# The Development of a Matrix for Prioritizing Interventions and Research to Address American Indian Cancer Disparities

APHA Session 4014.0: "Advancing community-based public health: The application of innovative methods, strategies, and tools in CBPR"

The aim of the Southwest American Indian Collaborative Network (SAICN) is to reduce cancer disparities in American Indians in the Southwest by closing the gap between the needs of tribal communities and the promise of cancer prevention and cure. This aim can be achieved through community-based participatory research, education and training programs. SAICN is structured as a network of six cores: Policy, Research, Outreach and Services, Administration, Education and Training, and Data and Evaluation. The mission of the Data and Evaluation Core is to promote the development of community-based participatory research (CBPR) in American Indian communities in the Southwest. This mission can be achieved in part by promoting the accurate collection and reporting of cancer in American Indian communities, and providing data-driven recommendations to reduce cancer disparities these communities experience.

A disparity is important to consider when there is an intervention that can correct the disparity and result in a benefit to the community. The following key questions can be asked:

A) Which measures of cancer disparity are important?
B) For which cancer sites are they important?
C) What are the possible interventions to address these important disparities?
D) How wide is the impact of the intervention?
E) What is the relative cost of the intervention?

To generate a narrowed list of recommended actions that efficiently control cancer through primary, secondary and tertiary prevention strategies, the Data and Evaluation Core developed a comparison matrix. The matrix is intended to present scientifically sound actions, their costs, and benefits for use by community health decision makers in prioritizing actions that are likely to reduce their community's burden of cancer. The matrix is accompanied by a profile of the burden of cancer in American Indians in Arizona, which is based on the most recent data available from the Arizona Cancer Registry and the New Mexico Tumor Registry (selected sections from cancer profile on pages 3-6).

The matrix is divided into two sections (pages 7-8). The six disparity measures in Matrix A (Prioritizing interventions and research to address American Indian cancer disparities) were selected based on their burden in American Indians in Arizona and, more importantly, the availability of evidence-based interventions to reduce these disparities. These interventions (which include promoting mammography for early detection of breast cancer and colonoscopy for early detection of colorectal cancer) were identified using recommendations from the US Preventative Services Task Force. The seven disparity measures in Matrix B (Lesser opportunity cancers) are cancers for which there are currently no evidence-based intervention strategies. These cancers have been identified as priorities for tribal communities in Arizona based on concerns voiced by community members and the relatively high burden of these cancers in American Indians in Arizona. Both matrices include a column entitled "Research question to ask"; this column allows community leaders to define a research agenda to further explore risk factors and intervention strategies to address cancer-related disparities that are of particular concern in their communities. Community leaders are ultimately responsible for completing the final column of the matrix, which establishes their community's priorities for cancer interventions and cancer research.

The process of developing the intervention matrix began in early 2006 and involved extensive research on evidence-based cancer prevention strategies, research on the effectiveness, costs and benefits of these strategies, and identifying and compiling cancer burden and cancer screening data from the Arizona

Cancer Registry, the New Mexico Tumor Registry, and the Indian Health Service. The matrix has undergone extensive review by members of SAICN's Data and Evaluation Core and Community Advisory Board, and has been revised and updated to respond to feedback and concerns from these members (see pages 9-10). This process has ensured that the matrix continues to reflect the priorities and needs of tribal communities in Arizona, and supports SAICN's aim to promote CBPR in tribal communities.

The Data and Evaluation Core is currently developing a workshop and toolkit based on the intervention matrix for tribal leaders, tribal health directors and health planners. The goal of this workshop is assist tribal leaders and health planners in using the matrix to determine their Tribe's priorities for cancer prevention and/or research. Once these priorities have been established, SAICN will continue to assist Tribes in implementing their cancer control plans through its network of partnerships and cores.

**Discussion Questions**

1. The incidence rate of cancer in American Indians in Arizona is lower than the rate in the general population. For the years 2001-2003, the incidence rate of cancer for American Indians in Arizona was 208.1 cases/100,000, while the rate in the total population of Arizona was 423.5 cases/100,000. Figure 2 (page 5) compares the incidence rates of cancer for selected sites, by race/ethnicity, for the years 2001-2003, and Figure 4 (page 6) compares the incidence rates of breast cancer by race/ethnicity for the years 1995-2003. The data show that American Indians have the lowest rates of breast, colorectal, prostate and lung cancer compared to other groups in Arizona. However, American Indians have among the worst outcomes for five-year survivorship for breast and colorectal cancer (Figure 3, page 5) and data on breast cancer show that American Indian women are diagnosed at a later stage compared to other racial/ethnic groups (Figure 5, page 6).

    a. How can these data be used to prioritize efforts to reduce health disparities? Does prioritizing mean making a choice between investing in primary prevention vs. secondary/tertiary prevention?

    b. What are the costs/benefits of promoting interventions in low-incidence populations?

2. Most tribal communities in the Southwest have younger populations compared to the general population. How will this difference affect prevention/intervention strategies in these communities? Do the recommendations from USPSTF need to be adjusted to account for this?

3. How do we balance providing information and recommendations with keeping a community's priorities first (when does the CB part of CBPH/CBPR get lost)?

4. What are the costs and benefits of investing in evidence-based prevention/interventions vs. investing in research? Are these approaches mutually exclusive?

5. Can this tool be adapted for use in other tribal communities or other populations that experience cancer health disparities? What would this process involve?

**Southwest American Indian Collaborative Network**
http://www.itcaonline.com/program_saicn.html

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**Selected pages from the American Indian Intervention Matrix for Addressing Cancer Disparities**

## Overall Cancer Burden

First, we present general information about the burden of cancer in American Indians in Arizona in *Table A,* showing the count of cases by year. Then, in *Table B & C* we show the count for specific cancer sites diagnosis and mortality.[1] The counts of cancer cases in Arizona are obtained from the Arizona Cancer Registry (which records cases seen at non-IHS facilities) and the New Mexico Tumor Registry (which records cases seen at IHS facilities in Arizona and New Mexico).

**Table A.**

Count of Incident Cancer by Sex and Year; Arizona, Sum of the reported cases diagnosed during 2001-2004; American Indians; All cancer sites [Source: AZ Cancer Registry, IBIS, run date 12/13/2006.]

| Year | Male | Female | Total |
|---|---|---|---|
| **2001** | 161 | 183 | 344 |
| **2002** | 157 | 176 | 333 |
| **2003** | 177 | 213 | 390 |
| **2004** | 155 | 206 | 361 |
| **Total** | 650 | 778 | 1,428 |

**Figure 1. Distribution of Incident Cancer Case for American Indians, Arizona, 1999-2003.**

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Source: Arizona Cancer Registry, IBIS. July 30, 2007

**Table B.**

Count of Incident Cancer by Sex and Year; Arizona, Sum of the reported cases diagnosed during 2001-2004 (**4-year totals and average**); American Indians [Source: AZ Cancer Registry, IBIS, run date 9/21/2007]

| Cancer Sites | 4-yr Male | 4-yr Female | 4-yr Total | Yearly Average |
|---|---|---|---|---|
| Breast | 1 | 173 | 174 | 44 |
| Kidney/Renal Pelvis* | 86 | 49 | 135 | 34 |
| Colorectal | 52 | 51 | 103 | 26 |
| Prostate* | 126 | . | 126 | 32 |
| Lung and Bronchus | 43 | 38 | 81 | 20 |
| Corpus Uteri and Uterus, NOS | . | 80 | 80 | 20 |
| Stomach* | 34 | 23 | 57 | 14 |
| Non-Hodgkins Lymphoma* | 34 | 22 | 56 | 14 |
| Liver | 30 | 23 | 53 | 13 |
| Leukemia* | 31 | 21 | 52 | 13 |
| Pancreas* | 19 | 29 | 48 | 12 |
| Thyroid* | 8 | 39 | 47 | 12 |
| Ovary* | . | 39 | 39 | 10 |
| Cervix Uteri | . | 29 | 29 | 7 |
| Oral Cavity | 10 | 9 | 19 | 5 |
| Cutaneous Melanoma* | 6 | 11 | 17 | 4 |
| Urinary Bladder | 9 | 3 | 12 | 3 |
| Hodgkins Lymphoma* | 3 | 1 | 4 | 1 |
| Other* | 158 | 138 | 296 | 74 |
| Total | 650 | 778 | 1,428 | 357 |

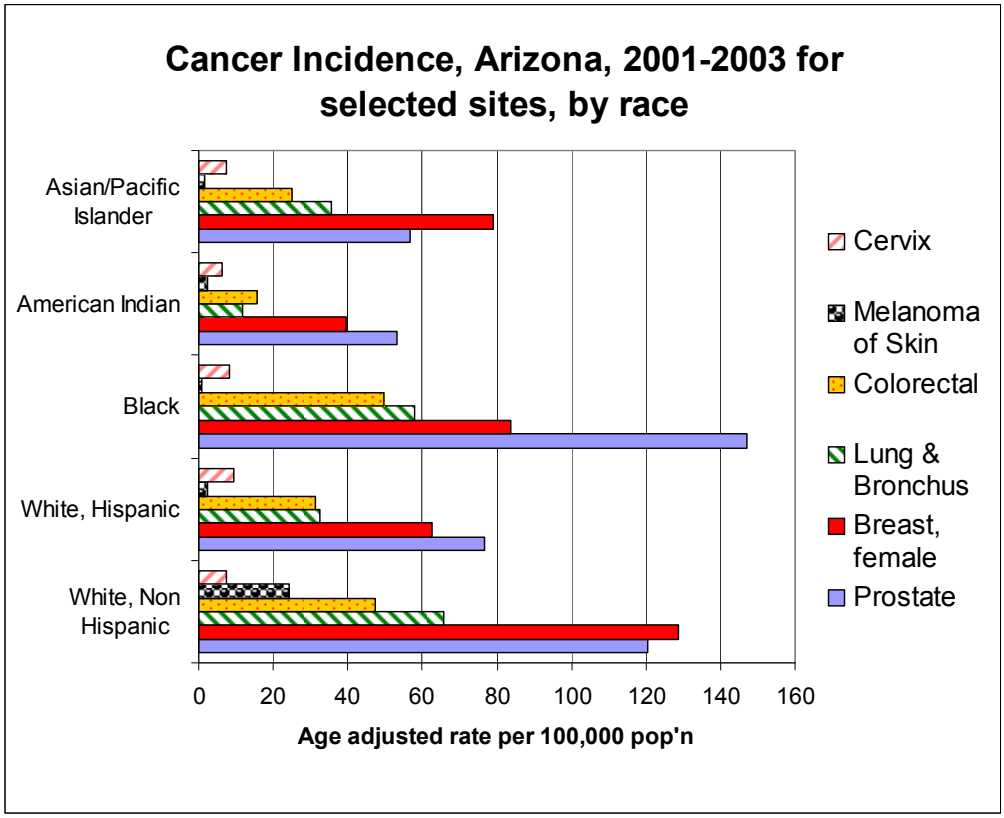
*These are cancer sites for which primary or secondary prevention programs are not yet evidence-based. That is to say, the benefits of prevention or early detection in the average-risk population are still unclear for this cancer site.

[1] To generate your own queries see the ACR website **http://www.azdhs.gov/phs/phstats/acr/index.htm**

**Table C.**

| Count of Cancer Mortality by Sex and Year; Arizona, Sum of the reported cases diagnosed during 2001-2006 (**6-year totals and average**); American Indians [Source: AZ Health Status and Vital Statistics] | | | |
|---|---|---|---|
| **Cancer Sites** | **6-yr Male** | **6-yr Female** | **Yearly Average** |
| **Trachea, Bronchus And Lung** | 45 | 42 | 15 |
| **Liver** | 37 | 39 | 13 |
| **Stomach** | 42 | 33 | 13 |
| **Kidney** | 47 | 24 | 12 |
| **Breast** | - | 70 | 12 |
| **Colon, Rectum And Anus** | 34 | 30 | 11 |
| **Pancreas** | 30 | 32 | 10 |
| **Prostate** | 57 | - | 10 |
| **Non-Hodgkin's Lymphoma** | 22 | 22 | 7 |
| **Leukemia** | 19 | 23 | 7 |
| **Ovary** | - | 42 | 7 |
| **Cervix** | - | 25 | 4 |
| **Corpus Uteri** | - | 17 | 3 |
| **Esophagus** | 16 | 34 | 3 |
| **Uterus** | - | 17 | 3 |
| **Meninges, Brain And CNS** | 10 | 6 | 3 |
| **Bladder** | 6 | 8 | 2 |
| **Lip, Oral Cavity And Pharynx** | 10 | 2 | 2 |
| **Skin** | 6 | 2 | 1 |
| **Larynx** | 2 | 1 | 1 |
| **Hodgkin's Disease** | - | - | - |
| **Other Sites** | 87 | 84 | 29 |
| **Total** | 470 | 553 | 171 |

**Figure 2. Cancer Incidence by Race for Selected Sites, Arizona, 2001-2003.**




Source: Arizona Cancer Registry, IBIS. Dec 13, 2006

**Figure 3. Colorectal and Breast Cancer 5-year Survivorship by Race, 1990-2004.**

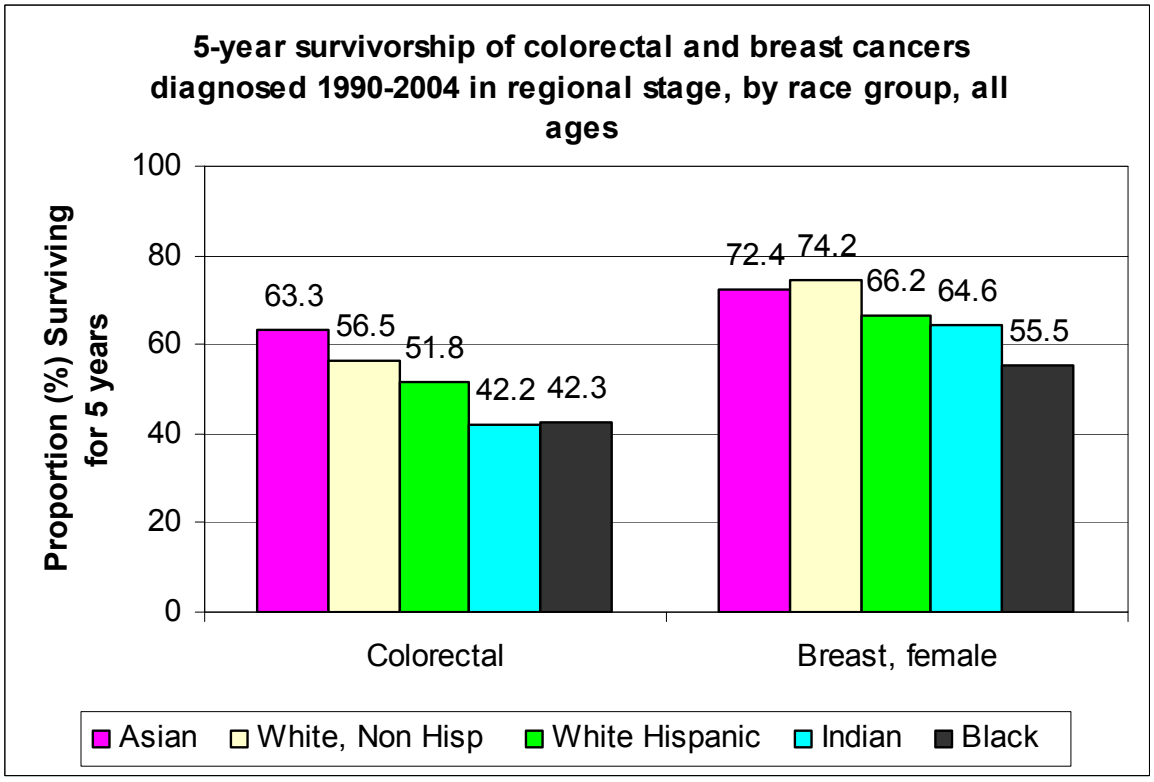
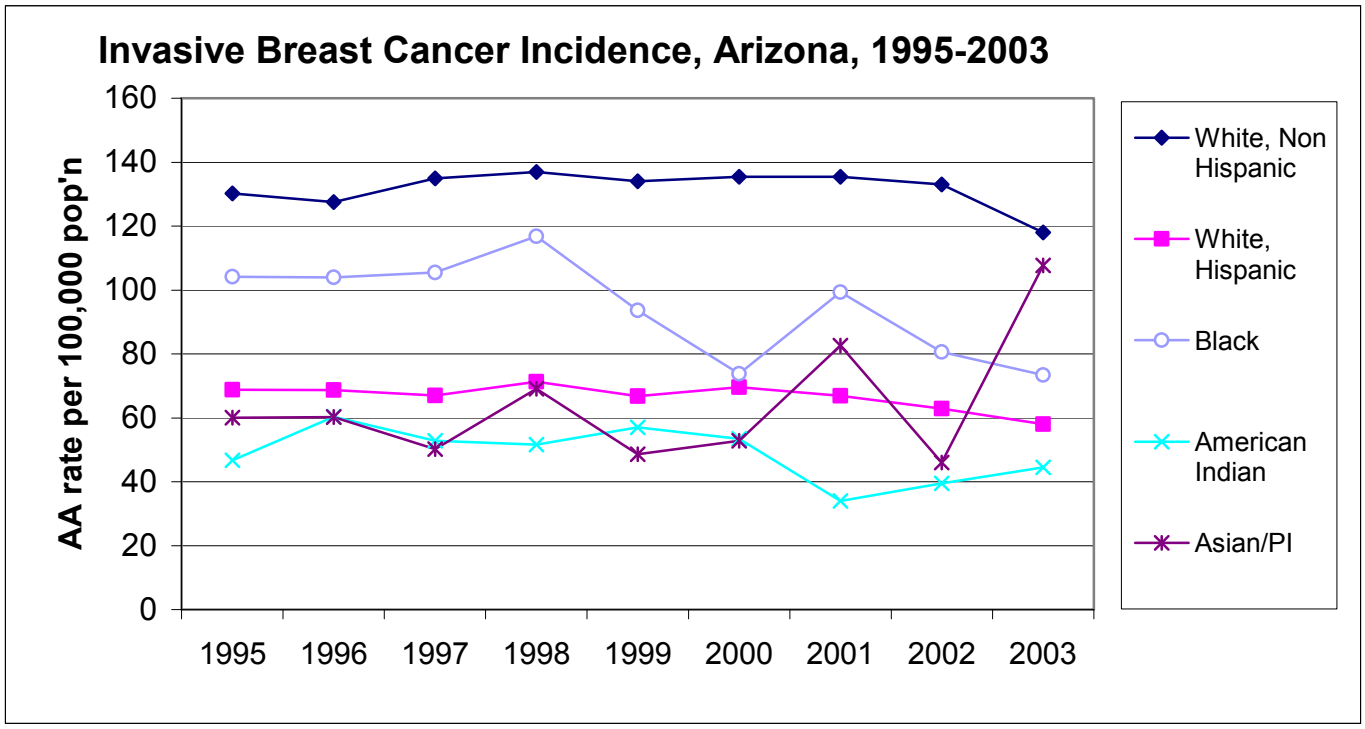
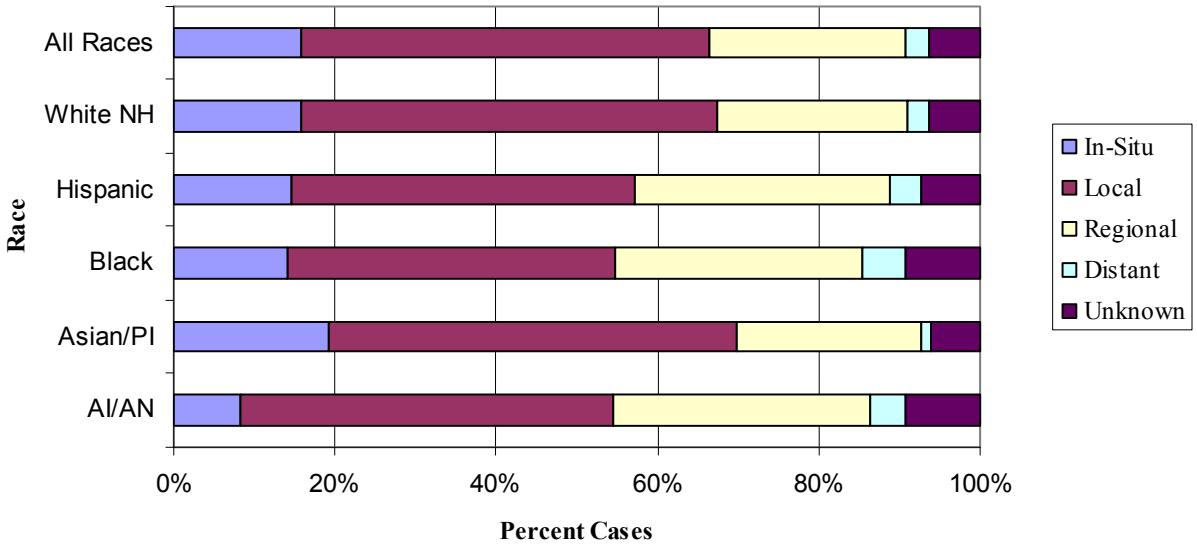


**Figure 4. Incidence Rate of Breast Cancer, Arizona, 1995-2003.**




Source: Arizona Cancer Registry, IBIS. Dec 13, 2006

**Figure 5. Breast Cancer, Stage at Diagnosis by Race, 1995-2002.**




Source: Archana Minnal, MPH, 2005, unpublished analysis of ACR data.

## Matrix A: Prioritizing interventions and research to address American Indian cancer disparities. (The list is in no particular order.)

| Disparity Measure | Scale of Problem in AZ American Indians (4-year avg)^ | Risk Factors & Potential Interventions | Intervention Metric for American Indians (3-year avg) [%; baseline*; *Target if known*] | How well does intervention work? [i] [high-med-low] Addt'l benefit? | Important cultural aspects to consider (pos or neg) | For an Average-risk Population … | | Research Question to Ask# Ease of implementation in this pop'n | Priority# for Intervention / Priority# for Research |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | | Cost and Health Benefit of Intervention | Number to Screen& to Save One Life | | |
| **Previously high (now equal) AI incidence rate of:** 1) Cervical Cancer | Invasive cervical cancer cases, 2001-2004: 7 | • Increase utilization of Pap smear; • Provide HPV Vaccination; • Encourage abstinence | % women aged 21-64 w/ Pap recorded w/in 3 years = 55.8% (Phx Area); ___% (Tuc Area); ___% (Nav Area); *IHS 2010 goal: 90%* | Incidence rates in AI droopped in recent years; now are lower than in White pop'n. | | $14,000 per year of life saved from cervical screening at age 20-74 once every 3 years[ii] | 1,254 (range 1,140 - 1,367) All ages | What intervention has worked well? | |
| **Low AI incidence rates of cancer:** 2) Tobacco-linked cancers | Tobacco-related cancer cases, 2001-2004: Oral: 5 Lung: 18 Bladder: 3 | • Adult smoking cessation programs • Youth smoking prevention programs | % of patients 18 and over who are active clinical tobacco users (2006-7 avg) = 18.1% (Phx Area); ___% (Tuc Area); ___% (Nav Area); *IHS 2010 goal: none* | Unknown effectiveness in Native American cultures | Some tribes use tobacco in sacred ceremonies | $1,100/QALY saved for adult counseling by clinician[iii] | | What factors led to low smoking rates? Are smoking rates increasing? | |
| **Late stage in AIs of:** 3) Breast Cancer | Invasive breast cancer cases, 2001-2004: 42 | • Promote mammography | % women aged 52-64 with mammogram recorded w/in 2 years = 28.4% (Phx Area); ___% (Tuc Area); ___% (Nav Area); *IHS 2010 Goal: 70%* | The low incidence rate in AIs creates false positive screening tests | | $22,000/QALY saved for biennial MMG of women age 50-69[iv] | 691 (range 543 - 838) Age 50+ | | |
| **Late stage in AIs of:** 4) Colorectal Cancer | Invasive colorectal cancer cases, 2001-2004: 25 | • Promote colonoscopy | % of people aged 51-80 w/ CRC screening recorded (any method)= 13.7% (Phx Area); __% (Tuc Area); __% (Nav Area); *IHS 2010 goal: 50%* | The low incidence rate in AIs creates false positive screening tests | | $11,900 (range $7300 to $22,000) per life-year saved using colonoscopy[v] | See note.[vi] 237 (range 42-431) Age 70+; Unknown for Age 45-74 | Can family history improve the yield? | |
| **Utilization of:** 5) end-of-life service [this is difficult to measure or document] | Deaths from all malignant neoplasms: 2003 = 169 2004 = 192 2005 =177 | • At-home or institutional hospice services • ?? Patient navigator | ? | In past, few AIs lived long enough to get cancer. | "Death" is a difficult topic to discuss in many cultures. | Not available | Not applicable | -Hospice survey for cultural services. -What works? | |
| **High rate in AI of : (other risk factors)** 6) [BRFS; special surveys?] | For obesity, despite high overall BMI the cancer rates are quite low in AI. | • Obesity is linked to cancer of gall bladder, breast, urinary bladder, uterus, kidney, ovary, colon, prostate | % of patients aged 2-74 overweight/obese = 75.5%; % of patients aged 20-74 overweight/obese = 85.6%; *IHS 2010 goal: <=15% obesity in adults* | Obesity has proven difficult to control; would also help control diabetes. | | $10,000/QALY saved for physician counseling about physical activity[vii] | unknown | | |

Data Source: Phoenix Area Clinical Reporting System 2005-07 (represents Phoenix Area clinical service units and users only, GY 2007 = July 1 2006-June 30 2007)

^ ACR = Arizona Cancer Registry # Community leaders will complete these columns.

& The striked-out figures refer to an "average risk" population, which is not the case for Indians, who are at lower-than-average risk.

## Matrix B: Lesser opportunity cancers (The list is in no particular order.)

| Disparity Measure | Scale of Problem in AZ American Indians (4-year avg)^ | Risk Factors; Potential Interventions | Intervention Metric for Amreican Indians [%; baseline; target] | Relative Effectiveness of Intervention [high-med-low] | Relative Cost and Benefit of the Intervention | Research Question to Ask# | Priority# for Intervention<br>Priority# for Research |
|---|---|---|---|---|---|---|---|
| **High incidence rate of:**<br>7) Liver Cancer | Invasive liver cancer cases, 2001-2004: 13 | • Alcohol avoidance; CAGE questionnaire<br>• Hepatitis B immunization<br>• Screen for Hepatitis C | Not applicable | unknown | unknown | | |
| **incidence rate of:**<br>8) Melanoma of skin | Invasive cutaneous melanoma cancer cases, 2001-2004: 4 | • Reduce sun exposure, especially in childhood | Not applicable | unknown | Not applicable | | |
| **High incidence rate of:**<br>9) Kidney and renal pelvis Cancer | Invasive kidney & renal pelvis cancer cases, 2001-2004: 33 | • No proven intervention; needs research | Not applicable | Not applicable | Not applicable | | |
| **incidence rate of:**<br>10) Pancreas Cancer | Invasive pancreas cancer cases, 2001-2004: 12 | • No proven intervention; needs research | Not applicable | Not applicable | Not applicable | | |
| **incidence rate of:**<br>11) Prostate Cancer | Invasive prostate cancer cases, 2001-2004: 30 | • Early detection has not been shown to prolong life | unknown | unknown | | | |
| **incidence rate of:**<br>12) Stomach Cancer | Invasive stomach cancer cases, 2001-2004: 14 | • Avoid alcohol, tobacco, and pickled or salty foods<br>• Screen for Helicobacter pylori | Not applicable | Not applicable | Not applicable | | |
| **incidence rate of:**<br>13) Gallbladder Cancer | | • Risk factor = gallstones and obesity | Not applicable | unknown | Not applicable | | |

^ ACR = Arizona Cancer Registry

# Community leaders may complete these cells.

**Table D. Comments from community and SAICN members as the matrix was developed.**

<table>
<tr><th>Comment or Issue</th><th>Response</th></tr>
<tr><td>Tribal Health Director</td><td></td></tr>
<tr><td>Is there a family history assessment of cancer that can be used to address the individual's risk of cancer?</td><td>This question is relevant because a positive family history may help target screening programs and raise the predictive value of the screening test. For most cancer sites it is not possible to quantify the risk that a positive family history adds to an individual's risk. An exception is breast cancer. The website http://www.cancer.gov/bcrisktool/ allows a woman to determine risk for breast cancer. It includes family history as one of the factors.</td></tr>
<tr><td>NCI/CIS Coordinator at ACR</td><td></td></tr>
<tr><td>1. To increase confidence and understanding of the counts, can we describe the completeness of case ascertainment?<br><br>2. What was the proportion of cases in the Arizona registry that were not classified as to race/ethnicity?</td><td>1. Since 1995 the ACR has achieved the registration of approximately 90-95% completeness of cases as determined by the quality assessment by the North American Association of Central Cancer Registries. In order to accurately count cases among the American Indian population, the ACR exchanges data with the New Mexico Tumor Registry and the Indian Health Service. This exchange allows the ACR to include cases seen only at the IHS facilities.<br>2. The table below displays information about unclassified race. In general, the unclassified proportion is very low.<br><br>2. Proportion of cases diagnosed 1995-2003 for which the race/ethnicity is coded as "Other or unknown" [Source: AZ Cancer Registry; IBIS]
<table>
<tr><th>Cancer Sites</th><th>"Other" race including Unknown Race</th><th>All races combined</th><th>Proportion coded as "Other and Unknown Race"</th></tr>
<tr><td>Oral Cavity</td><td>57</td><td>4,000</td><td>1.4%</td></tr>
<tr><td>Stomach</td><td>47</td><td>2,992</td><td>1.6%</td></tr>
<tr><td>Colorectal</td><td>137</td><td>20,812</td><td>0.7%</td></tr>
<tr><td>Pancreas</td><td>22</td><td>4,352</td><td>0.5%</td></tr>
<tr><td>Lung and Bronchus</td><td>171</td><td>28,006</td><td>0.6%</td></tr>
<tr><td>Cutaneous Melanoma</td><td>122</td><td>7,852</td><td>1.6%</td></tr>
<tr><td>Breast</td><td>378</td><td>28,725</td><td>1.3%</td></tr>
<tr><td>Corpus Uteri and Uterus, NOS</td><td>65</td><td>4,459</td><td>1.5%</td></tr>
<tr><td>Cervix Uteri</td><td>38</td><td>1,745</td><td>2.2%</td></tr>
<tr><td>Ovary</td><td>35</td><td>3,377</td><td>1.0%</td></tr>
<tr><td>Prostate</td><td>1,493</td><td>27,500</td><td>5.4%</td></tr>
<tr><td>Urinary Bladder</td><td>124</td><td>9,693</td><td>1.3%</td></tr>
<tr><td>Kidney/Renal Pelvis</td><td>43</td><td>5,320</td><td>0.8%</td></tr>
<tr><td>Thyroid</td><td>65</td><td>3,184</td><td>2.0%</td></tr>
<tr><td>Hodgkins Lymphoma</td><td>12</td><td>953</td><td>1.3%</td></tr>
<tr><td>Non-Hodgkins Lymphoma</td><td>107</td><td>7,324</td><td>1.5%</td></tr>
<tr><td>Leukemia</td><td>55</td><td>4,430</td><td>1.2%</td></tr>
<tr><td>Other cancers</td><td>259</td><td>26,335</td><td>1.0%</td></tr>
</table></td></tr>
<tr><td></td><td></td></tr>
<tr><td>We should note that BRFSS does not reach into the rural Indian community very well because of the poor telephone coverage on most reservations.</td><td>This is a good point. At a conference in Nov 2006 Cheryl Mason of the Navajo Epidemiology Center noted that 60% of the homes on the Navajo Reservation lack a land-line telephone and thus Navajo's would be underrepresented in statewide telephone surveys, such as the BRFSS. Look for the few tribe-sponsored and tribe-specific surveys.</td></tr>
<tr><td></td><td></td></tr>
</table>

| Comment or Issue | Response |
|---|---|
| **Dr. ----** : Does increased calcium intake reduce the incidence of colorectal cancer? | This is a potential research question. |
| | |
| **Researcher, Arizona Cancer Center** | |
| Engage healers. Health literacy. | Tribes are aware of the value and importance of traditional healers to their members. Health literacy remains a challenge. |
| | |
| **Private Provider** | |
| Spirituality. Access to care. Transportation. | These aspects can affect efforts and the effectiveness of interventions. These vary between tribes. Issues relating to spirituality probably cannot be measured. In Alaska they offer a referral to a spiritual healer when patients are discharged. |
| | |
| **Private Provider** | |
| Understanding how the cancer "system" works. | Navigators appear to be effective. The "system" is tribe-specific and will be known best by individual tribes. |
| | |
| **Anon.** | |
| Disparities in funding, resources, providers, presence of community based organizations, leadership. | |
| We should add "opportunity for research" as a measure of cancer disparity. | |
| | |
| **County Tobacco Coordinator** | |
| "Healing" needs to consider both external and internal aspects. | Traditional healing ceremonies are "external." On the other hand, western medicine treatments are often aimed internally; this may be perceived negatively. |
| For some patients, speaking of death might be perceived negatively. | End of life treatment should focus positively on easing of suffering and pain. This is a topic that can be researched with families. |
| | |
| **Anon.** | |
| Are we diagnosing cancer early enough? (i.e. age at diagnosis, stage) | |
| Is the proportion of unknown survivorship or follow-up status the same across all the racial/ethnic groups? | |

**Endnotes**

[i] **http://www.prevent.org/content/view/51/104/**

[ii] Partnership for Prevention, 2001, citing Eddy, Ann Int Med 1990;133(3);214-226.

[iii] Solberg, Am J Prev Med 2006;31(1):62–71

[iv] op cit 2, citing Salzman, Ann Intern Med 1997;127(11):955-65.

[v] Maciosek, Am J Prev Med 2006;31(1):80-89

[vi] See Taylor WC. A 71-year-old woman contemplating a screening colonoscopy. JAMA March 8, 2006. V.295(10):1161-1167.

[vii] op cit 2, citing Coffield, Am J Prev Med 2001;21(1):1-9