3	90	
Obesity / Diabetes			1	90	
Domestic Violence / Abuse			3	60	
Health Promotion / Disease Prevention		90	5	340	
Obesity		50	5	180	
HC Facilities Construction		10	2	110	
Water / Sanitation Projects			4	180	
Infectious Diseases			1	10	
Emergency Medical Services	20		1	20	
Behavioral Health/A/SA/MH	90		2	190	
Renal Disease/Dialysis			1	30	
Total # of Priorities	10	10			

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The American Indian Cancer Collaborative for Women's Health [U57 DP001138]
Demographics, Historical Trauma, Racial Misclassification, Cancer Data, Barriers

Contract Health Services (IHS CHS) (cont.)


- Since so few urban AIs have private insurance (15-40%), when diagnosed with cancer, they return to the reservation to get care.
- They have to re-establish residency on the reservation before they are eligible for CHS (usually 6 months)

 AIAN Cancer Patterns, Indian Health Service (IHS) Contract Health Services (CHS);
Messaging, Materials, Literacy 103

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Contract Health Services (IHS CHS) (cont.)


- Once residency established, they have to be listed on the CHS priorities
- If this is during a time when CHS monies are short (e.g., summer), the patient may not be referred out to treatment services for another 6-9 months.

 AIAN Cancer Patterns, Indian Health Service (IHS) Contract Health Services (CHS);
Messaging, Materials, Literacy 104

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Contract Health Services (IHS CHS) (cont.)

- If the cancer was stage 2 at the time of diagnosis while in the city, the patient has experienced a 9-18 month interval between the time of diagnosis and initiation of cancer care.
- The stage 2 cancer usually has become stage 3 or 4 (more expensive and invasive treatments than for stage 2)

 AIAN Cancer Patterns, Indian Health Service (IHS) Contract Health Services (CHS);
Messaging, Materials, Literacy 105

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Demographics, Historical Trauma, Racial Misclassification, Cancer Data, Barriers


Contract Health Services (IHS CHS) (cont.)

NOTE: Some of the Indian casinos *that have made profits*, have helped purchase PRIVATE health insurance that usually addresses the CHS "issues"

AIAN Cancer Patterns, Indian Health Service (IHS) Contract Health Services (CHS):
Messaging, Materials, Literacy

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Messages and Materials

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Messages

Related to family vs. personal benefit
Have a mammogram to be a well woman!

Insignificant ->no effect in Indian Country
Have a mammogram to show your daughters how a well woman behaves

AIAN Messages and Materials

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The American Indian Cancer Collaborative for Women's Health [U57 DP001138]
Demographics, Historical Trauma, Racial Misclassification, Cancer Data, Barriers

Messages

- TV PSA with young Alaska Native boy standing next to rocking chair. *"Today is my birthday. The best gift I could have is my grandma back. She died of breast cancer."*
- TV Moderator: *"Mammograms can identify cancer while it is curable. Schedule your mammogram today."*

AIAN Messages and Materials 109

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Educational Message - Effective

- Culturally relevant, appropriate, respectful, sensitive, competent
- Tailored to local community
- Stress behaviors that benefit overall health rather than limiting the benefits to cancer only
- i.e., low fat, high fiber diet and CVD, diabetes, obesity

AIAN Messages and Materials 110

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Messages

- Messages at appropriate literacy level (average for *all US* = 5-7th grade reading level)
- Nurse's comment on website
 - I thought your website was designed for elementary children. Are Indian people really that dumb?

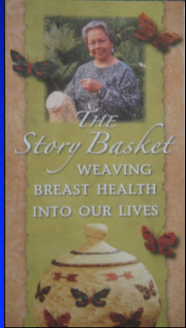
AIAN Messages and Materials 111

111

The American Indian Cancer Collaborative for Women's Health [U57 DP001138]
Demographics, Historical Trauma, Racial Misclassification, Cancer Data, Barriers

Educational Message - Effective

- Story telling
- Family-based, emotional message
- Messages delivered by local women from the community
- Use of "health" rather than "cancer"




AIAN Messages and Materials 112

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Education Booth Messages

- Native Survivor, "Ask Me. I have a story."
- Culturally relevant graphics and icons
- Native music playing at the booth



AIAN Messages and Materials 113

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Developing the Materials

Same process as for refining your message (words, phrases)


Focus groups – ideas, guidance or evaluate →

Option: verbatim transcripts coded for qualitative "themes"

Pilot via interviews →

Refine →

Pilot test →



AIAN Messages and Materials 114

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The American Indian Cancer Collaborative for Women's Health [U57 DP001138]
Demographics, Historical Trauma, Racial Misclassification, Cancer Data, Barriers

Materials Checklist

DESIGN 3 or less "features" on each page

- ⌚ Headers to clarify text that follows
- ⌚ Use of underlining, bold for emphasis only
- ⌚ Font (e.g., Arial – letters without curly cues or similar "additions")
- ⌚ Visually appealing layout
- ⌚ Colors and cultural significance
- ⌚ Graphics / photos

AIAN Messages and Materials 115

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Examples of Factors That Influence The Effectiveness Of Audio And Visual Materials

- ⌚ Story-telling format for the message
- ⌚ Delivered by Native elder with traditional speaking dialect (especially by local survivor)
- ⌚ Use of circles -- Linear scales are ineffective with elder Native women (HS education and less)

AIAN Messages and Materials 116

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Examples Of Factors That Influence The Effectiveness Of Audio And Visual Materials

Medicine Wheel vs. Circle of Life

- ⌚ Respectful use of graphics, icons, cultural artwork
- ⌚ Avoid using colors in printed materials that are "sacred"
- ⌚ Health literacy is understandable
- ⌚ Verbal, vocal, non-verbal communication styles acceptable to tribal community


AIAN Messages and Materials 117

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The American Indian Cancer Collaborative for Women's Health [U57 DP001138]
Demographics, Historical Trauma, Racial Misclassification, Cancer Data, Barriers

Examples Of Factors That Influence The Effectiveness Of Audio And Visual Materials

- ☞ Rate of speech (i.e., Native elder women *usually* speak slower than non-Native women)
- ☞ Use of pause between speakers (i.e., non-Natives frequently talk on top of one another's words)
- ☞ Illustrates respect for family and /or elders
- ☞ Focuses on local people (e.g., pictures, quotes, or stories from them)


 AIAN Messages and Materials 118

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Factors That Influence The Effectiveness Of Materials

☞ Other Costs considerations:

- ☞ Of duplicating or reproducing
- ☞ Of photocopying black and white versions when monies are low
- ☞ Of assembling the product
- ☞ Of mailing the product
- ☞ General newspaper advertisement for high cost versus free or low cost from tribal newspaper


 AIAN Messages and Materials 119

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Factors That Influence The Effectiveness Of Materials

☞ Other Format considerations:

- ☞ Video tape versus DVD
- ☞ Audiotape versus CD Rom
- ☞ Glossy high cost brochure / poster that limits the number that can be reproduced
- ☞ Size of the product (small enough to fit in one's purse)


 AIAN Messages and Materials 120

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Factors That Influence The Effectiveness Of Materials

Other Format considerations:

- ⊕ Is the "take home message" clearly apparent from the product?
- ⊕ Is there too much information?
- ⊕ Is there "white space" on the product?
- ⊕ Does the product include "interactivity"?
- ⊕ Did you verify clarity of the material after a week or so with elder?

 AIAN Messages and Materials 121


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Factors that influence the effectiveness of materials

Other Dissemination considerations

- ⊕ Ability to post or leave copies at:
 - Market
 - School
 - Clinic
 - Casino
 - Urban Indian clinic web site

NOTE: more AI elders using computers


 AIAN Messages and Materials 122

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Factors that influence the effectiveness of materials

Other Dissemination considerations

- ⊕ Ability to have Press Releases or announcements
 - Played on the local Indian radio station
 - Played at a reasonable time
 - Played TV or cable station that locals watch
 - Printed in tribal publications

 AIAN Messages and Materials 123


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Demographics, Historical Trauma, Racial Misclassification, Cancer Data, Barriers

Cultural Messages and Materials

didn't work

A MAMMOGRAM:
A PICTURE THAT
COULD SAVE YOUR
LIFE



message

graphics

1 eye =
dishonest

river symbols

124

124

Having a mammogram isn't painful,



**it is having one too late that hurts
your family**

125

**Examples of Tribally Created Cancer Pain
Brochures**

Developed through *Enhancing Cancer Pain
Control among American Indians*

National Cancer Institute R25 CA65648 (P.I.
TE Elliott)

Karen Johnson, MPH; Thomas E. Elliott, MD
FACP; Barbara A. Elliott, PhD; and John Day,
BA

AIAN Messages and Materials

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Native
Affairs

i-3377; Native American Cancer Research
w.NatAmCancer.org

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Examples of Tribally-developed cancer pain brochures

Four different tribal group cancer pain brochures are presented here:

- White Earth
- Fond du Lac
- Leech Lake
- Red Lake Nation

AIAN Messages and Materials
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1995 Karen Johnson NCI Grant Frances #1

AIAN Messages and Materials
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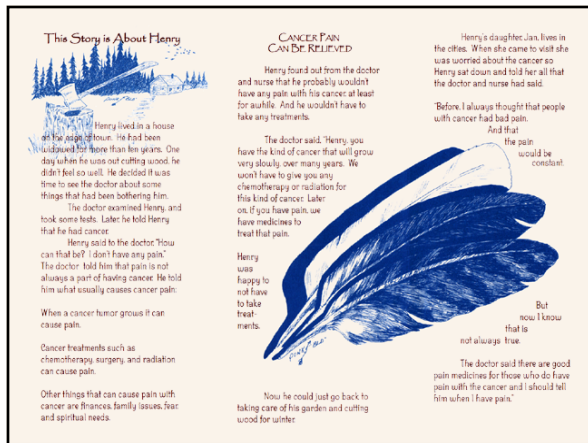
This Story is about Frances

AIAN Messages and Materials
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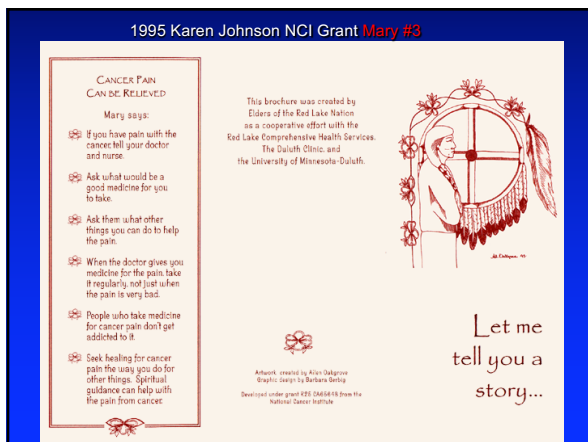
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130

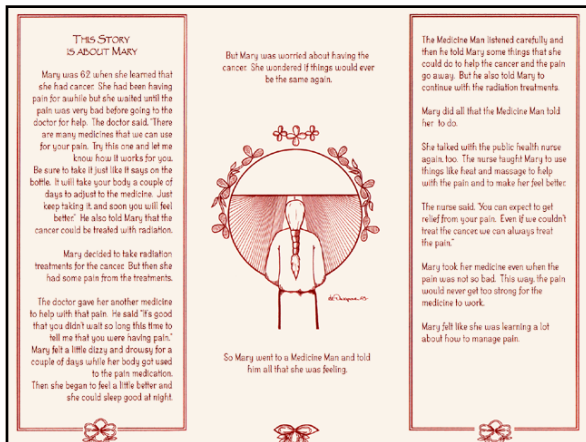


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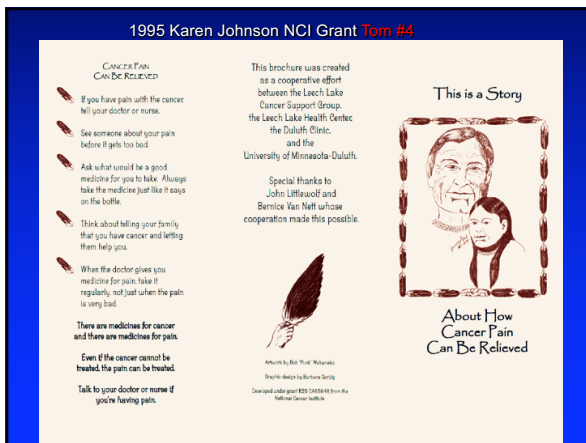


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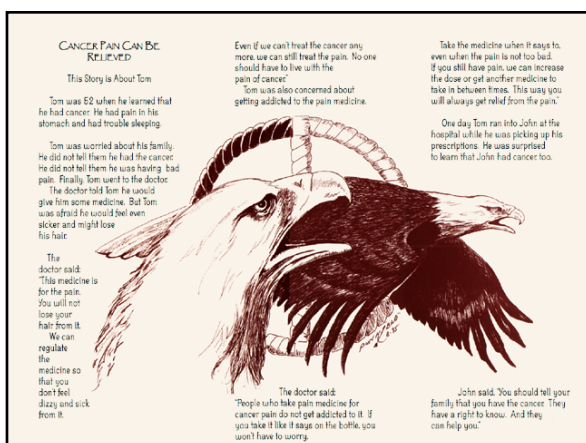
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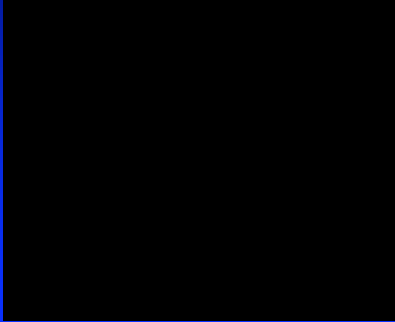
Cultural Messages and Materials

- No Message or Material is appropriate to all urban or tribal communities.
- All need some local modification (may be through verbal instruction while the product is being used)

AIAN Messages and Materials 136

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NACR's Public Service Announcement



AIAN Messages and Materials 137

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What does the graphic of the empty chair mean to you?



AIAN Messages and Materials 138

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Demographics, Historical Trauma, Racial Misclassification, Cancer Data, Barriers

What do you think about the words in the inside panel of the brochure

What do you think of the graphic of the woman? What "message" does she communicate?

Native American women, like most women today, are caretakers for their families. Caretakers can easily forget their own health needs. One way to take care of yourself is to have a PAP test.




AIAN Messages and Materials

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What do you think about the words in the inside panel of the brochure

What do you think of the graphic of the woman? What "message" does she communicate?



CONGRATULATIONS!

You had a Pap test. You are taking care of yourself.

The Pap test is an early warning system. It is an important way of finding changes that could lead to cancer of the cervix.

Your clinic has your Pap results. What do the results mean? What is the next step?

This booklet will help explain your Pap test results and what to do next.

Your body needs special care throughout your life!

AIAN Messages and Materials

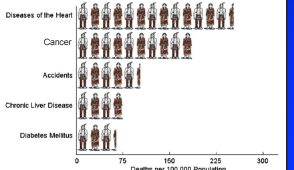
140

Educational Materials - Ineffective

Linear layout (Likert scale on surveys [okay for young AIAN, but not elders]; pain scales)

Scientific graphs (e.g., bar) –Changed to people rather than "bars" and made sense to the community

DEATH RATES, LEADING CAUSES: AGES 45 TO 64 YEARS




AIAN Messages and Materials

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Demographics, Historical Trauma, Racial Misclassification, Cancer Data, Barriers

Educational Materials

- “The only thing I noticed that I had start going more often than what I did before and it was mostly at night, it wasn't during the day, it was mostly at night “
- Concepts, e.g., “risk factors” not under-stood by community;
- 18 months to develop and inter-tribal pilot test the “shield”



Chuck Frederick
[Chippewa]
Dx 1992 Prostate

AIAN Messages and Materials 142

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The shield in these slides represents your protection (shield of health) against things that may make you more susceptible to cancer (cancer risks)


The larger the holes and the more number of holes in the shield, the less likely it is to protect you from cancer or other health problems

NOTE: the web page version is animated for breast and CRC



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- The woman's “shield” of protection against cervix cancer may include daily physical activity, healthy, low fat, limit tobacco to ceremonial use only, and so on
- What does this shield tell you about this woman's cancer risks?



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Example of Cervix Cancer risks that "damage" her shield of protection include:

1. Early age at first intercourse (16 years old or younger)
2. More than 5 different sexual partners in your whole life
3. Having sex with partners who have had many sexual partners
4. Sexually transmitted diseases (HPV -human papilloma virus) which may also cause genital warts
5. Herpes virus
6. HIV infection
7. Exposure to cigarette smoke (smoking and second hand smoke)
8. Giving birth to more than 4 children
9. Long term use of oral contraceptives
10. Diets low in carotene, Vitamins C and E



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Health Literacy

Available within "Word®", but several other literacy programs work just as well, if not better

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Literacy

- The ability to read and write
- QUESTION:** What does, "health literacy" mean?
- The ability to obtain, read, understand, and use health care information



Thank you, Barry Weiss, M.D., for the slides

Health Literacy

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The American Indian Cancer Collaborative for Women's Health [U57 DP001138]
Demographics, Historical Trauma, Racial Misclassification, Cancer Data, Barriers

Overlooked Because They Don't Fit The Stereotype

- Many National Adult Literacy Survey (NALS-1) readers
 - Are born in the U.S.A. (75%)
 - Are white (50%)
 - Hold full or part-time job (40%)
 - Finished high school (25%)

Thank you, Barry Weiss, M.D., for the slides

Health Literacy 148

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National Adult Literacy Survey (NALS) 1992
[JAMA: 1999; 281:6: 552-557]

NALS Level 1 (functionally illiterate, 20% of US population)

CAN	CANNOT
o Sign name	o Use bus schedule
o Find expiration date on food container	o Enter background info on Social Security appl
o Total bank deposit entry	o Find Intersection on street map

Health Literacy 149

149

National Adult Literacy Survey (NALS) 1992

Almost 50% US Population were functionally illiterate (NALS 1) or marginally illiterate (NALS 2)

NALS 1 (20%)	NALS 2 (27%)
o Sign name	o Use bus schedule
o Find expiration date on food container	o Enter background info on SS application
o Total bank deposit entry	o Find Intersection on street map

Health Literacy 150

150


The American Indian Cancer Collaborative for Women's Health [U57 DP001138]
Demographics, Historical Trauma, Racial Misclassification, Cancer Data, Barriers

NALS Levels 3-5

Level 3: write brief letter explaining error on credit card bill




Level 4: State in writing an argument made in lengthy newspaper article

Level 5: Use information in table to complete graph including labeled axes


 Health Literacy 151

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Easier-to-understand

-  Short sentences
-  Limited use of words that have multi-syllables (like "mammogram")
-  Avoid jargon and abbreviations

Thank you, Barry Weiss, M.D., for the slides

 Health Literacy 152

152



Flesch-Kincaid Grade Level

Available within "Word®", but several other literacy programs work just as well, if not better

 153

i-3377; Native American Cancer Research
w.NatAmCancer.org

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Flesch-Kincaid Grade Level

- This formula rates text on a U.S. grade-school level.
- A score of 8.0 means that an eighth grader can understand the document
- For most standard documents, aim for a score of approximately 5.0 to 7.0 grade level

Health Literacy 154

154

Literacy – NACR's Modifications (cont.)

- Average reading level for all US (i.e., not limited to AIANs) is grade 7.
- Typically, the reading level is 2 years under highest grade of completion, so high school graduate SHOULD be able to read 9th grade.

Health Literacy 155

155

Literacy – NACR's Modifications (cont.)

- Conversely, some people with only 9th grade education have self-taught themselves and may read at much higher level (like grade 14)
- Thus, NACR aims for grade reading levels 5, 6, and 7 for our materials unless we know it is a technical or professional audience.

Health Literacy 156

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The American Indian Cancer Collaborative for Women's Health [U57 DP001138]
Demographics, Historical Trauma, Racial Misclassification, Cancer Data, Barriers

Literacy – NACR's Modifications (cont.)

- In Word, go to "tools"
- Scroll down to "options"
- Click on tab for "spelling and grammar"
- Last option on that pull-down screen is "show readability statistics". Check the box
- Block the paragraph in Word that you want to check.

Health Literacy 157

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Literacy – NACR's Modifications (cont.)

- In Word, click on "Tools"
- Click on "Spelling and Grammar".
- Once the program checks the paragraph, a box comes up asking if you want to check the rest of the document.
- Click "no" and then the readability scale will be displayed.
- The bottom 3 items are the important ones.

Health Literacy 158

158

Literacy – NACR's Modifications (cont.)

- Passive sentences – you want this to be as close to 0% as possible. Higher percentages (like 40% and higher) of passive sentences makes comprehension more difficult, particularly for elders.
- Flesch Reading Ease – you want this to be as close to 100% as possible

Health Literacy 159

159

Literacy – NACR's Modifications (cont.)

- Flesch-Kincaid Grade Level** – you want this to be 7.0 and lower.
- When this item shows “0” it means that insufficient amount of text was blocked (like if you blocked a single bullet phrase) ...
- so you have to check more than this amount of text to get an estimate of literacy.

Health Literacy 160

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Readability Scales

Readability Statistics	
Counts	
Words	88
Characters	419
Paragraphs	1
Sentences	8
Averages	
Sentences per Paragraph	8.0
Words per Sentence	11.0
Characters per Word	4.6
Readability	
Passive Sentences	12%
Flesch Reading Ease	60.1
Flesch-Kincaid Grade Level	7.6

What do you want this percentage to be?

What do you want this number to be?

What do you want this number to be?

OK

Health Literacy 161

161

Things to keep in mind ...

- Technical terms potentially decrease comprehension even further
- This complexity is independent of the number of syllables
- For example, “elephant” and “placebo” have the same number of syllables, yet most people understand “elephant” but not “placebo”


Health Literacy 162

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Objective 3: by the end of this session, the participant will be able to:

- Identify culturally sensitive communication methods and techniques for Native American outreach efforts.

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Examples of AIAN Cultural Beliefs

NOTE: Tribal Nations are very different from one another

164

Common Values Among Natives

- Sharing and generosity
- Allegiance to family, community, and tribe
- Respect for elders
- Non-Interference
- Orientation to present time
- Harmony with Nature
- Respect for status of the Woman and the Child

Carol Locust, Univ AZ, Tucson

Communication, Outreach Strategies

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Demographics, Historical Trauma, Racial Misclassification, Cancer Data, Barriers

Common beliefs related to Spirituality

- ☐ A belief in an unseen power, Great Mystery or Creator
- ☐ All things in the universe are related
- ☐ Worship reinforces bonds between the individual, family, and community (our relatedness)
- ☐ Spirituality is intimately connected to our health

Communication, Outreach Strategies 166

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Respective Core Values

<u>Traditional Native</u>	<u>Main Stream US Society</u>
Cooperative	Competitive
Group/Tribal Emphasis	Freedom, Progress, Efficiency
Extended Family Important	Individualism
Modesty	Sexy
Patience/Passive (SW)	"Getting Ahead in Life"
Generous/Non-Materialistic	Material Comfort
Respect for Age	Youth Envy
Spirituality	External Conformity
Indirect Criticism	Direct Criticism
Harmony with Nature	Conquest of Nature


Communication, Outreach Strategies 167

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Communication Methods

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Patient-Provider Communication



Note: see NACR's website
<http://www.NatAmCancer.org>
click on tree (left side of screen)
then click on the leaf
"communication"

Communication, Outreach Strategies 169

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Culture and Body Language

- The use of the body, facial expressions, gestures, etc. in "non-verbal" communication
- Body language has meanings that are specific to each culture
- Your provider is probably of a culture that is different from yours

Communication, Outreach Strategies 170


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Culture and Body Language


- Your provider's body language may have meanings that differ from how such gestures or expressions are used within your culture
- Most providers trained in modern medicine are taught to use direct eye contact




Communication, Outreach Strategies 171

171



Culture and Direct Eye Contact


 If your tribal culture does not use direct eye contact with people other than close relations, your provider will need to be informed of this practice

-  You can tell the provider yourself
-  You can have a family member explain this practice to the provider
-  You or your family can write a note to the provider


Communication, Outreach Strategies






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Culture and Direct Eye Contact


 In most providers' training, lack of eye contact reflects:

-  Dishonesty
-  Lack of understanding
-  Fear
-  Disrespect
-  Or many other emotions which may not be your intention




Communication, Outreach Strategies

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Culture and Direct Eye Contact

-  For most tribal Nations, direct eye contact is normal behavior
-  For some tribal Nations, direct eye contact is invasive of private thoughts – and is disrespectful
-  For other tribal Nations, direct eye contact is reserved for family and trusted friends only

Communication, Outreach Strategies

174

Native
Res.
174




Culture and Personal Space

- Every individual has a sense of space that s/he prefers to not have others within (personal space), unless "invited"
- Sometimes this personal space is as wide as outstretched arms ... For others it may be as short as 1 foot
- The patient and provider need to find a space distance that is comfortable to both to have good communication

Communication, Outreach Strategies

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Culture and Touch

- Some people are raised with a lot of hugging, kissing, and touching
- For these individuals, to reach out and touch someone (like the hand or forearm) is only a friendly or comforting gesture
- For most patients the personal touch shows that the provider cares for the patient

Communication, Outreach Strategies

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Culture and Touch

- Such gestures by providers can be misinterpreted by patients
- For the patient who has been physically or sexually abused, touch may not be comforting ...
- For others who come from a very modest culture, touching may only be appropriate for very close relations

Communication, Outreach Strategies

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Native
Affairs
177




Communication, Outreach Strategies

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Culture and Gestures

- Many tribal cultures use few or small gestures only
 - In very modest cultures, large gestures are rarely used
 - Pointing is considered disrespectful by some tribal cultures (some will point using the lips only)

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Communication, Outreach Strategies

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Culture and Gestures

- If the provider does gestures that make you uncomfortable, you need to let him/her know. S/he is just unfamiliar with your cultural practices.
- You can tell the provider yourself
- You can have a family member explain this practice to the provider
- You or your family can write a note to the provider

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Communication, Outreach Strategies

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Culture and Gestures

- Nodding the head to show you understand what the provider is saying is commonly understood
 - But for some tribal cultures, head nodding is not a common practice
 - You or your family can explain this is not a common gesture among your community
 - You or your family can write a note to the provider

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Demographics, Historical Trauma, Racial Misclassification, Cancer Data, Barriers

What is "good" communication?

QUESTION: What is a "communication"?

It means how well you are able to understand other people and how well they are able to understand you




Communication, Outreach Strategies 181

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What is "Good" Communication?


It includes people talking, listening, writing and/or reading so that there is a clear understanding by everyone

Communication patterns differ among groups, leading to problems in understanding and in making one understood.



Communication, Outreach Strategies 182

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Styles of Learning

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Demographics, Historical Trauma, Racial Misclassification, Cancer Data, Barriers

Styles of Learning

- Research suggests that most people focus on one learning style:
 - Oral learners (thrive on lectures, need to read notes out loud to enhance memory)
 - Written learners (thrive on texts, need to write out notes to enhance memory)
 - Visual learners (thrive on graphics, need to draw things out to enhance memory)
- Education works best when you have something for **EVERYONE**

Communication Strategies 184

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Enhancing Learning

- Regardless of learning style, experiential learning is the key to concrete memory
 - "Doing" learning activities are better than "show and tell" by improving
 - "Muscle" memory
 - Instant recall
 - Interactive games increase information retention
 - Positive emotions improve comprehension
 - Practice makes "perfect"

Communication Strategies 185

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Lessons Learned from Workshops with American Indians

- Start meetings in the late morning
- People will still come in "late"
 - "Indian time"
- Culture focuses on cooperation
 - Some may hesitate to critique others
 - Group will thrive when all can contribute and contributions are positively acknowledged
- Group activities improve engagement

Communication Strategies 186

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Reinforcing Learning

- Use small groups to:
 - Encourage reflection and discussion
 - Allow people to expand on concepts and critically think about the topics
 - Creative projects put learners "outside the box" and increases innovation
- Provide summaries, debriefings
- Follow-up and Refresher trainings

Communication Strategies 187

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Levels of Readiness

- Prochaska suggests that different "stages of readiness" influence health education
- Messages may be better received when tailored to stages. This may explain:
 - Increases in knowledge that have little to no impact on changes (not ready)
 - Knowledge that is not kept over time
 - Those that embrace healthier lifestyles

Communication Strategies 188

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Levels of Readiness

- Repeating information using different methods can help address "readiness"
 - Three times
- Using multiple strategies may help meet diverse target audience needs
 - Native Americans may rely more on oral or graphic learning styles (not text)

Communication Strategies 189

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Demographics, Historical Trauma, Racial Misclassification, Cancer Data, Barriers



Motivational Communication

- Adapted from motivational interviewing
See: http://en.wikipedia.org/wiki/Motivational_interviewing
- Non-judgmental, non-confronting
- Goal is to increase awareness of
 - Behavioral consequences
 - Long term risks
 - Motivations for small, "do-able" steps
 - Visions of a better future

Communication Strategies 190

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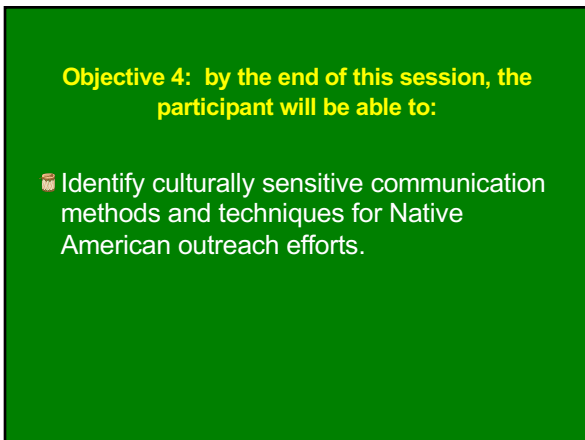


Key Elements for Native American Stories

- Highlight families as well as the storyteller
- Include "local" community members
 - Not celebrities
- Tribe or region specific graphics will increase those taking and using the product
 - Focus groups and trash cans

Communication Strategies 191

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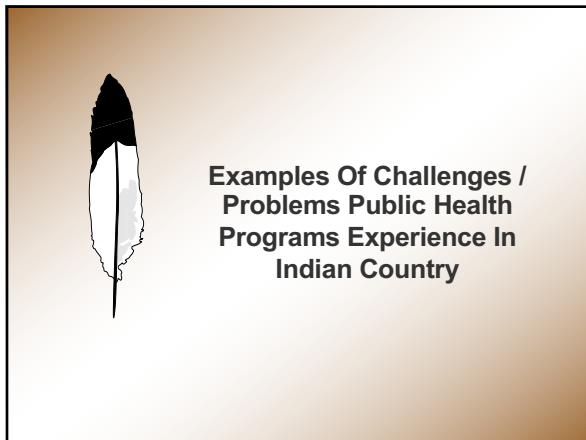


Objective 4: by the end of this session, the participant will be able to:

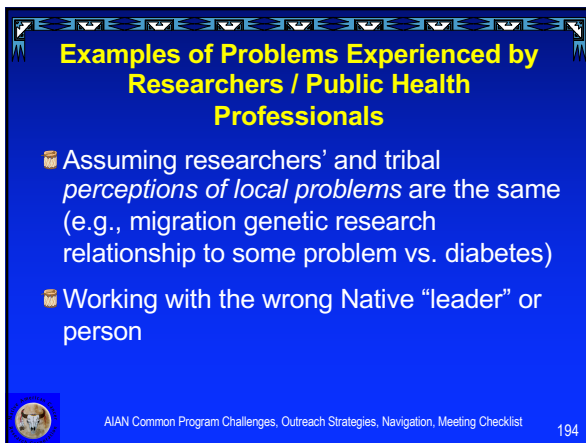
- Identify culturally sensitive communication methods and techniques for Native American outreach efforts.

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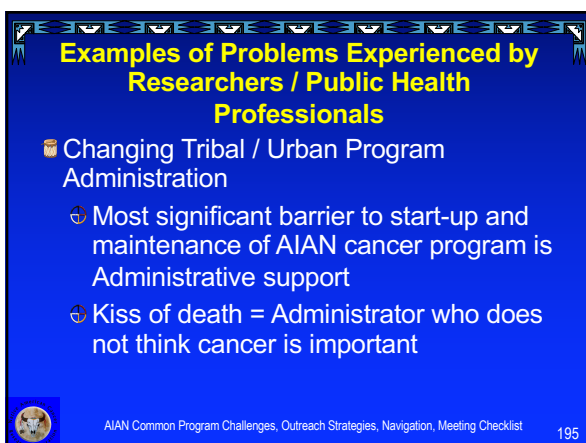
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Demographics, Historical Trauma, Racial Misclassification, Cancer Data, Barriers

Examples of Problems Experienced by Researchers / Public Health Professionals

- Throwing money at Native community to use as they wish, but give researcher the data (disrespectful)
- Researcher obtains letter of support / commitment from Native organization for grant application and then is not heard from again until time for competitive grant renewal

AIAN Common Program Challenges, Outreach Strategies, Navigation, Meeting Checklist 196

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Examples of Problems Experienced by Researchers / Public Health Professionals

- High turnover within Native community project staff (usually related to insufficient budget)
- Researcher saying or implying, "I don't care how you get it, but give me the data"
- Budget (volunteerism from Native community, but academicians receive salaries or buy-out for class loads)

AIAN Common Program Challenges, Outreach Strategies, Navigation, Meeting Checklist 197

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"If the problem is in the community, the solution is in the community"

Gilbert H. Friedell, M.D.
Director Emeritus, Markey Cancer Control Program

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Demographics, Historical Trauma, Racial Misclassification, Cancer Data, Barriers


Example of Project Approval Processes among IHS / Tribal / Urban Programs

- Local Tribal Committee for partnerships / decision-makers / leaders →
- Tribal Resolutions / ordinance →
- Tribal Research Committee/IRB →
- IHS Area IRB →
- IHS National IRB approvals

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What are criteria for community based participatory research (CBPR) or approach (CBPA)?

 AIAN Common Program Challenges, Outreach Strategies, Navigation, Meeting Checklist 200

200

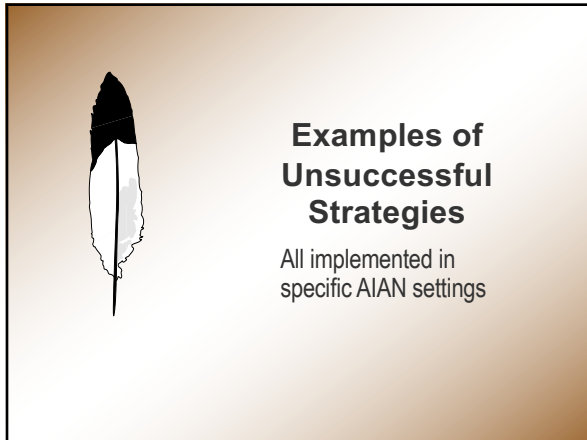
Equal partner and decision-making role on every step / phase of the research project

- ⌚ Planning the project
- ⌚ Identifying the hypothesis
- ⌚ Formulating the research plan
- ⌚ Analyzing the data
- ⌚ Writing the reports
- ⌚ Disseminating and presenting project findings (publications, professional and community meetings)

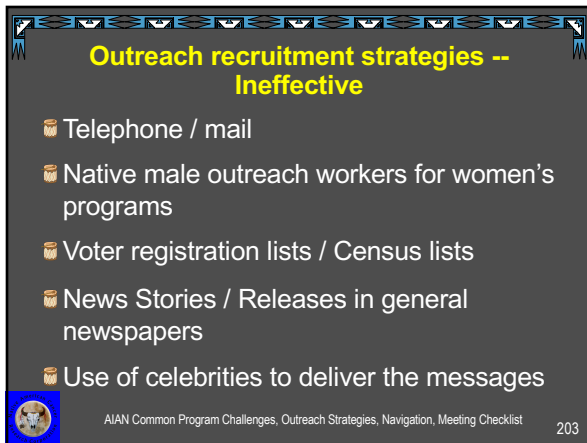
 AIAN Common Program Challenges, Outreach Strategies, Navigation, Meeting Checklist 201

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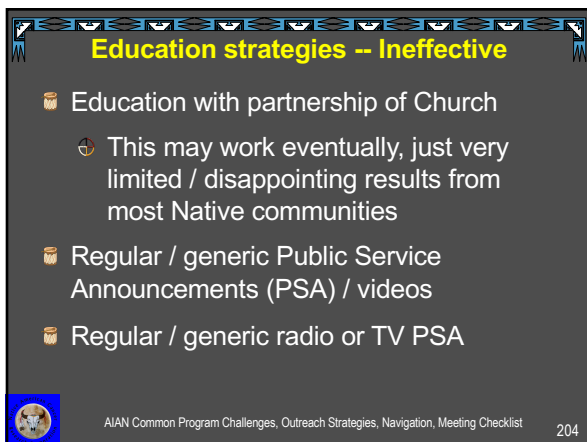
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Demographics, Historical Trauma, Racial Misclassification, Cancer Data, Barriers



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Breast Health Services -- Ineffective

- Mobile mammography in city within 50 miles of Native community
 - worked for urbans** but not for reservation-based women
- Male health provider for women's programs
- County health screening services
- General hospital / health care facility screening services



AIAN Common Program Challenges, Outreach Strategies, Navigation, Meeting Checklist

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Examples of Successful Strategies

All implemented in specific AIAN settings

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Successful Strategies for Breast and Cervical Cancer Screening Among American Indian and Alaska Native Women

Carlyn Orians, Paula Lantz, Edward Liebow, Jennie Joe, Linda Burhansstipanov, Julie Erb

Battelle
Center for Public Health Research
4400 Sand Point Way, N.E. • Suite 100
Seattle, Washington 98105-5000



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Demographics, Historical Trauma, Racial Misclassification, Cancer Data, Barriers

Strategies for program start-up


- Find good staff
 - Coordinator committed to making it work
 - Support staff who create welcoming environment for women
 - Data management staff
 - Outreach workers who know the community

 AIAN Common Program Challenges, Outreach Strategies, Navigation, Meeting Checklist 208

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Strategies for program start-up


- Find good providers
 - Value preventive health
 - Willing to provide more than clinical services, i.e., education
 - Preferably female

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Strategies for program start-up

- Public education and outreach
 - Early emphasis on this component to develop constituency
 - Messages that are positive and culturally relevant
 - "Gifting"
 - Personal contact and use of targeted media

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Demographics, Historical Trauma, Racial Misclassification, Cancer Data, Barriers

Strategies for program start-up


- 📋 Tribal and administrative support
 - ➡ Create ownership and support
 - ➡ Good communication

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Strategies to sustain a program


- 📋 Ensure women have a good experience
 - ➡ Respectful care that honors women
 - ➡ Privacy
 - ➡ Follow-up and tracking
- 📋 Communicate
 - ➡ With clients
 - ➡ With tribal administration and other staff
 - ➡ With CDC and outside partners

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Strategies to sustain a program

- 📋 Use community elders and resources
 - ➡ Ongoing outreach
 - ➡ Survivor experiences
 - ➡ Advisors


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Demographics, Historical Trauma, Racial Misclassification, Cancer Data, Barriers

Strategies to sustain a program


- 📋 Evaluate and change
 - ➡ Keep track of who is being screened and who isn't
 - ➡ Monitor quality and access
 - ➡ View change as positive, not sign of failure

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Screening service delivery models


- 📋 Screening clinic model
 - ➡ Special screening clinics or screening days
 - ➡ Services disbursed geographically
 - ➡ Mobile mammography
- 📋 Integrated model
 - ➡ Screening part of existing well-woman care
 - ➡ Established facilities and providers

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Factors in selecting delivery model

- 📋 Number of tribes served by program.
- 📋 Size of the geographic area served.
- 📋 Health care delivery context of tribal health services.

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Demographics, Historical Trauma, Racial Misclassification, Cancer Data, Barriers

Summary from Battelle Study

Communities served by these programs have benefited from the American Indian/Alaska Native Initiative:


- ☞ New services offered to women.
- ☞ Greater awareness of breast and cervical cancer screening and of preventive health in general.

 AIAAN Common Program Challenges, Outreach Strategies, Navigation, Meeting Checklist 217

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Summary from Battelle Study

- ☞ Cancers detected and treated.
- ☞ Interest in extending this model to meet other health care needs in their communities.

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Key strengths of the program model

- ☞ The early detection program is comprehensive in nature
 - ⊕ program does more than offer screening services
 - ⊕ public education, tracking and follow-up, partnerships, and professional education equally important

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Key strengths of the program model

- ⊕ comprehensive approach creates community orientation towards prevention
- 🏠 The tribal programs are locally controlled
 - ⊕ greater self determination
 - ⊕ ability to shape program to meet needs of the community
 - ⊕ services delivered through trusted institutions and individuals

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Outreach Recruitment Strategies -- Effective

QUESTION: What does “multiple strategies” mean?

QUESTION: Are “multiple strategies” needed to successfully recruit most non-Native under-screened women?


QUESTION: What would you guess was one of the *most* successful approaches?

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Outreach Recruitment Strategies -- Effective

- 🏠 *Multiple* strategies relevant to local AIAN community
- 🏠 One-on-one recruitment
- 🏠 Lay health advisors, Navigators (Native Sisters), Community Health Representatives
- 🏠 Telephone calls or visits to remind woman of her appointments


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Outreach Recruitment Strategies -- Effective


- Native Cancer Survivors on staff as outreach workers
- Native American Navigators (Native Sisters)
- "Gifting" and incentives for completing screening appointment
- News Stories / Releases in Tribal or Urban newsletters or newspapers

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Education Strategy - Effective


- Story Telling
- One-on-one delivery w/ culturally specific videos, fliers, brochures
- Native-specific PSAs / Videos
- Native-specific Radio or TV (e.g., Raven, Native American Calling, Alter-Native)
- Educational Activities need to include the sharing of healthy food
- Community programs, workshops presentations by local women

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Breast Health Services -- Effective

- Mobile mammography within the Native community
- Female health provider
- Native-specific clinic screening

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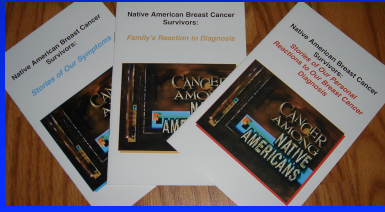


AIAN Common Program Challenges, Outreach Strategies, Navigation, Meeting Checklist


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Story Telling

- Natural way for patients to explain and to understand (see side bar on NACES QOL Tree)



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AIAN Common Program Challenges, Outreach Strategies, Navigation, Meeting Checklist

227

Story Telling

- Effective within outreach, education, support materials
- More effective with *local* AIAN person rather than a celebrity

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AIAN Common Program Challenges, Outreach Strategies, Navigation, Meeting Checklist

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Native Sisters / Navigators


- Understand IHS / Contract Health Service (CHS) budgetary limitations (created by Congress)
- Use alternative ways to overcome IHS CHS
 - See "help and support" limb on the "Native American Cancer Education for Survivors" QOL Tree

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Demographics, Historical Trauma, Racial Misclassification, Cancer Data, Barriers

Increase Time Spent with Patient and Family to Discuss CT / Tx

- Healthcare Institutions focus on business = providers allowed 15 minutes per patient visit
- Alternative: Daniel Petereit, MD, Rapid City Regional Hospital, SD
 - Clinical Trial Explained in 2 sessions (one with family present)
 - 1 hour each session
 - ~30 AI patients recruited/retained in ATM genetic study!!!

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**Sub-Objective:
Identify factors that
increase the
successfulness of
navigation models (Native
Sisters) in Indian Country.**

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Native Sisters



Back Row: Brenda Seals, Lisa Harjo, Terri Rattler
Front Row: Denise Lindstrom, Audrey Marshall, Rose Lee

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i-3377; Native American Cancer Research
w.NatAmCancer.org

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Characteristics of the Native Sisters

- Native³
- Respected by the community (credibility in the community)
- Model healthy behaviors
- Passion for helping community members
- Education varies (service vs. grant)





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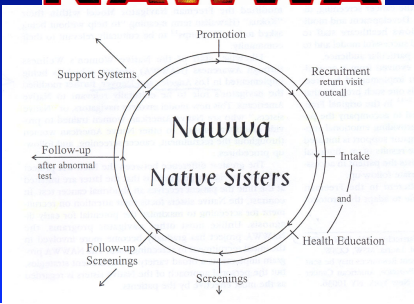
NAWWA Background / History / Evolution

- 1994 to present NAWWA [RWJF, Komen] →
- 1998 "Increasing Mammography for Urban American Indian Women" [NCI R25 CA77665] →
- 1999 to present "Colorado Women's Cancer Control Initiative" [Colorado Department of Public Health and Education] →
 - 2002 "Increasing Mammography Screening among Medically Underserved Women" [NCI R25 CA 96540] →
 - (1996 Network) 2004 "Native American Cancer Education for Survivors" [Komen #POP0503920, #POP0202135, NCI R25 CA 101938]
 - 2006 Prevention / Early Detection Native American Tobacco Education (NATE) Coalition; Native American Prevention of Obesity (NAPO) [Colorado Department of Public Health and Education]



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NAWWA



Native Sisters' 1994-1997 Functions²



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Demographics, Historical Trauma, Racial Misclassification, Cancer Data, Barriers

Native Sisters' Roles 1994-1997²


- Assisting the women who are participating in screening mammography examinations.
- Providing social and emotional support for any Native woman who participates in the screening program and requires assistance.
- Accompanying Native "clients" to follow-up appointment.
- Collaborating with technical professionals who provide mammography and clinical breast examination services by taking a leadership role implementing the follow-up from breast cancer screening.

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Native Sisters' Roles 1994-1997²


- Communicating with "clients" who receive abnormal screening results and assisting them in obtaining their preference(s) for follow-up treatment (including traditional American Indian healing and Western medicine) on a one-to-one basis.
- Assisting with the recruitment of women for early detection cancer screening.
- Assisting DIC and CHA disseminate monthly announcements related to NAWWA screening.

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Native Sisters' Roles 1994-1997²

- Assisting the Chair of the Elders Standing Committee by preparing a monthly meeting agenda and discussion with elders about community services offered through NAWWA.
- Attending and participating during cultural events where recruitment efforts are being implemented (e.g., help sign up women for the appointments, escort women to the screening van; provide emotional support).
- Seeking out Traditional Healers' for women.
- Providing support for the client's family.

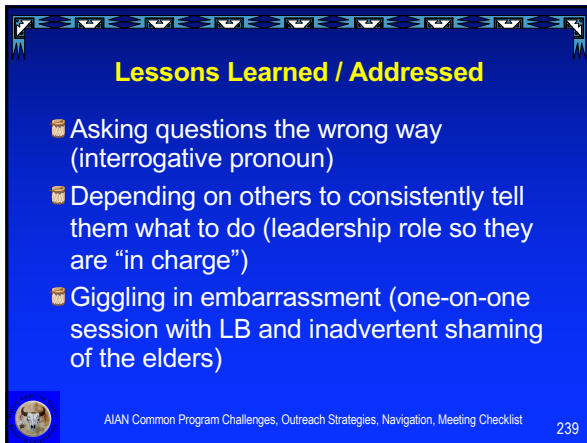
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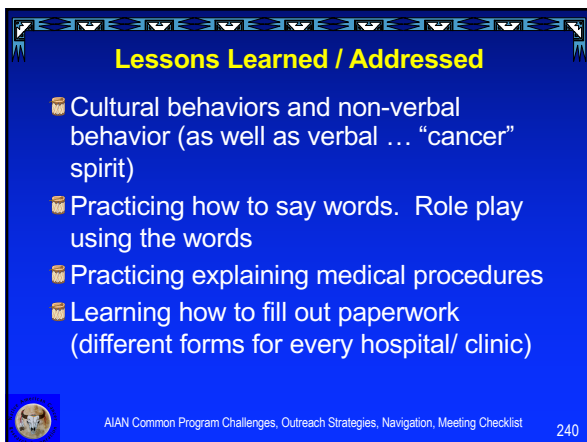
The American Indian Cancer Collaborative for Women's Health [U57 DP001138]
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The American Indian Cancer Collaborative for Women's Health [U57 DP001138] Demographics, Historical Trauma, Racial Misclassification, Cancer Data, Barriers

Lessons Learned / Addressed

- Guessing at an answer rather than saying they'll check and get back to the patient within the next day or two
- "Surprise" visits role playing as community woman – harder to provide navigation with supervisor than with the community, but good experience for learning to think fast and get organized
- Unorganized (flip chart, insufficient booklets)

Evaluation observational form

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Excerpt from the teaching observation inventory

The Navigator instructor:

- Had materials organized and ready to use when needed? ☐ Yes ☐ No
 - Comments:
- Clearly explained the participant objectives and content ☐ Yes ☐ No
 - Comments:
- Answered participant questions accurately and clearly ☐ Yes ☐ No
 - Comments:
- Directed eye contact to the participants rather than elsewhere ☐ Yes ☐ No
 - Comments:
- Implemented participant interactive activity appropriately ☐ Yes ☐ No
 - Comments:
- Used the ARS appropriately
 - Provided verbal and slide instructions on how to use the keypads ☐ Yes ☐ No
 - Comments:
 - Collection of:
 - Demographic items ☐ Yes ☐ No
 - Comments:
 - Pre-workshop knowledge, attitude, and behavioral items ☐ Yes ☐ No
 - Comments:
 - Embedded opinion or interactive items ☐ Yes ☐ No
 - Comments:
 - Post-workshop knowledge, attitude, and behavioral items ☐ Yes ☐ No
 - Comments:
 - Workshop evaluation items ☐ Yes ☐ No
 - Comments:
 - Overall summary of what the Navigator did well
 - Overall summary and recommendations for what the Navigator needs to improve

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Lessons Learned from Native Sisters / Navigator Programs (these will be skimmed)

- Community-based and -driven programs have many benefits for the community¹
- These take longer to organize and receive funding in comparison to clinical studies.¹
- Healthcare facilities should train and support culturally competent Navigators¹

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Native
Research

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The American Indian Cancer Collaborative for Women's Health [U57 DP001138]
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Skimming of Lessons Learned (continued)

- Program Protocols dependent on funding (i.e., what exists one year may or not exist the next year)²
- Each setting used promotion and recruitment strategies appropriate to the local AI community²




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Skimming of Lessons Learned (continued)

- L.A. and Denver Sisters shared useful information and innovative strategies with one another²
- Sisters' Programs in both settings successful (i.e., 90% of AI participants re-screened as recommended by providers)²



Denver



Los Angeles

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NACR Native Sisters/Navigator Lessons Learned *Published* prior to 2006 (skimming)

- The process needs to be initiated during community education and awareness (focus on prevention)
- Need special efforts for "recruitment to screening" to maximize potential for early diagnosis rather than initiate at time of diagnosis²
- Strategies need to be respectful of our elders³
- Takes 3-5 years to become accepted by the community³


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Skimming Published Lessons Learned (cont.)


- Need to pursue long-term funding (constant effort due to unstable access to funding)³
- Begin with the women's program until men start asking, "what about us?"³
- When you cannot get the men involved, go through the women³
- When asked about "Native Brothers" for Navigation, most AI men said "no"; women were better for these functions or they wanted their wife or sister trained

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Skimming Published Lessons Learned (cont.)

- Navigation desired for overall health, not limited to "cancer"^{3, 6}
- Messages need to be simple, consistent, relevant to overall health and honor our ancestors³
 - "We are standing on the shoulders of our ancestors"*
 - "We need to be healthy again"*
- Sisters' Protocols must address barriers beyond "poverty" (e.g., must be inclusive of psycho-social and sociocultural issues;
 - "If you say the word, 'cancer', you are spreading the cancer spirit to others")*

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Skimming Published Lessons Learned (cont.)

- The Sisters use culturally respectful strategies to increase Natives participation in early detection care"^{3, 6}
- Culturally specific and respectful messages need to be modified for the local Native community³
 - "Have a mammogram to be a well woman" = ineffective*
 - "Take part in well women screening to stay healthy and live to teach your grandchildren"*
- Sisters' Protocols must be tailored to the local community (e.g., Denver and L.A. were similar, but had definite differences)³


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Skimming Published Lessons Learned (cont.)


- No Navigator model that is successful in one setting can simply be implemented into another community. They all require tailoring to be respectful for the new setting.^{3, 6}
- The tailoring of the protocol must be implemented through local AIAN leadership³
- The Sisters require extensive training (40-120 hours) and refresher sessions (quarterly), as well as respond to issues the Navigators are dealing with but for which they did not feel comfortable addressing³

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Skimming Published Lessons Learned (cont.)


- Sisters need to receive a competitive salary and when feasible, full-time with benefits.³
 - ⊕ If not, after trained they are hired by diabetes, HIV and other departments
- The tailoring of the protocol must be implemented through local AIAN leadership³
- The Sisters require extensive training (40-120 hours) and refresher sessions (quarterly), as well as respond to issues the Navigators are dealing with but for which they did not feel comfortable addressing³

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Skimming Published Lessons Learned (cont.)


- Peer education (among Native Sisters) very effective and practical
- Native Sisters advocate for the Patients ...
 - ⊕ Using "I Messages" even though *no* tribal Nation ever talks this way
 - ⊕ But provider can understand the "I Message" rather than traditional story-telling strategies

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Skimming Published Lessons Learned (cont.)


 **HIPAA**

- ⊕ Need approval for every clinic / hospital in which the Native Sister works with patients
- ⊕ Separate paperwork for every clinic / hospital
- ⊕ Confidentiality with family members


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RECENT Challenges Sisters Address


 **Transportation**

- ⊕ Need to purchase supplemental auto insurance to cover both the Native Sister and the patient in case of an accident
- ⊕ Otherwise, the Sister's personal auto insurance gets "hit" with the accident expenses
- ⊕ Ground travel costs ... high cost of gasoline and Sisters may drive 100s of miles
- ⊕ Parking lot full – strategies to keep the patient comfortable inside the clinic until Sister finds parking space


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RECENT Challenges Sisters Address

 **Clinical Settings**

- ⊕ Tours and meet all cancer and therapy related staff (especially the receptionist)
- ⊕ Gets copies of forms specific to each department

 **IHS is *not* insurance**

- ⊕ Alternative funding sources for service and treatment delivery (see the limb, "Help and Support" on the NACES QOL Tree, NatAmCancer.org)

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New Lessons

- Community-based vs. clinic vs. combination
- Native Sisters and cultural appropriateness
- Clinical settings and access to services

AIAN Common Program Challenges, Outreach Strategies, Navigation, Meeting Checklist

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Example of Navigator Training

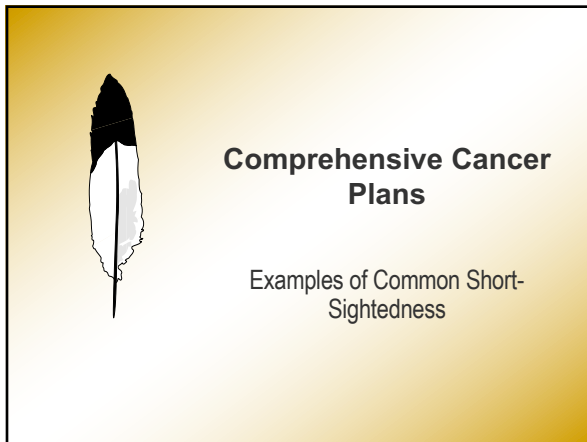
NOTE: Lesson = video tape all training sessions

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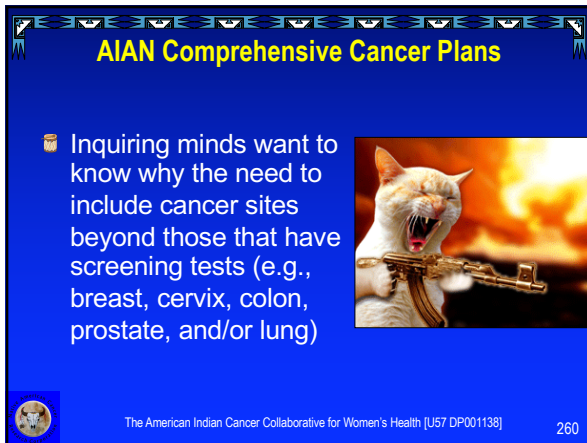
Name of Training	Lead Facilitator	Date
Orientation of Project	Linda Burhanasiponov	Feb 20, 2002
"Cancer" overview	Linda Burhanasiponov	Feb 25, 2002
Cultural concepts of breast cancer	Linda Burhanasiponov	March 10, 2002
Confidentiality	Linda Burhanasiponov	March 15, 2002
Recruitment and Informed Consent Process	Judy Harlow	March 21, 2002
Survey Implementation	Linda Burhanasiponov and Judy Harlow	March 22, 2002
Introduction to XP Windows Software	Tom Martin	May 7, 2002
Confidentiality - Concepts	Linda Burhanasiponov	May 7, 2002
Using the Internet Safely	Tom Martin	May 8, 2002
Breast Cancer 101	Paula Espinoza	May 8, 2002
Word Processing	Tom Martin	May 9, 2002
Tailored Questions - Computer Software	Tom Martin	May 28, 2002
Follow up on earlier trainings	Linda Burhanasiponov and Judy H	May 28, 2002
Breast Cancer 101- Part II	Alice Bradley	May 29, 2002
Navigating the Denver Health System	Grace Atkins	June 4, 2002
Library Tour and Services	Margaret Bandy	July 15, 2002
Power Point	Tom Martin	July 2, 2002
Breast Cancer 102	Sister Ann / Linda Krebs	July 8/9, 2002
Safety Precautions (white in the field)	Police Guest Speaker	July 15, 2002
Hormone Replacement Therapy	Linda U. Krebs	July 21, 2002
Excel	Tom Martin	July 23, 2002
Access	Tom Martin	July 25, 2002
Confidentiality - DNA	Grace Atkins	July 28, 2002
QWCC	Melanie / Mary Kay	July 30, 2002
Training and Follow-up	Judy Harlow	August 1, 2002
Improving Treatment Skills	Linda / Sister Ann / Paula	August 6, 2002

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w.NatAmCancer.org



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The American Indian Cancer Collaborative for Women's Health [U57 DP001138] Demographics, Historical Trauma, Racial Misclassification, Cancer Data, Barriers


Why?

Because once you have a comprehensive cancer plan, potential funders want you to identify your proposal/ application based on the needs identified within the published cancer plan



What in heavens name did we accidentally do?

But, a Plan is better than no Plan at all, ahem (and you can revise your plan)



The American Indian Cancer Collaborative for Women's Health [U57 DP001138]

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So what does this mean?

If your "supposed" *Comprehensive Cancer Plan* does not include:

- childhood cancer
- multiple myeloma
- brain cancer
- head and neck cancer

And you discover that you have an issue with these cancers, funders may hesitate to award your grant because these cancers were not identified as priorities



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Your Plan Might be a Redneck

If your plan is limited to only those types of cancer that have screening tests (breast, cervix, colon, lung, prostate)

If your plan omits segments of your population, such as childhood cancer

If your plan neglects uncommon types of cancer

If your plan neglects quality of life for survivors



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Demographics, Historical Trauma, Racial Misclassification, Cancer Data, Barriers


Your Plan Might Be a Redneck

- If your plan ignores access to care issues, such as insufficient IHS CHS monies by June of each fiscal year
- If your plan omits delays in access to care due to insufficient policies
- If your plan neglects chronic cancer or palliative care
- If your plan is limited to environmental pollution rather than behavior

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Checklist for Meeting Preparations




This list is common for any meeting and is included here for your information ... little to no time will be spent reviewing items unless you want clarification on some item please.

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Preparing for Meetings with Tribal Groups

- Have a key contact that you can ask questions
- Apologize early if you make a mistake or don't know something
- Become familiar with the history of the tribe
- Ask about the correct pronunciation for key names, areas, and symbols
- Look at a map of the area, a museum


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Demographics, Historical Trauma, Racial Misclassification, Cancer Data, Barriers

Setting up Meetings


- Prepare an agenda in advance and let the group discuss any changes first
- Arrange to have food at the meeting
- When possible, send written invitations
- Be sensitive to the lack of email, computer resources for some tribes
- Make sure you avoid ceremonial days or other events

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Setting Up Meetings (cont.)

- Check with local contacts to ensure most appropriate place.
- If more than one tribe/partner, treat them equally
- Work with local contacts to make sure that the right people will be at the meeting to accomplish your goals

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First Meetings

- Use formal titles, especially for elected officials
- Shake hands with people as you meet
- Don't worry if some people don't look you in the eye
- Thank your hosts for inviting you
- Be open to a prayer to start the meeting
- Make sure to greet elders and pay attention when they talk





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During Meetings


-  Wait for others to stop speaking before you start, interrupting is considered rude
-  Make sure that you ask elders or tribal their opinions on critical issues
-  Pauses are normal. Don't feel like you have to fill in time
-  Take notes and rephrase important points to ensure that ideas are accurate










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After the Meeting

-  Follow-up with information or commitments with 10 days
-  Communicate by phone, not just in writing
-  Thank members for their contributions
-  Make repeat visits to the tribe
-  Build lasting relationships
-  Send out minutes, written summaries
-  Include reminders for others



Native Sisters Patient Navigation – Native American Cancer Research <http://NatAmCancer.org>

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Tribal Outreach -- Cancer Information Web Pages



“The American Indian / Alaska Native Initiative on Cancer” (“Spirit of E.A.G.L.E.S.”) [U01 CA86098]
<http://nativeamericanprograms.org>
The BEST source of Native-specific cancer information!

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Tribal Outreach -- Cancer Information Web Pages

 **Native American Cancer Research**
<http://www.NatAmCancer.org>

Examples of free downloads:

- Free downloads of slides from the 5 "Get on the Path to Health" Curricula (breast, cervix, colon, lung, prostate) [each has 6-7 modules]
- "Clinical Trials Education for Native Americans"
- "Native American Palliative Care" Curriculum
- "Native American Cancer Education for Survivors" (NACES) (quality of life interactive education)
- FACT Sheets: Native Elder Cancer Survivors, Tobacco, full continuum of cancer (coming soon)

 Communication Strategies 274


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Tribal Outreach -- Cancer Information Web Pages

University of Michigan Health Systems
Marilyn Roubidoux, M.D. Associate
Professor of Radiology
Mammogram Detective

Provider version: www.med.umich.edu/lrc/breastcancerdetective
Patient version: www.med.umich.edu/lrc/bcdpatient

Mary Alice Trapp, Breast Health Bingo
(same website as provider version of detective)

 Communication Strategies 275

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Give Yourself a Hand!



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