

# **Urban American Indian/Alaska Native Breast and Cervical Cancer Screening Service Description**

**September 2005**



A division of the Seattle Indian Health Board

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**Executive Summary  
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This report provides baseline data on efforts to provide breast and cervical cancer services for populations of urban American Indian and Alaska Native (AI/AN) women who reside in the service areas of 34 Urban Indian Health Organizations (UIHO). There are 19 states with one or more UIHOs. The 34 UIHOs were surveyed January-March 2005 to gather information on the UIHO service population demographics, the types and level of breast and cervical cancer services provided, the rates of screening, and the key social determinants that affect screening practices. Thirty three UIHOs responded to the survey. In addition, State breast and cervical health programs for each of the 19 states with a UIHO were surveyed April-May 2005 to gather information on state AI/AN demographics, number of AI/AN women screened by the state program, key social determinants affecting screening practice and AI/AN representation on state advisory coalitions. All 19 states participated in the survey.

## **Background**

### **Description of Urban Indian Health Organizations**

In 1976 the Indian Health Care Improvement Act (PL94-437) was passed, spelling out the federal government's responsibilities for Indian Health. Title V of the Act specifically provided language "to establish programs in urban centers to make health services more accessible to urban Indians." The Indian Health Service (IHS), the agency responsible for carrying out the Indian Health Care Improvement Act, contracts and grants to 34 independent, private, not-for-profit urban health organizations across the country. Urban Indian health receives approximately 1% of the overall IHS budget.

The 34 organizations are as different as the individuals they serve. They serve approximately 150,000 clients annually, with a service area of 82 U.S. counties in 19 states. UIHO services range from offering full comprehensive primary medical to outreach and referral sites, where clients are connected to local non-Indian health providers.

A major obstacle for the UIHOs is the lack of data on the populations they target and serve. Although IHS keeps extensive records on the AI/AN populations living on or near the reservations, very little effort is made to incorporate the UIHO data into the IHS data collection system. In addition, substantial miscoding of AI/AN race on vital records has been well documented.<sup>1,2</sup> Such errors have resulted in consistent underestimation of infant mortality, injuries, cancer incidence, and mortality rates.<sup>3,4,5,6</sup> Therefore, disparities are likely to be undetected and unmonitored. Without accurate data, it is not possible to assess the true need for programs to address health disparities. These present challenges in efforts to collectively describe the health status of the urban AI/AN population, and to ensure that programmatic and policy decisions which address AI/AN health are correctly made.

The 34 UIHOs are located in 19 states (Table 1).

**Table 1. List of Urban Indian Health Organizations by State.**

<i>State</i>	<i>Name of UIHO</i>	<i>Location</i>
Arizona	Native Americans for Community Action	Flagstaff, AZ
	Native American Community Health Center	Phoenix, AZ
	Inter-Tribal Health Care Center	Tucson, AZ
California	Bakersfield American Indian Health Project	Bakersfield, CA
	Fresno Indian Health Association	Fresno, CA
	United American Indian Involvement, Inc.	Los Angeles, CA
	Sacramento Urban Indian Health Project, Inc.	Sacramento, CA
	San Diego American Indian Health Center	San Diego, CA
	Indian Health Center of Santa Clara Valley, Inc.	San Jose, CA
	American Indian Health & Services	Santa Barbara, CA
	Native American Health Center	Oakland, CA
Colorado	Denver Indian Health and Family Services	Denver, CO
Illinois	American Indian Health Service of Chicago, Inc.	Chicago, IL
Kansas	Hunter Health Clinic	Wichita, KS
Massachusetts	North American Indian Center of Boston, Inc.	Jamaica Plain, MA
Michigan	American Indian Health and Family Services	Detroit, MI
Minnesota	Indian Health Board of Minneapolis	Minneapolis, MN
Montana	Indian Health Board of Billings, Inc.	Billings, MT
	North American Indian Alliance	Butte, MT
	Indian Family Health Center	Great Falls, MT
	Helena Indian Alliance	Helena, MT
	Missoula Indian Center	Missoula, MT
Nebraska	Nebraska Urban Indian Health Coalition	Lincoln, NE
Nevada	Nevada Urban Indian, Inc.	Reno, NV
New Mexico	First Nations Community Health Source	Albuquerque, NM
New York	American Indian Community House	New York, NY
Oregon	Native American Rehabilitation Association of the NW, Inc.	Portland, OR
South Dakota	South Dakota Urban Indian Health, Inc.	Pierre, SD
Texas	Urban Inter-Tribal Center	Dallas, TX
Utah	Indian Walk-In Center	Salt Lake City, UT
Washington	Seattle Indian Health Board	Seattle, WA
	N.A.T.I.V.E. Project	Spokane, WA
Wisconsin	United Amerindian Health Center, Inc.	Green Bay, WI
	Gerald L. Ignace Indian Health Center, Inc.	Milwaukee, WI

**Description of National Breast and Cervical Cancer Early Detection Program**

The National Breast and Cervical Cancer Early Detection Program, administered by the Centers for Disease Control and Prevention (CDC), helps low income, uninsured, and underserved women gain access to lifesaving screening programs for early detection of

breast and cervical cancers.<sup>7</sup> Established in 1991, the program is currently implemented in all 50 states, 4 U.S. territories, the District of Columbia, and 13 AI/AN organizations, of which one is specifically focused on an urban AI/AN population.

NBCCEDP continues to support an array of strategies that work together synergistically to achieve these results. Examples of some of these strategies include:

- Coalitions and Partnerships
- Public Education and Outreach
- Professional Education: Enhancing Health Care at the Source
- Screening, Follow-Up, and Case Management
- Quality Assurance for Screening and Follow-Up.
- Improving Access to Treatment

## **Key Findings**

### **Demographics**

Nearly 70% of AI/AN in the United States live in cities, as opposed to non-urban reservations. From the 2000 Census, 1,000,254 AI/AN were reported in 1999 to reside in the 34 UIHO service areas. Of these, 573,225 report AI/AN as their only race. The 34 UIHO contract with the Indian Health Service to provide healthcare to the urban AI/AN population.

Of the 573,225 who identified themselves as only AI/AN, 195,890 (34%) were females 18 years and older and 47,654 (8%) were females between 50 and 64 years.

Of the 195,890 AI/AN females 18 years and older, 45,451 (23%) were living at 100% of poverty; 7,596 (4%) between 50 and 64 years were living at 100% of poverty.

Of the 688,606 AI/AN females 18 years and older living in these 19 states, 161,890 (24%) were living at 100% of poverty.

### **Breast and Cervical Cancer Screening Services**

Table 2 summarizes breast and cervical cancer screening numbers for states and UIHOs. In the 2003 fiscal year (FY), the UIHO collectively served 150,725 women; 89,298 (60%) were AI/AN. The state breast and cervical health programs collectively served an average annual of 9,694 AI/AN women.

Of 34 UIHO, 32 offer breast and cervical cancer early detection services. On-site mammography is available at one UIHO and off-site referrals are provided by 30 UIHO. On-site clinical breast exams are provided by 22 UIHO and off-site referral for breast exams are provided by 8 UIHO. On-site pelvic exams are provided by 19 UIHO and off-site referral for pelvic exams are provided by 7 UIHO.

As part of the breast and cervical cancer early detection services offered by the 25 UIHOs with data, 2,111 women were provided mammography in FY2003 (Table 3). For the same time period, 4,749 women 18 years and older and 2,583 women between 50 to 64 years were provided clinical breast exams. 6,697 women 18 years and older and 1,927 women between 50 to 64 years were provided pelvic exams.

### **Social Determinants Affecting Screening Practices**

Various key social determinants and barriers that affect screening practices were identified by the UIHO. These included: transportation, lack of interest/education or awareness, funding, referral to non-AI/AN clinics, staffing, wait times for appointments, homelessness, poverty, mobile population, lack of services/equipment and/or mobile mammogram services, embarrassment/shyness, childcare and lack of insurance.

States also identified various key social determinants affecting screening practices. These included: geographic isolation, cultural barriers and beliefs, lack of insurance, education, historical relationship with IHS, access, fear, communication, childcare, and lack of funding to provide services.

### **Reimbursement**

Of the 32 UIHO that provide breast and cervical cancer early detection services, 21 receive state BCHP reimbursement, 18 receive Medicare reimbursement, 21 receive Medicaid reimbursement, and 16 receive private insurance company reimbursement. Ten UIHO have state contracts or memorandum of agreements; 16 are interested in receiving such contracts that include reimbursement for services.

Of the 9,694 AI/AN women collectively screened by the state programs, 9,128 were screened with federal dollars and 333 were screened with state dollars. There were 2,034 AI/AN women screened with tribal dollars. None were screened exclusively with Susan B. Komen dollars and none of the states were aware of other sources through which AI/AN women were screened.

### **Coalitions and Partnerships**

Seven UIHOs participated on state advisory committees or coalitions for breast and cervical cancer, and ten reported attending state continuing education functions.

Fourteen states had any AI/AN representation on their state advisory coalition for breast and cervical cancer or cancer committees. Five states have AI/AN representation for their state comprehensive cancer control program and two states have AI/AN representation on their breast and cervical cancer coalition. Six states had a tribal representative, two states had an urban AI/AN representative and four states had both tribal and urban representatives.

## **Recommendations**

In summary, our results document an unmet level of need in breast and cervical cancer services among the AI/AN who reside in urban areas. Both UIHOs and states reported many factors influencing screening behaviors. Targeting these barriers should be an important part of increasing the screening rates in this population.

However, other types of barriers less easily identified, were found. Inconsistencies in the data reported by UIHOs and states for common questions suggested a lack of knowledge and awareness of NBCCEDP partners' activities. For example, twelve to 13 states had no knowledge about Tribal or other screening programs for AI/AN women. This lack of information translated into small numbers of UIHOs (eight) that reported MOAs with their states for conducting breast and cervical cancer screening. Several states reported a lack of collaboration and coordination between the NBCCEDP partners. In general, there existed a lack of awareness and/or coordination related to screening activities between the UIHO, the Tribes and the States.

One of the NBCCEDP strategies includes developing coalitions and partnerships. While knowledge, communication, and coordination are all critical for achieving this, cultural competency is essential for developing successful collaborations within the AI/AN community. This is supported by findings from the states' survey that identified cultural barriers and beliefs as the second most common social determinant to affect screening.

Addressing and increasing breast and cervical cancer screening rates in the urban AI/AN population requires all of the above. Strategies to mend the disconnect between the different partners should consider increased education, communication, improved urban AI/AN representation on state committees and coalitions, as well as utilization of liaisons. In order to maximize resources and promote greater efficiency, liaisons with knowledge and sensitivity towards AI/AN cultural issues, a proven track record in technical assistance, and an established relationship with the UIHO, is essential for successfully reaching the urban AI/AN population.

Developing collaborative partnerships between urban Indian health organizations, the Tribes, and the state programs appear to be an important step towards increasing the breast and cervical screening rates in the AI/AN population. These collaborations may potentially be further translated into future program planning and intervention strategies that target this population.

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**Table 2. Number of Women Screened by State and UIHOs**

<b>States</b>	<b>Number of AI/AN Women Screened by State</b>	<b>Number of Women Screened by UIHO*</b>
Arizona	294 <sup>1</sup>	≥368
California	≥2063	>502
Colorado	266 <sup>2</sup>	≥170
Illinois	112 <sup>3</sup>	≥43
Kansas	143	≥1421
Massachusetts	27 <sup>4</sup>	≥3
Michigan	675 <sup>2, 5</sup>	DNA
Minnesota	593 <sup>6</sup>	DNA
Montana	350 <sup>7</sup>	≥1273
Nebraska	825	≥301
Nevada	94 <sup>8</sup>	0
New Mexico	2784 <sup>9</sup>	≥1000
New York	1586	DNA
Oregon	33 <sup>7</sup>	≥476
South Dakota	1404	≥137
Texas	≥23	≥650
Utah	87 <sup>10</sup>	DNA
Washington	208 <sup>11</sup>	>524
Wisconsin	214 <sup>9</sup>	≥202

DNA=Data not available

\*Total number of women screened for all UIHOs in 2003 in the state

<sup>1</sup>Average annual number from 1999-2003

<sup>2</sup>Year 2004

<sup>3</sup>Total # AI/AN women with breast and/or cervical cancer screen; may be duplicate counts.

<sup>4</sup>Year 2003

<sup>5</sup>Age 40-49

<sup>6</sup>Average annual number from 1993-2005

<sup>7</sup>FY2004-2005

<sup>8</sup>Average annual number from 1997-2005

<sup>9</sup>FY2003-2004

<sup>10</sup>Average annual number from 1994-2004

<sup>11</sup> 6/30/04-1/31/05.

**Table 3. Number of Women Screened or Referred for Screening by UIHOs in 2003**

<b>Name</b>	<b>Location</b>	<b>Mammography Age 50-64</b>	<b>Clinical Breast Exam Age&gt;18</b>	<b>Pelvic Exam Age&gt;18</b>	<b>Total # Screened</b>
First Nations Community Health Source	Albuquerque, NM	200	150	1000	≥1000
Bakersfield American Indian Health Project	Bakersfield, CA	40	60	60	≥60
Indian Health Board of Billings, Inc.	Billings, MT	30	225	225	≥225
North American Indian Alliance	Butte, MT	8	48	48	≥48
American Indian Health Service of Chicago, Inc.	Chicago, IL	21	43	43	≥43
Urban Inter-Tribal Center	Dallas, TX	400	650	650	≥650
Denver Indian Health and Family Services	Denver, CO	20	170	112	≥170
American Indian Health and Family Services	Detroit, MI	DNA	DNA	DNA	DNA
Native Americans for Community Action	Flagstaff, AZ	DNA	DNA	DNA	DNA
Fresno Indian Health Association	Fresno, CA	68	41	41	≥68
Indian Family Health Center	Great Falls, MT	300	1000	1000	≥1000
United Amerindian Health Center, Inc.	Green Bay, WI	DNA	DNA	DNA	DNA
Helena Indian Alliance	Helena, MT	DNA	DNA	DNA	DNA
North American Indian Center of Boston, Inc.	Jamaica Plain, MA	<5	<5	<5	<15
Nebraska Urban Indian Health Coalition	Lincoln, NE	97	301	204	≥301
United American Indian Involvement, Inc.	Los Angeles, CA	DNA	DNA	DNA	DNA
Gerald L. Ignace Indian Health Center, Inc.	Milwaukee, WI	135	155	202	≥202
Indian Health Board of Minneapolis	Minneapolis, MN	DNA	DNA	DNA	DNA
Missoula Indian Center	Missoula, MT	30	DNA	DNA	≥30
American Indian Community House	New York, NY	DNA	DNA	DNA	DNA
Native American Health Center	Oakland, CA	121	136	326	≥326
Native American Community Health Center	Phoenix, AZ	19	368	365	≥368
South Dakota Urban Indian Health, Inc.	Pierre, SD	11	137	137	≥137
Native American Rehabilitation Association of the NW, Inc.	Portland, OR	93	476	408	≥476
Nevada Urban Indian, Inc.	Reno, NV	0	0	0	0
Sacramento Urban Indian Health Project, Inc.	Sacramento, CA	DNA	DNA	DNA	DNA
Indian Walk-In Center	Salt Lake City, UT	DNA	DNA	DNA	DNA
San Diego American Indian Health Center	San Diego, CA	12	48	48	≥48
Indian Health Center of Santa Clara Valley, Inc.	San Jose, CA	DNA	DNA	DNA	DNA
American Indian Health & Services	Santa Barbara, CA	DNA	DNA	DNA	DNA
Seattle Indian Health Board	Seattle, WA	411	300	300	≥411
N.A.T.I.V.E. Project	Spokane, WA	19	113	102	≥113
Inter-Tribal Health Care Center	Tucson, AZ	0	0	0	0
Hunter Health Clinic	Wichita, KS	71	323	1421	≥1421

DNA=Data not available

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## **Table of Contents**

Table of Contents	1
Executive Summary	2
Introduction	4
Background	5
Description of Urban Indian Health Organizations	6
Operational Definitions	7
Methods	8
Results	9
Estimated Population Served by Urban Indian Health Organizations	9
Estimated Female Population, by Age Group and Poverty	10
Description of Breast and Cervical Cancer Services	11
Breast and Cervical Cancer Screening Numbers	11
Key Social Determinates Affecting Screening	11
Reimbursement	12
Discussion	13
References	14
Appendix A. UIHI Breast and Cervical Cancer Screening Survey	15
Appendix B. Data Tables	18

## Executive Summary

This report provides baseline data on efforts to provide breast and cervical cancer services for populations of urban American Indian and Alaska Native (AI/AN) women who reside in the service areas of 34 Urban Indian Health Organizations (UIHO). A survey was designed to gather information on: the UIHO service population demographics, the types and level of breast and cervical cancer services provided, the rates of screening, and the key social determinants that affect screening practices.

- Nearly 70% of AI/AN in the United States live in cities, as opposed to non-urban reservations. From the 2000 Census, 1,000,254 AI/AN were reported in 1999 to reside in the 34 UIHO service areas. Of these, 573,225 report AI/AN as their only race. The 34 UIHO contract with the Indian Health Service to provide healthcare to the urban AI/AN population.
- Of the 573,225 who identified themselves as only AI/AN, 195,890 (34%) were females 18 years and older and 47,654 (8%) were females between 50 and 64 years.
- Of the 195,890 AI/AN females 18 years and older, 45,451 (23%) were living at 100% of poverty; 7,596 (4%) between 50 and 64 years were living at 100% of poverty.
- In the 2003 fiscal year (FY), the UIHO collectively served 150,725 clients; 89,298 (60%) were AI/AN.
- Of 34 UIHO, 32 offer breast and cervical cancer early detection services. On-site mammography is available at one UIHO and off-site referrals are provided by 30 UIHO. On-site clinical breast exams are provided by 22 UIHO and off-site referral for breast exams are provided by 8 UIHO. On-site pelvic exams are provided by 19 UIHO and off-site referral for pelvic exams are provided by 7 UIHO.
- As part of the breast and cervical cancer early detection services offered by the 25 UIHO with data, 2,111 women were provided mammography in FY2003. For the same time period, 4,749 women 18 years and older and 2,583 women between 50 to 64 years were provided clinical breast exams. 6,697 women 18 years and older and 1,927 women between 50 to 64 years were provided pelvic exams.
- Various key social determinants and barriers that affect screening practices were identified by the UIHO. These included: transportation, lack of interest/education or awareness, funding, referral to non-AI/AN clinics, staffing, wait times for appointments, homelessness, poverty, mobile population, lack of services/equipment and/or mobile mammogram services, embarrassment/shyness, childcare and lack of insurance.

- Of the 32 UIHO that provide breast and cervical cancer early detection services, 21 receive state BCHIP reimbursement, 18 receive Medicare reimbursement, 21 receive Medicaid reimbursement, and 16 receive private insurance company reimbursement. Ten UIHO have state contracts or memorandum of agreements; 16 are interested in receiving such contracts that include reimbursement for services. Seven UIHO participated on state advisory committees or coalitions for breast and cervical cancer, and ten report attending state continuing education functions.

Our results document an unmet level of need in Breast and Cervical Cancer services among the AI/AN who reside in urban areas. These and additional findings may help to direct all future program planning and intervention strategies that target these populations.

## **Introduction**

In an effort to better understand the Breast and Cervical Cancer Screening efforts among urban American Indians and Alaska Natives (AI/AN), the Urban Indian Health Institute (UIHI) conducted a survey to determine the services and rates of screening of 34 non-profit urban Indian health organizations (UIHO). The 34 UIHO are funded under Title V of the Indian Health Care Improvement Act and contract with the Indian Health Service under special arrangement to increase urban AI/AN access to health care.

The survey was designed to gather information on the demographics of the service population of the UIHO, the types and level of breast and cervical cancer services provided, the rates of population screened, and any key social determinants that may affect screening practices. This survey was implemented in all 34 UIHO to create a national picture of breast and cervical cancer screening services available to the urban AI/AN population.

### **Background**

Nearly 70% of AI/AN in the United States live in cities, as opposed to non-urban reservations<sup>1</sup>. From the 2000 Census, 1,000,254 AI/AN were reported residing in the service areas of the 34 non-profit urban Indian health organizations (UIHO) that contract with the Indian Health Service. Of which, 573,225 reported AI/AN race only. Despite these large numbers, the Federal health care policy for the AI/AN population continues to focus largely on those living on reservations in rural reservations.

The migration of AI/AN from rural reservations to cities reflects the federal government “relocation” policies during the 1950’s; AI/AN were forcibly moved from reservations into cities to promote assimilation into mainstream United States’ society. The mandatory relocation policy was discontinued 30 years ago; however migration to urban settings continues to occur due to employment, education, and housing opportunities. The survey focus on breast and cervical cancer screening services available to the urban AI/AN population is not meant to suggest that the non-urban AI/AN population are any less important than the urban population. Describing the health status of all AI/AN people, whether they reside in urban or rural areas, is the ultimate common goal for such efforts.

Limited data are available concerning cancer prevalence rates of AI/AN. Even less is known about the prevalence in the urban AI/AN population. With respect to urban AI/AN breast and cervical cancer prevalence, very few studies have been published. Risendal et al (1999) reported a little more than half (53.0%) of the urban American Indian women surveyed in Phoenix reported they had received a clinical breast examination in the last year, and 35.7% indicated they had received a mammogram in the last 2 years.<sup>3</sup> Utilizing the same study sample, Risendal also reported three-quarters (76.1%) of urban American Indian women surveyed received a Pap smear within the past 3 years, but only 49.5% received a Pap smear within the last year.<sup>4</sup> This study concluded that the cancer screening rates observed in urban American Indian women are far below current national estimates and Healthy People 2000 Objectives.

The five-year breast cancer survival rate of 49% for American Indian women is lower than all other ethnic and racial groups living in the United States. Li et al. reported American Indian women faced a 10% to 70% greater risk of dying after a breast cancer diagnosis as compared to non-Hispanic whites in 11 SEER sites. Also, American Indians in 11 SEER sites were more likely to be diagnosed with tumors that were more advanced than for non-Hispanic whites and Asian/Pacific Islanders<sup>1</sup>.

Li noted while biological differences could be a contributing factor, he suspects that lack of access to health care is the largest factor behind the increased mortality rates for American Indians.<sup>2</sup> The establishment and maintenance of breast cancer/mammography outreach efforts and clinical services for AI/AN women is important. Urban AI/AN do not typically have access to health care provided the Indian Health Service.

In recognition of this public health burden, the Breast and Cervical Cancer Mortality Prevention Act of 1990 (Public Law 101-354) was amended in 1993, to permit direct funding of tribes, tribal organizations, and urban health centers that serve American Indians and Alaska Natives to provide screening and early detection services to eligible women. The American Indian/Alaska Native Initiative of the National Breast and Cervical Cancer Early Detection Program (NBC-CEDP), administered by the Centers for Disease Control and Prevention (CDC), currently provides funding to 13 tribal programs, of which one is specifically focused on an urban AI/AN population<sup>5</sup>.

Although data is extremely limited, other information pertaining to breast and cervical cancer rates in the AI/AN population is found largely in national estimates. Breast and cervical cancer rates reported to the National Center for Health Statistics for years 1990-1999 indicated that in some UIHO service areas the rates of breast cancer are as high as 36 per 100,000.

The limited data available on urban AI/AN and the study findings confirm the limited access of urban AI/AN to preventive health services and encourage a more active and supportive role for cancer control and screening activities in this special population.

### **Description of Urban Indian Health Organizations**

In 1976 the Indian Health Care Improvement Act (PL94-437) was passed, spelling out the federal government's responsibilities for Indian Health. Title V of the Act specifically provided language "to establish programs in urban centers to make health services more accessible to urban Indians." The language of the Act states the responsibility of the Federal government to Indian people; it does not give priority to location, federal recognition, tribal status, or size of tribe. However, the distribution of resources has demonstrated the priority areas. Urban Indian health receives approximately 1% of the overall Indian Health Service budget.

Despite the disproportionate and inadequate resource distribution, the program for urban Indian health does endure. The Indian Health Service (IHS), the agency responsible for

caring out the Indian Health Care Improvement Act, contracts and grants to 34 independent, private, not-for-profit urban health organizations across the country . They serve approximately 150,000 clients annually, with a service area of 82 U.S. counties, in 19 states.

The 34 programs are as different as the individuals they serve. One of the veteran organizations is the Seattle Indian Health Board, with 35 years of caring for the Seattle urban AI/AN community. It provides many levels of care, from community outreach, to full comprehensive primary medical services. In contrast, the more recent organization to contract with the IHS is the Fresno Native American Health Center, which started in 2002. Currently, they do not provide direct health care; rather outreach and referral services are provided for their clients that connect them to local non-Indian health providers.

A major obstacle for the urban Indian health organizations (UIHO) is the lack of data on the populations they target and serve. Demonstrating effectiveness and the impact of services on the urban AI/AN communities on a national level is nearly impossible without adequate and accurate data. Although IHS keeps extensive records on the AI/AN populations living on or near the reservations, very little effort is made to incorporate the UIHO data into the IHS data collection system. Almost no technological infrastructure support was provided to the 34 UIHO, and as a result, they used what available resources there were to record client health information, delivery of services, and patient billing. The 34 organizations do not share one data system. Each is implementing individualized systems that are deemed the most reasonable for their individual organization needs; this is often based on what they could financially afford and support. Some UIHO have complete medical records systems whereas others may use paper records to record transportation services or other activities. These present challenges in efforts to collectively describe the health status of the urban AI/AN population. Such information is critical in advocating for additional resources to continue and expand services to this often ignored and grossly underserved American Indian and Alaska Native population.

## **Operational Definitions**

The following definitions explain how terms are applied in this project. Because there are many terms common to the lexicon of those working in this field, it is important to provide standardization for all audiences. Also, many definitions may be politically charged, including the definition of an American Indian/Alaska Native. For this reason, the legal definitions are provided to avoid any misunderstandings.

### American Indian/Alaska Native (AI/AN)

The definition of an AI/AN is taken from the Indian Health Care Improvement Act (PL94-437). “Indians or Indian, unless otherwise designated, means any person who is a member of an Indian tribe, and such terms shall mean any individual who (1), irrespective of whether he or she lives on or near a reservation, is a member of a tribe, band, or other organized group of Indians, including those tribes, bands, or groups terminated since 1940 and those recognized now or in the future by the State in which

they reside, or who is a descendant, in the first or second degree, of any such member, or (2) is an Eskimo or Aleut or other Alaska Native, or (3) is considered by the Secretary of the Interior to be an Indian for any purpose, or (4) is determined to be an Indian under regulations promulgated by the Secretary. "Indian tribe" means any Indian tribe, band, nation, or other organized group or community, including any Alaska Native village or group or regional or village corporation as defined in or established pursuant to the Alaska Native Claims Settlement Act (85 Stat. 688), which is recognized as eligible for the special programs and services provided by the United States to Indians because of their status as Indians."

#### Urban Indian

"Urban Indian means any individual who resides in an urban center, and who meets one or more of the four criteria listed above in the definition of an Indian (Indian Health Care Improvement Act PL94-437)."

#### Urban Indian Health Organization

"Urban Indian Health Organization (UIHO) or "Urban Indian organization" means a nonprofit corporate body situated in an urban center, governed by an urban Indian controlled board of directors, and providing for the maximum participation of all interested Indian groups and individuals, which body is capable of legally cooperating with other public and private entities for the purpose of performing the activities described in Title V of the Indian Health Care Improvement Act (Indian Health Care Improvement Act PL94-437)."

## **Methods**

### **Survey Instrument**

To fulfill the scope of work for this project, the UIHI developed a survey instrument based on a previous survey conducted by the National Indian Women's Health Resource Center (see Appendix A for survey). Although there were no patient identifying data gathered, the UIHI and UIHOs are protected in sharing such information through data sharing agreements. The survey instrument consisted of questions focused on the following areas:

- Service Area Demographics
- Client Demographics
- Program Services
- Reimbursement

The survey was distributed electronically or conducted verbally over the phone to the 34 urban Indian health organizations. Responses were entered directly into the computer, eliminating data entry and data cleaning steps.

**Service Area Definition**

Data were analyzed according to UIHO service areas that comprise counties designated by each program as the location in which a significant number or proportion of their patients or clients reside.

**Data Analysis**

De-identified vital statistics datasets with limited geography were received from the National Center for Health Statistics (NCHS). Vital statistics and 2000 U.S. Census data were analyzed using VistaPHw software created by Public Health – Seattle & King County. VistaPHw is a user-friendly Windows-based software package which was modified to allow for analysis of census and vital statistics data for customized geographic areas corresponding to the service areas for the 34 UIHOs. The rates of health indicators are computed using population estimates and numerator files for deaths.

**Survey Response**

A total of 89 individual attempts were made to all 34 UIHO. One program (Sacramento) is in transition and not currently running, hence we were not able to survey the program. Therefore, 31 of 33 eligible programs responded (93.9% response rate). Twenty five provided data, and 5 were unable to provide data.

**Poverty Definition**

Following the Office of Management and Budget's (OMB's) Directive 14, the Census Bureau uses a set of money income thresholds that vary by family size and composition to detect who is poor. If a family's total income is less than that family's threshold, then that family, and every individual in it, is considered poor. The poverty thresholds do not vary geographically, but they are updated annually for inflation with the Consumer Price Index (CPI-U). The official poverty definition counts money income before taxes and excludes capital gains and non-cash benefits (such as public housing, Medicaid, and food stamps)<sup>1</sup>.

**Active Users Definition**

Total number of unduplicated clients a UIHO serves in a fiscal year.

# Results

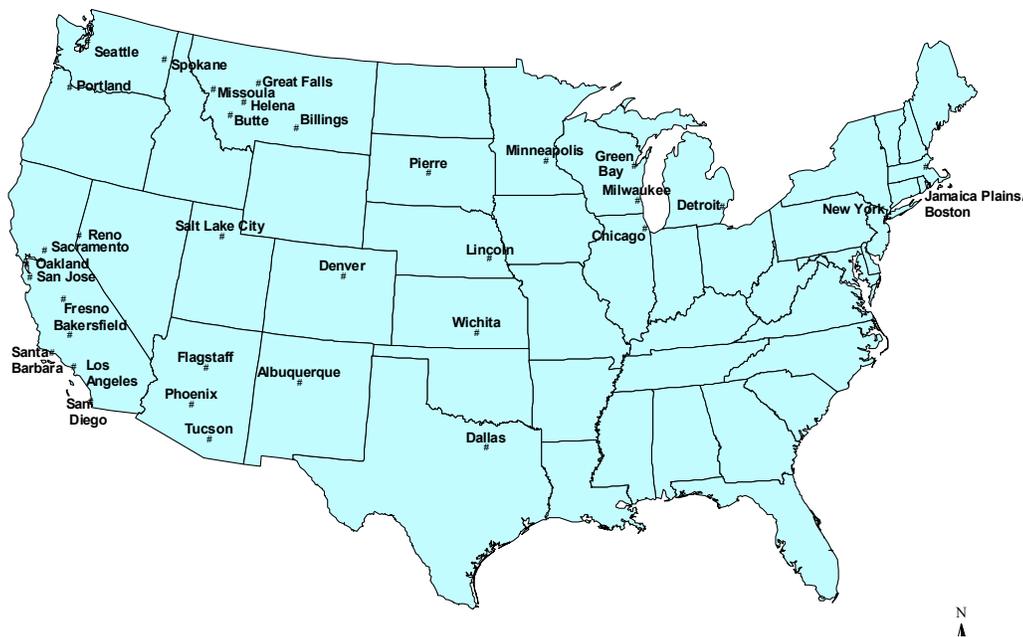
## Urban Indian Health Organization Profiles

Data collection occurred during the month of January-March 2005.

### Service Area Demographics

The service areas of the UIHO consist of 82 counties in 19 states (Figure 1).

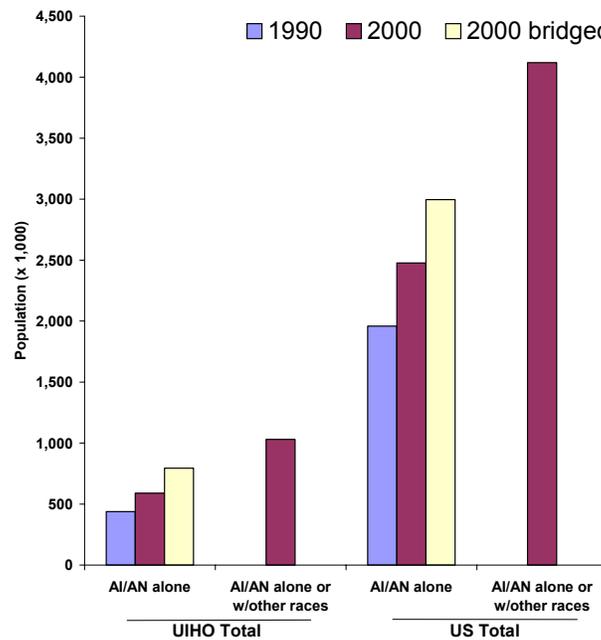
**Figure 1. Cities with Urban Indian Health Organizations funded by the U.S. Indian Health Service, 2003.**



On the 2000 U.S. Census over four million Americans indicated their racial background to be American Indian or Alaska Native (AI/AN) alone or in combination with another race. The 2000 census was the first in the nation's history to allow persons to identify as one or more races. Of those identifying as AI/AN, approximately 60%, or two and a half million persons, identified as AI/AN alone. The 1990 census, however, allowed only one race selection, thus making direct comparisons to the 2000 census difficult. Since many

vital statistics measures have depended on the single race designation allowed in the 1990 census, the U.S. National Centers for Health Statistics (NCHS) have developed “bridged” population estimates based on the 2000 census which are in the single race categories similar to the 1990 census. Using these bridged population figures, NCHS estimates that in 2000 nearly three million Americans (an increase of over 50% from 1990) would have been likely to self-identify as AI/AN if they had been asked about their race in the same manner as on the 1990 census (Figure 2). In addition, nearly 800,000 AI/AN (an increase of over 80% compared to the 439,000 who self-identified as AI/AN in 1990) would be living in UIHO service areas.

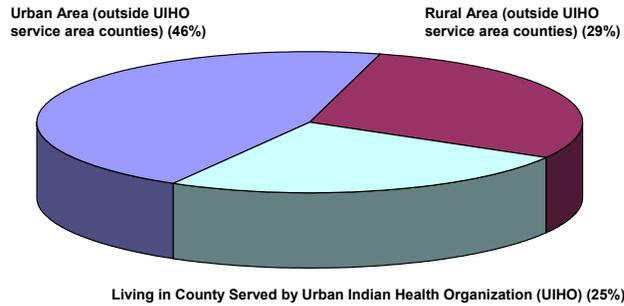
**Figure 2. American Indian/Alaska Native population living in Urban Indian Health Organization (UIHO) service areas and US Total, 1990 and 2000.**



Source: 1990 and 2000 U.S. Census.  
 Bridged estimates developed by U.S. National Center for Health Statistics  
 (<http://www.cdc.gov/nchs/about/major/dvs/popbridge/popbridge.htm>).

Of the persons who identified themselves as AI/AN alone or in combination with some other race, one quarter (25%) lived in counties served by UIHO (Figure 3, Appendix B-1). Another 46% of Indians, however, lived in census defined urban areas which lay outside UIHO service areas.

**Figure 3. American Indian and Alaska Native population residing in the U.S., 2000.** Source: U.S. Census 2000



Among the 573,225 individuals who identified as only AI/AN residing in the UIHO service areas in 1999, 195,890 (34%) were females 18 years and older (Appendix B-2). 47,654 (8%) were females between 50 to 64 years.

**Estimated Female Population, by Age Group and Poverty**

Among the 195,890 females who identified as only AI/AN residing in the UIHO service areas in 1999, 45,451 (23%) were 18 years and older living at 100% of poverty (Appendix B-3). 7,596 (4%) were females between 50 to 64 years, living at 100% of poverty.

**Client Demographics**

In fiscal year 2003 the UIHO served 150,725 clients; 89,298 (60%) were AI/AN.

**Description of Breast and Cervical Cancer Services**

32 of the 34 UIHO offer breast and cervical cancer early detection services. Mammography is offered onsite for one UIHO and offered offsite by referral for 30 UIHO. Clinical breast exams are offered onsite for 22 UIHO and offered offsite by referral for 8 UIHO. Pelvic exams are offered onsite for 19 UIHO and offered offsite by referral for 7 UIHO.

Table 1: Program Services

Offer Breast and Cervical Cancer Early Detection Services	32
Mammography	1 onsite, 30 offsite
Clinical Breast Exam	22 onsite, 8 offsite
Pelvic Exam	19 onsite, 7 offsite

## **Breast and Cervical Cancer Screening Numbers**

Of the 32 UIHO who offer breast and cervical cancer early detection services, 25 provided data on the number of women screened. From the data collected, mammography screening services were provided to 2,111 women age 50-64 in FY2003. 4,749 women 18 years and older were provided clinical breast exams and 2,583 women between 50 to 64 years were offered clinical breast exams in FY 2003. 6,697 women 18 years and older were provided pelvic exams, and 1,927 women between 50 to 64 years were offered pelvic exams.

## **Key Social Determinants Affecting Screening**

UIHO identified various key social determinants and barriers affecting screening practices. Transportation was the top barrier reported, such as having to travel long distances to reach a referral site offering mammograms free of charge or services provided too infrequently. The second barrier reported was lack of interest/education or awareness. Funding was the third barrier reported, mainly due to age and income restrictions of state programs, but also not being able to fund incentives. Examples included women who do not qualify for Medicaid or Medicare with no private insurance and diagnostic and treatment services for women outside the age limits. Additionally, the limitations of being an outreach and referral site and having to refer to clinics not specific for AI/AN resulted in delays in receiving services and non-compliance. Difficulties in recruiting and retaining staff were also reported, including having a female provider. The wait time for an appointment or referral and having no-shows for appointments was another common barrier. Some women felt it was the responsibility of the clinic to advise or remind women to come in for screening, some did not want to know or did not want to come for a yearly exam. Other issues included homelessness, poverty, mobile population, lack of services/equipment and/or mobile mammogram services from local hospitals, being embarrassed or shy about the procedure, childcare, and lack of insurance.

## **Reimbursement**

Of the 32 programs providing breast and cervical cancer early detection services, 21 are receiving state Breast and Cervical Health Program (BCHP) reimbursement, 18 are receiving Medicare reimbursement, 21 are receiving Medicaid reimbursement, and 16 are receiving reimbursement from private insurance companies. Ten of the 34 UIHO have a contract or memorandum of agreement (MOA) with their state program and 16 sites are interested in forming a partnership with their state agency to receive reimbursement for eligible women. Seven of the UIHO have participated on a state advisory committee or coalition for breast and cervical cancer, and 10 reported attending state continuing education functions.

Table 2: Reimbursement

Receiving state BCHP reimbursement	21
Receiving Medicare reimbursement	18
Receiving Medicaid reimbursement	21
Receiving private insurance reimbursement	16
State contract or MOA	10
Interested in receiving state reimbursement	16
Participated on state advisory committee or coalition for breast and cervical cancer	7
Attended state continuing education functions	10

## Discussion

The findings of this pilot project provide baseline data on breast and cervical cancer services among AI/AN clients of the 34 urban Indian health organizations.

Thirty two of the 34 urban Indian health organizations are providing breast and cervical cancer services. Many of the 32 organizations offering services reported limited ability to meet the demands of the population. Transportation, homelessness, mobile population, poverty, and access to mammography services are major barriers for the urban Indian health organizations. Culturally sensitive and appropriate outreach staff was reported to be a barrier for accessing the population at need. Many AI/AN woman in the urban Indian health organizations service area weren't aware of the benefits of screening and many more report that they are afraid to know the results of testing.

Vital health statistics show a severe underreporting of AI/AN. Racial misclassification of AI/AN populations on official documents has been well documented.<sup>6,7</sup> Such errors have resulted in consistent underestimation of infant mortality, injuries, cancer incidence, and mortality rates.<sup>8,9,10,11</sup> For example, infant mortality rates were found to be as much as 47% higher after correction for miscoding of AI/AN race on vital records.<sup>8</sup> Racial misclassification for the AI/AN population has been found in several regions and is likely to be systematic in nature. More than one study has reported a greater likelihood of racial misclassification of AI/AN populations who die in urban settings.<sup>11,12</sup> These studies emphasize the need to eliminate or minimize racial misclassification errors to ensure that programmatic and policy decisions which address AI/AN health are correctly made.

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**Appendix A: Survey of Breast and Cervical Cancer Screening Services**

1) Do you provide or refer clients for breast and cervical cancer early detection screening?

- Yes (if yes, skip to next section)
- No

2) Are you interested in providing or helping your clients to access breast and cervical cancer early detection screening?

- Yes
- No

**THANK YOU! END OF SURVEY**

---

**Breast Cancer Screening**

1) Do you provide mammography services:

- Onsite
- Offsite
- Not provided (skip to question 4)

2) Estimate the number of women ages 50-64 who received or were referred for a mammogram in 2003: \_\_\_\_\_

3) Do you provide clinical breast exams:

- Onsite
- Offsite
- Not provided (skip to next section)

4) Estimate the number of women age 18 and older who received or were referred for a clinical breast exam in 2003: \_\_\_\_\_

5) Estimate the number of women ages 50-64 who received or were referred for a clinical breast exam in 2003: \_\_\_\_\_

---

**Cervical Cancer Screening**

1) Do you provide pelvic exams:

- Onsite
- Offsite
- Not provided (skip to next section)

2) Estimate the number of women age 18 and older who received or were referred for a pelvic exam in 2003: \_\_\_\_\_

3) Estimate the number of women ages 50-64 who received or were referred for a pelvic exam in 2003: \_\_\_\_\_

---

### Reimbursement

1) Do you receive any third party reimbursement for these services?

Yes (if yes, skip to question 3)

No

2) Are you interested in finding out how you can form a partnership with your state agency for that segment of your population that may be eligible for state reimbursement?

Yes (skip to next section)

No (skip to next section)

3) Do you receive any third party reimbursement for these services from your state breast and cervical health program?

Yes

No (if no, skip to question 5)

4) Do you have a contract or memorandum of agreement with your state program?

Yes

No

5) Do you receive any third party reimbursement for these services from: (mark all that apply)

Medicare

Medicaid

Private insurance

Other source, such as Komen Foundation (specify): \_\_\_\_\_

---

### Coalition Participation and Continuing Education

1) Has the state ever invited you to be a part of their advisory committee or coalition for breast and cervical cancer?

Yes

No (skip to next section)

2) Have you attended any of their continuing education functions?

Yes

No

---

**Barriers**

1. Have you identified any barriers in offering these services to your clients? Please describe. \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

2. Have you identified any barriers your clients encounter in obtaining these services (examples might be; transportation, not interested, don't want to know, aren't aware of importance to screen, or general awareness of screening)? Please describe.

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**THANK YOU!**

## Appendix B: Data Tables

<b>Appendix B-1. American Indian Alaska Native Population, 2000 By Urban Indian Health Organization Area</b>	
<b>Place</b>	<b>Number</b>
US TOTAL	2,475,956
UIHO TOTAL	573,225
ALBUQUERQUE UIHO	23,175
BAKERSFIELD UIHO	9,999
BILLINGS UIHO	11,510
BUTTE UIHO	704
CHICAGO UIHO	15,496
DALLAS UIHO	29,037
DENVER UIHO	17,387
DETROIT UIHO	14,568
FLAGSTAFF UIHO	33,161
FRESNO UIHO	21,739
GREAT FALLS UIHO	3,394
GREEN BAY UIHO	5,374
HELENA UIHO	1,264
JAMAICA PLAIN UIHO	2,689
LINCOLN UIHO	6,714
LOS ANGELES UIHO	76,988
MILWAUKEE UIHO	7,582
MINNEAPOLIS UIHO	15,384
MISSOULA UIHO	2,193
NEW YORK UIHO	45,866
OAKLAND UIHO	22,635
PHOENIX UIHO	56,706
PIERRE UIHO	1,434
PORTLAND UIHO	6,785
RENO UIHO	9,308
SACRAMENTO UIHO	13,359
SALT LAKE UIHO	13,681
SAN DIEGO UIHO	24,337
SAN JOSE UIHO	11,350
SANTA BARBARA UIHO	14,225
SEATTLE UIHO	15,922
SPOKANE UIHO	5,847
TUCSON UIHO	27,178
WITCHITA UIHO	6,234
American Indian and Alaska Native single race category	
<b>Data Source:</b> 2000 U.S. Census	

<b>Appendix B-2. Population of American Indian and Alaska Native* Females by Age Category, 2000 Urban Indian Health Organization Areas</b>		
<b>PLACE</b>	<b>Age 18+</b>	<b>Age 50-64</b>
US TOTAL	829,574	226,123
UIHO TOTAL	195,890	47,654
ALBUQUERQUE UIHO	8,642	1,838
BAKERSFIELD UIHO	3,365	974
BILLINGS UIHO	3,596	867
BUTTE UIHO	235	50
CHICAGO UIHO	5,212	1,230
DALLAS UIHO	10,300	2,503
DENVER UIHO	6,135	1,354
DETROIT UIHO	5,346	1,411
FLAGSTAFF UIHO	10,375	2,684
FRESNO UIHO	7,312	1,877
GREAT FALLS UIHO	1,162	288
GREEN BAY UIHO	1,829	434
HELENA UIHO	425	122
JAMAICA PLAIN UIHO	979	278
LINCOLN UIHO	2,233	493
LOS ANGELES UIHO	25,239	6,357
MILWAUKEE UIHO	2,716	639
MINNEAPOLIS UIHO	5,388	1,213
MISSOULA UIHO	734	153
NEW YORK UIHO	15,259	4,320
OAKLAND UIHO	8,378	2,350
PHOENIX UIHO	19,093	3,306
PIERRE UIHO	415	94
PORTLAND UIHO	2,529	614
RENO UIHO	3,277	933
SACRAMENTO UIHO	4,911	1,320
SALT LAKE UIHO	4,418	622
SAN DIEGO UIHO	8,364	2,170
SAN JOSE UIHO	4,071	1,060
SANTA BARBARA UIHO	4,788	1,339
SEATTLE UIHO	5,869	1,493
SPOKANE UIHO	2,025	485
TUCSON UIHO	9,177	2,252
WITCHITA UIHO	2,093	531
*American Indian and Alaska Native single race category		
<b>Data Sources:</b>		
2000 U.S. Census		

**Appendix B-3.  
American Indian and Alaska Native\*  
Females With Incomes Below 100% Poverty Level  
By Age Category, Urban Indian Health Organizations, 1999**

<b>Place</b>	<b>Age 18+</b>	<b>Age 55-64</b>
US TOTAL	204,530	38,838
UIHO TOTAL	45,451	7,596
ALBUQUERQUE UIHO	1,969	221
BAKERSFIELD UIHO	750	135
BILLINGS UIHO	1,334	180
BUTTE UIHO	94	17
CHICAGO UIHO	993	154
DALLAS UIHO	1,489	252
DENVER UIHO	1,250	112
DETROIT UIHO	1,164	210
FLAGSTAFF UIHO	3,348	758
FRESNO UIHO	2,163	307
GREAT FALLS UIHO	471	33
GREEN BAY UIHO	383	70
HELENA UIHO	92	25
JAMAICA PLAIN UIHO	388	77
LINCOLN UIHO	797	120
LOS ANGELES UIHO	5,031	920
MILWAUKEE UIHO	687	146
MINNEAPOLIS UIHO	1,412	174
MISSOULA UIHO	201	8
NEW YORK UIHO	4,024	891
OAKLAND UIHO	1,055	207
PHOENIX UIHO	4,881	599
PIERRE UIHO	108	26
PORTLAND UIHO	577	63
RENO UIHO	675	195
SACRAMENTO UIHO	1,043	237
SALT LAKE UIHO	943	52
SAN DIEGO UIHO	1,639	298
SAN JOSE UIHO	561	128
SANTA BARBARA UIHO	739	119
SEATTLE UIHO	1,116	135
SPOKANE UIHO	575	77
TUCSON UIHO	3,119	594
WITCHITA UIHO	380	56

\*American Indian and Alaska Native alone population  
for whom poverty status is determined

**Data Source:**  
2000 U.S. Census

**Appendix B-4.  
AI/AN Breast Cancer Mortality Rates (Female only)  
1990-1999**

Place	Rate*	95% CI	
		LB	UB
US_TOTAL	14.89	13.98	15.85
UIHO_TOTAL	11.74	10.08	13.63
ALBUQUERQUE UIHO	9.38	3.27	23.68
BAKERSFIELD UIHO	0.00	0.00	0.00
BILLINGS UIHO	35.78	16.71	76.39
BUTTE UIHO	0.00	0.00	0.00
DETROIT UIHO	25.75	12.32	49.26
FLAGSTAFF UIHO	13.51	6.74	25.08
FRESNO UIHO	9.40	3.27	22.68
LOS ANGELES UIHO	8.33	5.02	13.39
MILWAUKEE UIHO	0.00	0.00	0.00
MINNEAPOLIS UIHO	22.08	9.14	49.80
MISSOULA UIHO	0.00	0.00	0.00
NEW YORK UIHO	5.13	2.17	10.48
OAKLAND UIHO	8.34	3.38	19.03
PHOENIX UIHO	9.52	4.44	19.43
PORTLAND UIHO	17.25	6.81	40.81
RENO UIHO	14.21	4.48	40.61
SACRAMENTO UIHO	16.92	5.67	40.47
SALT LAKE UIHO	34.43	9.85	129.89
SAN DIEGO UIHO	9.17	3.47	20.35
SAN JOSE UIHO	13.10	4.62	36.20
SEATTLE UIHO	33.28	18.90	59.31
TUCSON UIHO	9.43	3.16	22.44
WICHITA UIHO	35.12	13.04	86.94

\*Rate = Deaths per 100,000, age-adjusted to year 2000 US population.

**Data Sources:**

Death Certificate Data: U.S. National Center for Health Statistics

Population (July 1st): 1990-2002 U.S. Census populations with bridged race categories developed by the U.S. National Center for Health Statistics (<http://www.cdc.gov/nchs/about/major/dvs/popbridge/popbridge.htm>).

Note: These estimates are likely to differ from population estimates produced by local state and county health departments due to local variations in projection methodologies and should be used with caution.

**Appendix B-5.  
Cervical Cancer Mortality Rates  
1990-1999**

Place	All Races			AI/AN		
	Rate*	95% CI		Rate*	95% CI	
		LB	UB		LB	UB
US_TOTAL	3.23	3.20	3.26	3.88	3.43	4.38
UIHO_TOTAL	3.22	3.15	3.28	3.09	2.29	4.13
BAKERSFIELD UIHO	4.50	3.71	5.42	0.00	0.00	0.00
BILLINGS UIHO <sup>^</sup>	3.15	1.98	4.78	19.88	5.14	59.32
BUTTE UIHO	3.95	1.63	8.29	0.00	0.00	0.00
FLAGSTAFF UIHO	3.59	1.88	6.42	4.61	1.24	13.16
GREAT FALLS UIHO	2.39	1.14	4.48	0.00	0.00	0.00
HELENA UIHO	N/A	N/A	N/A	0.00	0.00	0.00
JAMAICA PLAIN UIHO	3.79	3.13	4.55	0.00	0.00	0.00
LOS ANGELES UIHO	3.67	3.49	3.86	0.00	0.00	0.00
MISSOULA UIHO	3.24	1.76	5.53	0.00	0.00	0.00
PHOENIX UIHO <sup>^</sup>	2.45	2.18	2.75	8.86	3.63	19.21
SACRAMENTO UIHO	2.86	2.42	3.34	0.00	0.00	0.00
SAN JOSE UIHO	2.58	2.21	2.98	0.00	0.00	0.00
SANTA BARBARA UIHO	2.44	2.07	2.86	0.00	0.00	0.00
WICHITA UIHO	2.75	2.17	3.44	0.00	0.00	0.00

Rate\* = Deaths per 100,000, age-adjusted to year 2000 US population.

N/A=not available

<sup>^</sup>Significantly higher for AI/AN compared to all races

**Data Sources:**

Death Certificate Data: U.S. National Center for Health Statistics

Population (July 1st): 1990-2000 U.S. Census populations with bridged race categories developed by the U.S. National Center for Health Statistics (<http://www.cdc.gov/nchs/about/major/dvs/popbridge/popbridge.htm>).

2000 estimates are based on April 1st, 2000 county figures adjusted to July 1st, 2000 national totals.

Note: These estimates are likely to differ from population estimates produced by local state and county health departments due to local variations in projection methodologies and should be used with caution.

# **Urban American Indian/Alaska Native State Breast and Cervical Cancer Program Description**

**Final Report  
August 2005**



A division of the Seattle Indian Health Board

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## Table of Contents

Table of Contents	1
Executive Summary	2
Introduction	3
Background	3
Methods	7
Results	9
Estimated Female Population, by Age Group and Poverty	9
Breast and Cervical Cancer Screening Numbers	10
Key Social Determinants Affecting Screening	13
Coalitions and Partnerships	15
Discussion	17
References	18
Appendix A. State Breast and Cervical Cancer Screening Survey	20

## Executive Summary

This report provides baseline data on efforts to provide breast and cervical cancer services for populations of urban American Indian and Alaska Native (AI/AN) women who reside in the 19 states with an Urban Indian Health Organization (UIHO). A survey was designed to gather information on: state population demographics, number of AI/AN women screened by reimbursement source, key social determinants affecting screening practice, and AI/AN representation on state advisory coalitions.

- Of the 688,606 AI/AN females 18 years and older living in these 19 states, 161,890 (24%) were living at 100% of poverty.
- The state breast and cervical health programs collectively served an average annual of 9,694 AI/AN women.
- Of the 9,694 AI/AN women collectively screened by the state programs, 9,128 were screened with federal dollars and 333 were screened with state dollars. There were 2,034 AI/AN women screened with tribal dollars. None were screened exclusively with Susan B. Komen dollars and none of the states were aware of other sources through which AI/AN women were screened.
- Various key social determinants and barriers affecting screening practices were identified by states. These included: geographic isolation, cultural barriers and beliefs, lack of insurance, education, historical relationship with IHS, access, fear, communication, childcare, and lack of funding to provide services.
- Fourteen states had any AI/AN representation on their state advisory coalition for breast and cervical cancer or cancer committees. Five states have AI/AN representation for their state comprehensive cancer control program and two states have AI/AN representation on their breast and cervical cancer coalition. Six states had a tribal representative, two states had an urban AI/AN representative and four states had both tribal and urban representatives.

Our results document an unmet level of need in breast and cervical cancer services among the AI/AN who reside in urban areas. Linking state, tribal and other screening programs with UIHOs and increasing AI/AN representation on cancer advisory councils may increase access to breast and cervical cancer early detection and treatment services for urban AI/AN.

## **Introduction**

In an effort to better understand the Breast and Cervical Cancer Screening efforts among urban American Indians and Alaska Natives (AI/AN), the Urban Indian Health Institute (UIHI) conducted a survey of states with an urban Indian health organizations (UIHO). There are 34 UIHO nationwide that are nonprofit agencies funded under Title V of the Indian Health Care Improvement Act and contract with the Indian Health Service under special arrangement to increase urban AI/AN access to health care.

The survey was designed to gather information on the demographics of the service population in states with an UIHO, the number of AI/AN women screened in the state, and any key social determinants that may affect screening practices. This survey was implemented in all 19 states with an UIHO to create a national picture of breast and cervical cancer screening services available to the urban AI/AN population.

## **Background**

### **Cancer and AI/AN**

Cancer is the second leading cause of death for AI/AN living in UIHO service areas.<sup>1</sup> While the incidence of cancer among AI/AN is lower than all other ethnic groups including whites in the U.S., AI/AN have the lowest five-year relative survival rate of all U.S. populations and cancer rates among AI/AN are increasing.<sup>2,3,4</sup> Cancer mortality rates have declined in the general population, but has remained level for AI/AN living in UIHO service areas.<sup>1</sup> Breast cancer mortality rates for most American Indians is lower than those for white, African American, and Hispanic women, but the rate of death due to the disease has risen in selected areas of the United States.<sup>4</sup>

Lack of access to and use of early-detection services may be a major contributor to the poor breast cancer survival rate among AI/AN.<sup>5,6</sup> A study found significant disparities in time to first cancer surgery for American Indian women compared to non-Hispanic White women, with American Indian women four times more likely to receive their first cancer surgery more than six months after diagnosis.<sup>7</sup>

Additionally, there are limitations with existing AI/AN cancer data, including racial misclassification, undercounting, coding errors, and small numbers making surveillance a challenge.<sup>8-14</sup>

### **Description of Urban Indian Health Organizations**

In 1976 the Indian Health Care Improvement Act (PL94-437) was passed, spelling out the federal government's responsibilities for Indian Health. Title V of the Act specifically provided language "to establish programs in urban centers to make health services more accessible to urban Indians." The language of the Act states the responsibility of the Federal government to Indian people; it does not give priority to location, federal recognition, tribal status, or size of tribe. However, the distribution of resources has

demonstrated the priority areas. Urban Indian health receives approximately 1% of the overall Indian Health Service budget.

### **Description of National Breast and Cervical Cancer Early Detection Program**

The National Breast and Cervical Cancer Early Detection Program, administered by the Centers for Disease Control and Prevention (CDC), helps low income, uninsured, and underserved women gain access to lifesaving screening programs for early detection of breast and cervical cancers.<sup>15</sup>

To help improve access to screening for breast and cervical cancers among underserved women, Congress passed the Breast and Cervical Cancer Mortality Prevention Act of 1990, which created CDC's National Breast and Cervical Cancer Early Detection Program (NBCCEDP). This program, funded with \$210 million in fiscal year 2004 appropriations, provides both screening and diagnostic services, including

- Clinical breast examinations
- Mammograms
- Pap tests
- Surgical consultation
- Diagnostic testing for women whose screening outcome is abnormal

Established in 1991, the program is currently implemented in all 50 states, 4 U.S. territories, the District of Columbia, and 13 American Indian/Alaska Native organizations, one of which is an UIHO. To date, it has

- Screened 1.9 million women
- Provided 4.6 million screening examinations
- Diagnosed 17,009 breast cancers; 61,474 precancerous cervical lesions; and 1,157 cervical cancers

NBCCEDP continues to support an array of strategies that work together synergistically to achieve these results. Examples of some of these strategies include:

#### **1. Coalitions and Partnerships**

The success of NBCCEDP depends on the complementary efforts of a variety of national organizations and other partners. CDC has joined with many such partners to help strengthen and maintain the infrastructure needed to implement NBCCEDP and other health programs focusing on underserved women. For example, CDC partners with Men Against Breast Cancer, the first national nonprofit organization to target and mobilize men in the fight against breast cancer. Through collaborations with other organizations, this program will reach African Americans, American Indians, Hispanics, and their partners.

#### **2. Public Education and Outreach**

Public education and outreach involve the design and delivery of clear and consistent messages about cervical cancer and the benefits of early detection, using a variety of methods and strategies to reach priority populations. States receive funds to create

and disseminate educational resources to women, especially those who are rarely or never screened. CDC often develops these materials to help states bolster public awareness campaigns.

### **3. Professional Education: Enhancing Health Care at the Source**

NBCCEDP's state, territorial, and tribal grantee programs educate a wide range of health care professionals, including physicians, nurses, radiologic technologists, and cytologists, on the key roles that they play in the early detection of breast and cervical cancers.

### **4. Screening, Follow-Up, and Case Management**

NBCCEDP provides national guidance on screening, diagnostic follow-up, and case management to ensure that current techniques and best practices are used in caring for women served by the program. Case management services help to ensure that women are screened at appropriate intervals, that they access appropriate diagnostic services in the event of abnormal test results, and that they receive appropriate medical treatment as needed. Case managers also may help women navigate the health care system (e.g., make sure that transportation is available and work with physicians to obtain free or reduced-cost services).

### **5. Quality Assurance for Screening and Follow-Up**

Health agencies that participate in NBCCEDP use mammography facilities certified by the American College of Radiology and cytology laboratories that follow the Clinical Laboratory Improvement Amendments of 1988. CDC provides screening and diagnostic guidelines to all NBCCEDP grantees and helps them evaluate their clinical services. Under CDC's guidance, all grantee programs develop strategies to ensure that women receive the best care possible.

### **6. Improving Access to Treatment**

In 2000, Congress passed the Breast and Cervical Cancer Treatment and Prevention Act to help make treatment services more accessible to women enrolled in NBCCEDP. This legislation gives states the option to provide Medicaid coverage for treatment of women enrolled in NBCCEDP who have a diagnosis of breast cancer, cervical cancer, or a related precancerous condition. To qualify for Medicaid coverage under the program, a woman must be under age 65, not otherwise eligible for Medicaid, without creditable health care coverage, screened through the state's Breast and Cervical Cancer Early Detection Program, and be found to need treatment for breast and/or cervical cancer or precancerous conditions.

CDC's partnership with the Centers for Medicare & Medicaid Services has helped states obtain approval for this Medicaid option from the U.S. Department of Health and Human Services. As of January 1, 2004, 49 states and the District of Columbia have received approved Medicaid amendments to participate in this program.

CDC estimates that approximately 20% – 21% of eligible women aged 50 to 64 years received Pap tests and mammograms through NBCCEDP. CDC will continue working—through research, partnerships, and grantee organizations—to increase access to breast and cervical cancer early detection and treatment services, to develop strategies for

improving rescreening rates among women enrolled in the program, and to implement public education and outreach strategies capable of reaching women who have rarely or never been screened. By linking UIHOs with state breast and cervical health programs, CDC hopes to increase access to breast and cervical cancer early detection and treatment services for urban AI/AN.

## Methods

### Data Collection

The survey consisted of questions focused on the following areas:

- State AI/AN demographics by poverty level
- Number of AI/AN women screened by reimbursement source
- Social determinants affecting screening practice
- AI/AN representation on state advisory coalitions

See Appendix A for the survey instrument. The survey was distributed electronically or conducted verbally over the phone to the 19 states with an urban Indian health organization funded under Title V of the Indian Health Care Improvement Act. State coordinators were contacted to respond to the survey questions. Demographic data on 100%FPL was obtained directly from the 2000 US census.

### Survey Response

Data collection occurred during the months of April-July 2005. A total of 79 individual attempts were made to all 19 states, with an average of 4 attempts per state to obtain a completed survey. All 19 states responded (100% response rate).

The 34 Urban Indian Health Organizations (UIHO) are located in 19 states (Table 1).

**Table 1. List of Urban Indian Health Organizations by State.**

<i>State</i>	<i>Name of UIHO</i>	<i>Location</i>
Arizona	Native Americans for Community Action	Flagstaff, AZ
	Native American Community Health Center	Phoenix, AZ
	Inter-Tribal Health Care Center	Tucson, AZ
California	Bakersfield American Indian Health Project	Bakersfield, CA
	Fresno Indian Health Association	Fresno, CA
	United American Indian Involvement, Inc.	Los Angeles, CA
	Sacramento Urban Indian Health Project, Inc.	Sacramento, CA
	San Diego American Indian Health Center	San Diego, CA
	Indian Health Center of Santa Clara Valley, Inc.	San Jose, CA
	American Indian Health & Services	Santa Barbara, CA
	Native American Health Center	Oakland, CA
Colorado	Denver Indian Health and Family Services	Denver, CO
Illinois	American Indian Health Service of Chicago, Inc.	Chicago, IL
Kansas	Hunter Health Clinic	Wichita, KS
Massachusetts	North American Indian Center of Boston, Inc.	Jamaica Plain, MA
Michigan	American Indian Health and Family Services	Detroit, MI
Minnesota	Indian Health Board of Minneapolis	Minneapolis, MN
Montana	Indian Health Board of Billings, Inc.	Billings, MT

	North American Indian Alliance	Butte, MT
	Indian Family Health Center	Great Falls, MT
	Helena Indian Alliance	Helena, MT
	Missoula Indian Center	Missoula, MT
Nebraska	Nebraska Urban Indian Health Coalition	Lincoln, NE
Nevada	Nevada Urban Indian, Inc.	Reno, NV
New Mexico	First Nations Community Health Source	Albuquerque, NM
New York	American Indian Community House	New York, NY
Oregon	Native American Rehabilitation Association of the NW, Inc.	Portland, OR
South Dakota	South Dakota Urban Indian Health, Inc.	Pierre, SD
Texas	Urban Inter-Tribal Center	Dallas, TX
Utah	Indian Walk-In Center	Salt Lake City, UT
Washington	Seattle Indian Health Board	Seattle, WA
	N.A.T.I.V.E. Project	Spokane, WA
Wisconsin	United Amerindian Health Center, Inc.	Green Bay, WI
	Gerald L. Ignance Indian Health Center, Inc.	Milwaukee, WI

## Results

### Estimated Female Population by Age Group and Poverty

Only 5 states (Arizona, Kansas, Michigan, Utah and Washington) were able to obtain data by age group and 250% federal poverty level (FPL). Table 2 shows the estimated American Indian/Alaska Native (AI/AN) population, by age group, 250% poverty level or less by state.

**Table 2. AI/AN Population  $\leq$ 250%FPL by Age Group**

	Age 18+	Age 50-64
Arizona <sup>1</sup>	38,358	5,244
Kansas	9,033	1,682
Michigan		1,540
Utah <sup>2</sup>	4,528	893
Washington		5,831 <sup>3</sup>

<sup>1</sup>Year 2002

<sup>2</sup>Age 40-64, 2004 Population Survey

<sup>3</sup>2000 Census and 1999-2004 BRFSS

Because of the difficulty in accessing the data on 250% poverty level or less by state, Table 3 is provided. Table 3 shows the estimated American Indian/Alaska Native (AI/AN) population, by age group, 100% poverty level or less by state.

**Table 3. AI/AN Population 100%FPL, by Age Group**

	Age 18+	Age 45-54	Age 55-64
Arizona	24,126	3,816	3,015
California	33,945	6,432	3,933
Colorado	4,238	728	399
Illinois	3,764	691	492
Kansas	2,564	432	285
Massachusetts	2,193	411	251
Michigan	6,551	1,130	808
Minnesota	5,475	820	479
Montana	6,029	823	639
Nebraska	1,849	260	175
Nevada	2,224	417	399
New Mexico	16,228	2,786	1,937
New York	11,973	2,309	1,277
Oregon	5,399	982	546
South Dakota	7,097	1,018	597
Texas	11,382	2,113	1,501
Utah	2,843	400	249
Washington	10,100	1,693	934
Wisconsin	3,910	603	328

## Breast and Cervical Cancer Screening Numbers

Fourteen states had data on the number of AI/AN women screened with federal or state dollars (Table 4). Among these 14 states, a total of 9,694 AI/AN women were screened by the state program. There were 9,128 AI/AN women screened with federal dollars and 333 with state dollars.

**Table 4. AI/AN Population screened with federal and state dollars**

	Federal	State	Total
Arizona <sup>1</sup>	288	6	294
California			
Colorado <sup>2</sup>	266		
Illinois <sup>3</sup>	N/A	N/A	112
Kansas	143	0	143
Massachusetts <sup>4</sup>	N/A	N/A	27
Michigan <sup>2</sup>	409	266 <sup>5</sup>	675
Minnesota	593 <sup>6</sup>	0	593
Montana	350 <sup>7</sup>	0	350
Nebraska	825	0	825
Nevada	N/A	N/A	94 <sup>8</sup>
New Mexico	2,784 <sup>9</sup>	0	2,794
New York	1553	33	1,586
Oregon	33 <sup>7</sup>	0	33
South Dakota	1,404		
Texas			
Utah <sup>10</sup>	58	28	86
Washington	208 <sup>11</sup>	0	208
Wisconsin	214 <sup>9</sup>	0	214

N/A=Not Available

<sup>1</sup>Average annual number from 1999-2003

<sup>2</sup>Year 2004

<sup>3</sup>Total # AI/AN women with breast and/or cervical cancer screen; may be duplicate counts. Blended funding stream, so breakdown by payer source not available

<sup>4</sup>Year 2003, no breakdown by payer source

<sup>5</sup>Age 40-49

<sup>6</sup>Average annual number from 1993-2005

<sup>7</sup>FY2004-2005

<sup>8</sup>Average annual number from 1997-2005

<sup>9</sup>FY2003-2004

<sup>10</sup>Average annual number from 1994-2004

<sup>11</sup> 6/30/04-1/31/05. Consider all women as screened by federal dollars

Only one state, Arizona, had data on number of women screened through tribal programs (Table 5). In Arizona, the average annual number of AI/AN women screened through tribal programs between 1999-2003 was 2,034 (268 Hopi and 1,766 Navajo). Four states (Utah, New York, Nebraska and Illinois) indicated there were no tribal screening programs in their states and 13 states did not know if there were any tribal programs. One state did not respond to the question.

**Table 5. Number of States with AI/AN women screened through tribal program**

	Number of States
Yes	1
No	4
Don't know	13
No response	1

There were no AI/AN women reported as screened through Susan B. Komen programs. Wisconsin, Utah and Nebraska said they received Komen funds, but none of the AI/AN women were screened exclusively through this program. Wisconsin used Komen funds for education. Oregon mentioned a small number of AI/AN women were screened using Komen funds, but they did not know the exact figure.

The majority (n=12) of states said it was unknown or that no data was available on women screened through other programs (Table 6). Oregon knew that urban AI/AN women were screened through the federal program at the Native American Rehabilitation Association of the Northwest, Inc. (NARA), but did have any specific data. Five states indicated women were not screened through any other programs in their states. Two states did not respond to the question.

**Table 6. Number of states with AI/AN women screened through other programs**

	Number of States
None	5
Don't know	12
No response	2

Table 7 reports the number of unique AI/AN women by age group who received a pap test by a federally funded program, as reported to the Centers for Disease Control and Prevention, Division of Cancer Prevention & Control.

**Table 7. Number of AI/AN women who received a pap test in program year 2004**

	<40	40-49	50-64	65+	Total
Arizona	1	5	43		49
California	66	216	271	8	561
Colorado		92	56	1	149
Illinois	6	19	33	1	59
Kansas		53	32		85
Massachusetts	1	2	3		6
Michigan	3	303	247	1	554
Minnesota		187	171		358
Montana	4	9	214	5	232
Nebraska	11	87	56	11	165
Nevada	2	53	62	2	119
New Mexico	19	494	1,119	68	1700

New York	38	43	34	3	118
Oregon		15	20		35
South Dakota	149	121	75		345
Texas	2	2	9		13
Utah	1	8	25	1	35
Washington	1	89	72	2	164
Wisconsin	1	5	5		11

Source: Centers for Disease Control and Prevention, Division of Cancer Prevention & Control.

Table 8 reports the number of unique AI/AN women by age group who received a mammogram by a federally funded program, as reported to the Centers for Disease Control and Prevention, Division of Cancer Prevention & Control.

**Table 8. Number of AI/AN women who received a mammogram in program year 2004**

	<40	40-49	50-64	65+	Total
Arizona	2	1	57	1	61
California	3	941	1053	66	2063
Colorado		48	118	3	169
Illinois	2	6	53	1	62
Kansas		13	41		54
Massachusetts	1		6		7
Michigan			266	3	269
Minnesota		97	183		280
Montana	10	23	316	9	358
Nebraska	1	26	96	27	150
Nevada		11	49	4	64
New Mexico	9	300	1,154	94	1557
New York			95	8	103
Oregon		1	36		37
South Dakota	7	12	53		72
Texas	1	5	17		23
Utah		38	55	6	99
Washington	2	37	124	8	171
Wisconsin	2	6	10		18

Source: Centers for Disease Control and Prevention, Division of Cancer Prevention & Control.

Table 9 summarizes the number of women screened by funding source.

**Table 9: Number of Women Screened by Funding Source**

Number of women screened with federal dollars*	9,128
Number of women screened with state dollars~	333
Number of women screened through tribal program^	2,034
Number of women screened through Komen	0
Number of women screened through other program	Not available

\*Data missing for CA, IL, MA, NV and TX.

~Data missing for CA, CO,IL, MA, NV, SD and TX

^Data for Arizona state only

### **Key Social Determinants Affecting Screening**

Sixteen states identified various key social determinants and barriers affecting screening practices. There were no barriers reported for Illinois and Nevada. One state did not respond to the question.

The main social determinants reported were: geographic isolation, cultural barriers and beliefs, lack of insurance, education, historical relationship with IHS, access, fear, communication, childcare, and lack of funding to provide services.

#### *Transportation/Geographic Isolation*

Transportation/geographic isolation was the most common barrier reported, mentioned by 13 states (NY, NM, AZ, WA, MT, SD, WI, KS, MI, NE, TX, CO, UT). Examples were:

- Mammography and treatment sites located long distances from the reservation.
- Mobile units limited in Indian country, and limits scheduling of women to periods when the mammography van is there.
- Lack of service providers, services only available for a short period of time.

#### *Cultural Barriers and Beliefs*

The second most common social determinant reported was cultural barriers and beliefs, mentioned by 10 states (AZ, NM, SD, UT, MA, MT, NY, CO, CA, WI). There were many examples given:

- Women's role in the family puts family before their own needs.
- Forgetting date of appointment, concept of appointments and scheduling non-traditional (you were not raised or taught to go by a watch it's not the Indian way).
- Bias against western medicine and non-native providers prevent women from obtaining services.
- Women won't come in unless sick
- Lack of culturally competent providers
- Beliefs about life and death
- Language
- Information transmission traditionally through word of mouth, not written materials

- Trust issues
- Cancer a new disease
- Religious beliefs
- Belief that checking for the disease will cause it to be real
- Attitudes about modern medical theory and treatment
- Lack of assertiveness in obtaining needed care
- People want to be serviced by native caregivers, reluctant to go to other sites
- Cultural barriers that prevent women from leaving the reservation for healthcare.
- Dislike/uncomfortable with the procedure
- Dislike/uncomfortable with male providers
- Belief that cancer is unlikely
- Cervical cancer not an issue for some native women

#### *Lack of Insurance*

Seven states (CO, MI, MN, UT, MA, AZ, NM) cited lack of insurance as a barrier to obtaining screening services. Many women are unemployed, living in poverty or do not have insurance. The cost and simply the inability to pay for services made it impossible for women to seek services. Urban AI/AN women were additionally at a disadvantage since there is no funding offered to obtain screening services and they do not have access to IHS service providers. Another barrier was having no health insurance, yet still not meeting the eligibility requirements to receive services under the state breast and cervical health program.

#### *Education*

Six states (CA, NY, SD, UT, NM, WI) cited education as a key social determinant affecting screening. Lack of general awareness about screening, knowledge of the importance of regular screening, and understanding the importance of mammography were discussed. Preventive medicine not being seen as a priority and seeking healthcare only when in pain and debilitated were other examples. Literacy, knowledge and awareness of services were barriers. Finally, the individual bringing the educational message was cited as an important determinant affecting screening behavior.

#### *Historical Relationship with IHS*

Four states discussed the history of service with IHS as a barrier, which left women feeling skeptical. Uneasiness with male caregivers and lack of Native providers in IHS was cited. Another important determinant was trust and consistency with tribes. This was difficult to achieve in IHS facilities due to frequent turnover among clinical staff. Turnover also contributed to the lack of knowledge among IHS staff of the state breast and cervical health program. In small isolated, communities such as the reservation, clinic staff are often from the community, making some women uneasy about sharing their personal information. Finally, mammography is not covered by IHS, making it difficult for service providers to promote cancer screening services.

#### *Access*

Access issues beyond geographic isolation and lack of insurance were discussed by 3 states. One problem was that urban AI/AN women are not accustomed to obtaining preventive services in mainstream society. Additionally, urban AI/AN women may

experience difficulty in accessing IHS for health care needs. Finally, even accessing care at nearby clinics was a barrier.

*Fear*

Three states said fear was a key determinant for AI/AN women. Examples were being afraid to speak the word cancer, fear of actually knowing they have cancer, and fear of cancer making you worry about the disease.

*Other Key Determinants*

Other key determinants mentioned were communication between programs, childcare and lack of funds for services. Two states said tribal, state and federal screening programs were not working closely together. In one instance, a state assumed women were being screened by the tribal program, yet in actuality the tribal screening program had ended. Hence, no outreach had been done to reach these AI/AN women. Another state mentioned the need for a consistent relationship between the central office and tribes, and a dedicated staff person to work with tribes. Having childcare so women could go for a screening appointment was also a barrier. Finally, there was insufficient funding to provide services to meet the needs. Long waitlists prevented women from being able to obtain screening services through the state breast and cervical health program.

**Coalitions and Partnerships**

Fourteen states had any AI/AN representation on their state coalitions or committees (Table 10). Two have AI/AN representation for breast and cervical cancer coalition only, 5 have AI/AN representation for comprehensive cancer control (CCC) only, 1 state has AI/AN representation for both, and 4 states did not specify whether AI/AN representation was for the breast and cervical cancer coalition or CCC. Three states have AI/AN representation on some other committee or coalition. Nebraska and Washington have AI/AN representation on their Program or Medical Advisory Committees. Montana is unique in that they have an American Indian Women's Health Coalition with both urban and tribal representatives.

**Table 10. AI/AN Coalition Representation**

	<b>Breast and Cervical Cancer Coalition</b>	<b>Comprehensive Cancer Control</b>	<b>Any AI/AN Representation</b>
Arizona	No	Yes	Yes
California	Yes	No	Yes
Colorado	DNS	DNS	Yes
Illinois	N/A	N/A	No
Kansas	DNS	DNS	Yes
Massachusetts	N/A	N/A	No
Michigan	Yes	Yes	Yes
Minnesota	No	Yes	Yes
Montana	No	No	Yes <sup>1</sup>
Nebraska	No	Yes	Yes <sup>2</sup>
Nevada	No	No	No
New Mexico	Yes	No	Yes
New York	Don't know	Don't know	Don't know
Oregon	No	Yes	Yes
South Dakota	DNS	DNS	Yes

Texas	N/A	N/A	No
Utah	DNS	DNS	Yes
Washington	No	No	Yes <sup>3</sup>
Wisconsin	No	Yes	Yes

N/A=not applicable

DNS=did not specify

<sup>1</sup> AI/AN representation on the American Indian Women's Health Coalition

<sup>2</sup>Also AI/AN representation on the Medical Advisory Committee

<sup>3</sup>Medical and Program Advisory Committees shared with South Puget Sound Intertribal Agency

Two states have an urban representative, 6 states have a tribal representative, 4 have both tribal and urban representation and 1 state had an AI/AN who was not representing either a tribe or urban (Table 11). One state did not know if the AI/AN person was a tribal or urban representative.

**Table 11. Type of AI/AN Coalition Representation**

	<b>Tribal or Urban</b>
Arizona	Tribal
California	Don't know
Colorado	Urban
Illinois	N/A
Kansas	Tribal
Massachusetts	N/A
Michigan	Tribal
Minnesota	Neither
Montana	Both
Nebraska	Both
Nevada	N/A
New Mexico	Urban
New York	N/A
Oregon	Tribal
South Dakota	Both
Texas	N/A
Utah	Tribal
Washington	Tribal
Wisconsin	Both

N/A=not applicable

## Discussion

The findings of this pilot project provide baseline data on breast and cervical cancer services among states with an urban Indian health organization funded by Title V of the Indian Health Care Improvement Act. UIHOs may be used to enhance screening services among urban AI/AN.

The results of this survey indicate low coverage for screening low-income AI/AN women by the state program. Of the 688,606 AI/AN women 18 and older in these 19 states, 9,694 or 1.4% are receiving services through the state breast and cervical health program. The majority of states were not aware of tribal screening programs nor any other potential screening programs in their states. Most states are screening AI/AN women using federal dollars. None of the states were screening AI/AN women exclusively through Susan G. Komen Foundation funds, and only one state had data for tribal screening programs.

Increasing communication and coordination between the state, tribal and other screening programs would help to obtain a complete picture of screening among AI/AN women. While AI/AN women living on reservation might be screened through tribal programs, the state cannot know the level of coverage for this population unless this information is obtained. Additionally, over 61% of AI/AN are now living in urban areas, and possibly less likely to receive screening services through tribal programs, hence the low rates of screening by the state program may be accurate for urban AI/AN women. Coordination between programs is needed to improve screening services for AI/AN women.

While it is unclear why screening levels for AI/AN women by the state program are so low, many barriers were cited that influence screening behaviors. The most common barriers reported were geographic isolation, cultural barriers and beliefs, lack of insurance, education, historical relationship with IHS, access and fear. Targeting these barriers may be a first step to increase screening rates in this population. Collaborative partnerships between urban Indian health organizations and the state programs may be an effective way of reaching this population in a culturally competent manner. With technical assistance and training the UIHOs could be the ideal setting to serve this hard to reach population.

Fourteen states had AI/AN representation on their state advisory coalition for breast and cervical cancer or comprehensive cancer control. Inclusion of AI/AN representation will ensure this population is not missed by the state program. Additionally, increasing participation on state advisory coalitions of AI/AN representatives who are familiar with the population and their community might facilitate development of strategies to increase screening participation among AI/AN.

Thirty two of the 34 urban Indian health organizations are providing breast and cervical cancer services. Many of the 32 organizations offering services report limited ability to meet the demands of the population. Better linkage between state breast and cervical health programs and UIHOs may enhance the ability to offer screening services for urban AI/AN.

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**Appendix A: Survey of State Breast and Cervical Health Programs**

1. What is the estimated American Indian/Alaska Native (AI/AN) population, by age group, at 250% poverty level or less in the state?
  - a. Age 18 and older \_\_\_\_\_
  - b. Age 50-64 \_\_\_\_\_
  
2. What is the number of AI/AN women screened by the state program:
  - a. with federal dollars \_\_\_\_\_
  - b. with state dollars \_\_\_\_\_
  
3. What is the number of AI/AN women screened by other programs in the state:
  - a. tribal \_\_\_\_\_
  
  - b. other dollars (Susan B. Komen, etc), specify:
 

<b>Source</b>	<b>Number screened</b>

4. Have you identified any barriers in offering these services to women? Please describe.

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5. Have you identified any barriers women report in obtaining these services (examples might be; transportation, not interested, don't want to know, aren't aware of importance to screen, or general awareness of screening)? Please describe.

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6. Do you have American Indian/Alaska Native representation on your state advisory coalition for breast and cervical cancer or comprehensive cancer control (CCC)?

- Yes  
 No

6a. Is this an urban or tribal representative?

- Urban  
 Tribal  
 Other/Don't know