Urban Indian Health Institute
*A Division of the Seattle Indian Health Board*

# Survey of Breast and Cervical Cancer Screening Services for Urban American Indian and Alaska Native Women: Aggregate Report

September 2010

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This report was supported by Cooperative Agreement Number U57/DP001118 from the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention, the Department of Health and Human Services, or the U.S. government.

Recommended Citation: Urban Indian Health Institute, Seattle Indian Health Board. Survey of Breast and Cervical Cancer Screening Services for Urban American Indian and Alaska Native Women: Aggregate Report. Seattle: Urban Indian Health Institute, 2010.

# TABLE OF CONTENTS




## ACKNOWLEDGEMENTS


*The Urban Indian Health Institute (UIHI), Seattle Indian Health Board would like to thank CDC for their support of the WEAVING Project.*

*The WEAVING Project is honored for the opportunity to work with all NBCCEDP-funded state programs, and the urban Indian health organizations. We thank you for the excellent work you do on a daily basis to support the health and well-being of your communities.*

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# EXECUTIVE SUMMARY

## Introduction

This report describes the aggregate findings from a survey of urban Indian health organizations and state Breast and Cervical Early Detection Programs regarding breast and cervical cancer screening services for urban American Indian and Alaska Native (AI/AN) women. This survey was both an expansion of and a follow-up to a similar survey conducted in 2005. Results are intended to identify strengths, needs and steps for the future related to cancer screening services for urban AI/AN women.

## Methods

We attempted to survey all 32 currently operating urban Indian health organizations (UIHO) and Breast and Cervical Cancer Early Detection Programs (BCCEDP) from 19 states with at least one UIHO. Surveys were emailed and mailed to the Executive Director of UIHO and Program Directors of state BCCEDP, or a designate of their choice. Surveys were also completed over the phone. The survey questions covered issues of reimbursement, service availability, eligibility, referrals, partnerships, and barriers to care.

## Results

Surveys were completed by 23 UIHO (72%) and 15 state BCCEDP (79%).

Key findings include the following:

- 57% of UIHO reported that they had a contract with their state BCCEDP; an increase from 29% in 2005
- 80% or more of state BCCEDP reported that mammography, clinical breast exams, and pap and pelvic exams were fully available to women in their state
- 70% or more UIHO reported that onsite and/or offsite clinical breast exams, pap and pelvic exams were fully available to their patients
- One-third of UIHO reported only limited availability of breast and cervical cancer treatment services for their patients within 1 hour drive
- Approximately half of state BCCEDP reported having an AI/AN representative on their state advisory committee or cancer coalition, although few were urban AI/AN representatives
- 60% of state BCCEDP reported being satisfied with their urban AI/AN partnership, and 50% of UIHO reported satisfaction with the BCCEDP partnership
- Transportation and financial limitations were the most commonly-mentioned barrier to care, similar to the 2005 survey

## Conclusion

The results of the 2010 survey provide a more detailed picture that can be used to inform service availability, successes, needs and possible next steps for UIHO and state BCCEDP. Results can build on efforts to ensure urban AI/AN women receive life-saving breast and cervical cancer screening services.

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# INTRODUCTION

For more information on the WEAVING Project, please visit:

www.theweavingproject.org

## Urban Indian Health Institute and The WEAVING Project: History of the Survey

WEAVING Resources for Urban Indian Women's Wellness (The WEAVING Project) is a CDC-funded project operated by the Seattle Indian Health Board's Urban Indian Health Institute. The WEAVING Project provides technical assistance to state breast and cervical cancer early detection programs (BCCEDP) and urban Indian health organizations (UIHO) to increase breast and cervical cancer screening among urban American Indian and Alaska Native (AI/AN) women.

In 2005, the Urban Indian Health Institute (UIHI) distributed a survey to state BCCEDP and UIHO to assess breast and cervical cancer screening capacity for urban AI/AN women. In 2010, a follow-up effort was conducted to collect more detailed information on breast and cervical cancer screening, treatment, and diagnosis services. It also included self-assessment questions on collaboration strengths, needs, gaps, and patient referral methods.

This report reflects the aggregate findings from the 2010 survey. The results are intended to assist UIHO and state BCCEDP in better understanding their strengths, needs and steps for the future to further support breast and cervical cancer screening services for urban AI/AN women. Information collected through this survey also will be used to help the WEAVING Project describe future technical assistance needs for state BCCEDP and UIHO.

# METHODS

A survey with instructions was emailed to the Executive Director of all urban Indian health organizations (UIHO) and state Breast and Cervical Cancer Program (BCCEDP) Directors in the 19 states with one or more UIHO. This was shortly followed by a hard copy of the survey sent by mail. Directors had the option to designate an alternate staff person to complete the survey, as well as complete the survey over the phone, for which a toll-free number was provided. For the three weeks following the mailing, two WEAVING Project Assistants attempted to reach by phone all programs that did not respond to the email or hard copy survey. A final email was sent to those Directors or their designate that could not be reached by phone after three attempts. If at any time a Director or their designate declined to answer the survey, no further attempts were made.

Survey data were entered into a database twice by separate project staff to reduce errors. All comments and questions were referred to the WEAVING Project Coordinator for final clarification, if needed.

**A note about data**

Not all questions were answered within each completed survey; therefore, the number of respondents for each question is included with the reported results. Percentages are calculated using the number of respondents for each individual question as the denominator.

As mentioned above, in 2005 the UIHI conducted a survey with UIHO and the same 19 states regarding their breast and cervical cancer screening services. Certain questions were similar to ones asked in the 2010 survey. When comparisons can be made, results from the 2005 survey are included alongside the 2010 results in a blue text box. However, it is important to note that while questions were similar between 2005 and 2010, they were not identical; therefore some caution should be taken when examining comparisons. For reference, the complete 2005 survey report can be found on our website at www.uihi.org/publications/reports.

The 2010 survey questions are included in side panels throughout this report, on the corresponding page in which the data are reported. For a copy of the complete survey tools, go to the WEAVING Project website at www.TheWEAVINGProject.org.

In this report, the term "patients" and "clients" are used interchangeably to represent the range of referral and on-site services provided by urban Indian health organizations, and to respect the different preferences of those working in the field.

# SECTION I: RESULTS FROM STATE BREAST AND CERVICAL CANCER EARLY DETECTION PROGRAMS

## State Breast and Cervical Cancer Early Detection Program Respondents

Out of 19 state programs with one or more UIHO, 15 (79%) responded to the survey. Twelve (80%) of respondents were Project Directors or Project Coordinators, and 3 (20%) were Outreach Specialists.

## Models of Reimbursement

NBCCEDP grantees adopt models of reimbursement, or service delivery models, unique to their public health infrastructure. These models are categorized as "centralized", "decentralized", or a combination of the two ("mixed"). This determines who is responsible for service provision, data collection and analysis, billing and reimbursement, public education, outreach, and priority-setting.

For organizations interested in becoming a contractor of their state BCCEDP, understanding the reimbursement model used by their state helps to inform their potential contract relationship with the state as well as the requirements of being a state contractor. For organizations that are not contractors, understanding the reimbursement model may help inform relationship building and referral collaboration efforts with the appropriate state BCCEDP contractors.

**State Survey, Question 4:** What reimbursement model does your state Breast and Cervical Cancer Early Detection Program use? A centralized model, decentralized model, or mixed model.

In this survey,

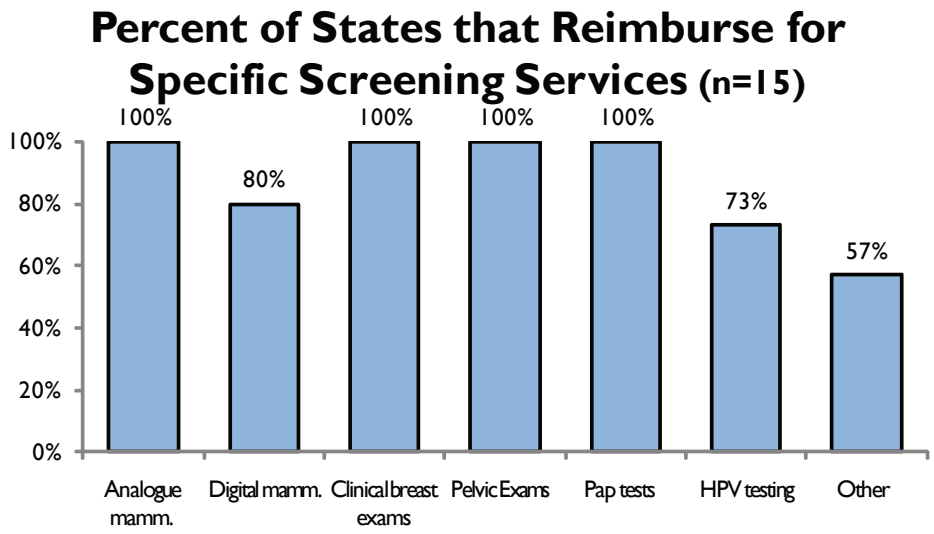
- **4 (27%)** states reported they have a **centralized model** of reimbursement. States with a centralized model provide clinical services in geographically separate offices. They pay the clinicians directly, and provide all case management, data entry, data analysis, billing, and reimbursement services. In this model, states perform all public education and outreach activities.
- **4 (27%)** states reported they have a **decentralized model.** With a **decentralized model**, states contract out all services to local health departments, private hospitals, and/or other entities. These contractors perform all clinical, outreach, billing, and educational services.
- **7 (46%)** of states reported they have a **mixed model.** States with a **mixed model** contract with other providers who themselves perform all clinical and case management services. The contractor(s) enter data, while the state conducts data analysis. All billing and reimbursement is performed by the contractor, as is public education and outreach. The state however will develop messages for public education and sets overall priorities.

# SECTION I: RESULTS FROM STATE BREAST AND CERVICAL CANCER EARLY DETECTION PROGRAMS

## State Reimbursement for Screening Services

State BCCEDP were asked to report whether or not a screening service was reimbursable through their program. All states reported they reimburse for analogue mammograms, clinical breast exams, pelvic exams, and pap tests, while fewer reported that they reimburse for digital mammograms and HPV tests.

**State Survey, Question 5:**
**A)** Which of the following services are reimbursable through your state's BCCEDP? Analogue mammography, digital mammography, clinical breast exams, pelvic exams, pap tests, HPV testing.




**B)** Are there other breast and cervical cancer screening services that are reimbursable?

Eight states reported other reimbursable services. Those mentioned were primarily diagnostic, and included: *ultrasound, computer-assisted diagnosis (CAD), colposcopy, fine needle aspiration, clinical consultation, loop electrode excision procedure (LEEP)* and *biopsy*.

# SECTION I: RESULTS FROM STATE BREAST AND CERVICAL CANCER EARLY DETECTION PROGRAMS

## State Availability of Services

State BCCEDP were asked whether certain services were fully available to eligible women in their state, not available, or whether there was limited availability. Fully available services were described as those available to all women without restrictions, while services that had limited availability had some restrictions in place. Examples of limited availability are: services are limited by time/day women could access them, there are geographical barriers or limits, or cost issues could present a barrier such as through high co-pays.

The following table displays results by topic area.

**State Survey, Question 6:** Please tell me about the availability of the following breast and cervical cancer screening services at your organization. For the following services, please let me know if the services are fully available, not available, or whether there is limited availability.

| | (n=15) | Fully Available | Limited Availabilty | Not Available |
|---|---|---|---|---|
| **Breast Cancer Screening** | Mammography | 80% | 20% | 0% |
| | Mobile mammography | 7% | 80% | 13% |
| | Clinical breast exams | 87% | 13% | 0% |
| **Cervical Cancer Screening** | Pelvic exams | 87% | 13% | 0% |
| | Pap tests | 80% | 20% | 0% |
| | HPV testing | 36% | 50% | 14% |
| **Diagnostic Care** | Diagnostic care for abnormal mammograms | 67% | 33% | 0% |
| | Diagnostic care for abnormal pap tests | 67% | 33% | 0% |
| **Treatment** | Breast Cancer Treatment within 1 hour | 27% | 73% | 0% |
| | Cervical Cancer Treatment within 1 hour | 27% | 73% | 0% |

# SECTION I: RESULTS FROM STATE BREAST AND CERVICAL CANCER EARLY DETECTION PROGRAMS

## State Eligibility for Screening Services

The NBCCEDP provides an eligibility baseline to their grantees, and grantees can choose to make additional criteria and/or select specific populations for targeted outreach. The NBCCEDP eligibility baseline includes: women at or below 250% of the federal poverty level (FPL); uninsured and underinsured: age 18- 64 years (cervical cancer screening); age 40-64 years (breast cancer screening) (http://www.cdc.gov/cancer/nbccedp/about.htm). The following tables display the age and income criteria for the 15 surveyed states:

**State Survey, Question 7:** Who is eligible for breast cancer screening services through your state BCCEDP?

| Age Criteria for Breast Cancer Screening Services (n=15) | | | |
|---|---|---|---|
| **Lower Age Limit** | **Number (%)** | **Upper Age Limit** | **Number (%)** |
| 40 Years | 12 (80%) | 64 Years | 9 (60%) |
| 50 Years | 3 (20%) | No Upper Age Limit | 6 (40%) |

**State Survey, Question 8:** Who is eligible for cervical cancer screening services through your state BCCEDP?

| Age Criteria for Cervical Cancer Screening Services (n=15) | | | |
|---|---|---|---|
| **Lower Age Limit** | **Number (%)** | **Upper Age Limit** | **Number (%)** |
| Age < 40 Years | 6 (40%) | 64 Years | 9 (60%) |
| 40 Years | 8 (53%) | No Upper Age Limit | 6 (40%) |
| 50 Years | 1 (7%) | | |

| Income Criteria for Breast and Cervical Cancer Screening Services (n=15) | |
|---|---|
| **Income Limit** | Number (%) |
| 200% FPL | 3 (20%) |
| 225% FPL | 2 (13%) |
| 250% FPL | 9 (60%) |
| No income limit | 1 (7%) |

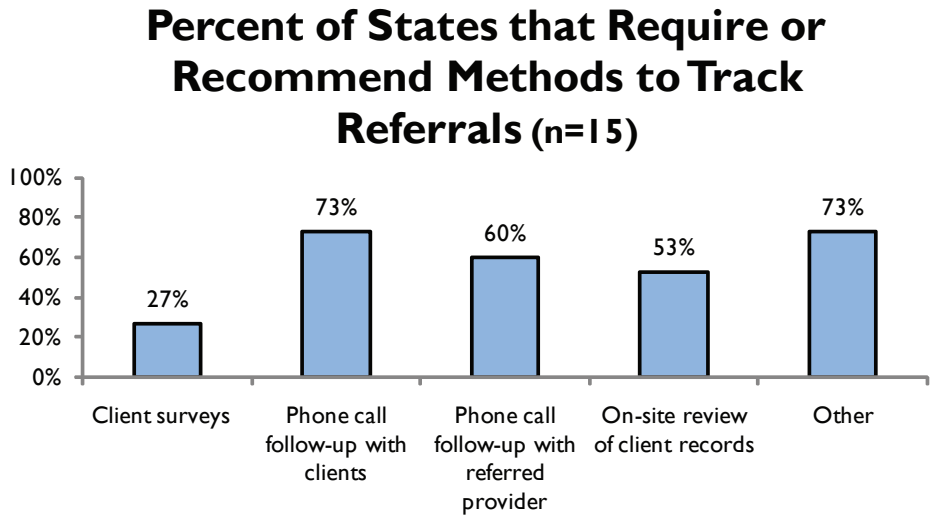
Some states also reported that they were able to extend the eligible age and/or income groups if a woman is symptomatic, high-risk, or rarely/never screened. These situations may require prior approval.

# SECTION I: RESULTS FROM STATE BREAST AND CERVICAL CANCER EARLY DETECTION PROGRAMS

## State Referrals

States were asked whether they required or requested their contractors to adopt certain methods to track patient referrals. The most common methods mentioned were phone call follow-up with patients and phone call follow-up with the referred provider. The majority also mentioned other methods that they recommend or require of their contractors.

**State Survey, Question 9:**
**A)** Does your state BCCEDP program require or recommend your service providers use any of the following methods to keep track of client referrals to make sure clients receive the referred service? Client surveys, phone call follow-up with client, phone call follow-up with referred provider, on-site review of client records.




**B)** Do you use any other method to keep track of client referrals?

Eleven states (73%) mentioned other tracking methods. The majority of these reported they use a centralized database that could be accessed by either the state program and/or providers, depending on the state.

# SECTION I: RESULTS FROM STATE BREAST AND CERVICAL CANCER EARLY DETECTION PROGRAMS

## State Partnerships with American Indian and Alaska Native Agencies and Communities

A main goal of the WEAVING Project is to increase the collaborations between urban Indian health organizations and their state BCCEDP. Because of this importance, state BCCEDP were asked multiple questions about relationships with AI/AN communities in their state, including urban AI/AN communities and agencies.

**State Survey, Question 10:** Does your program currently contract with any urban Indian health organization in your state to provide breast and cervical cancer screening to eligible women?

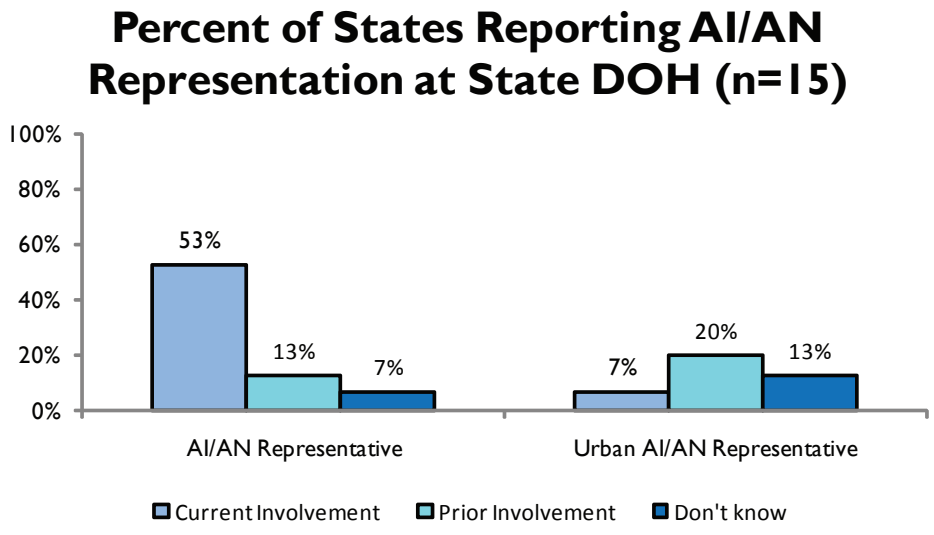
Nine (60%) of the 15 states surveyed reported current contracts or memoranda of agreement with at least one UIHO in their state.

**State Survey, Question 11:** Do you have currently, or have you had previously, an American Indian or Alaska Native representative on your state advisory committee, coalition for breast and cervical cancer, or comprehensive cancer control program?

**State Survey, Question 12:** Do you have currently, or have you had previously, specifically an urban Indian health organization representative on your state advisory committee, coalition for breast and cervical cancer, or comprehensive cancer control program?

States were asked whether they had an American Indian/Alaska Native representative on their advisory committee, coalition for breast and cervical cancer, or comprehensive cancer control program. They were also asked about an urban-specific AI/AN representative, and whether any representatives were currently involved or whether they had been involved in the past.

Results to these questions are below:




**State Survey, Question 13:** "Is there a tribal or American Indian/Alaska Native liaison within your Department of Health?

Those surveyed were also asked whether or not their state Department of Health had a tribal liaison, or someone who would represent tribal issues within the department. Sixty-seven percent of states reported they had a tribal liaison working in their Department of Health.

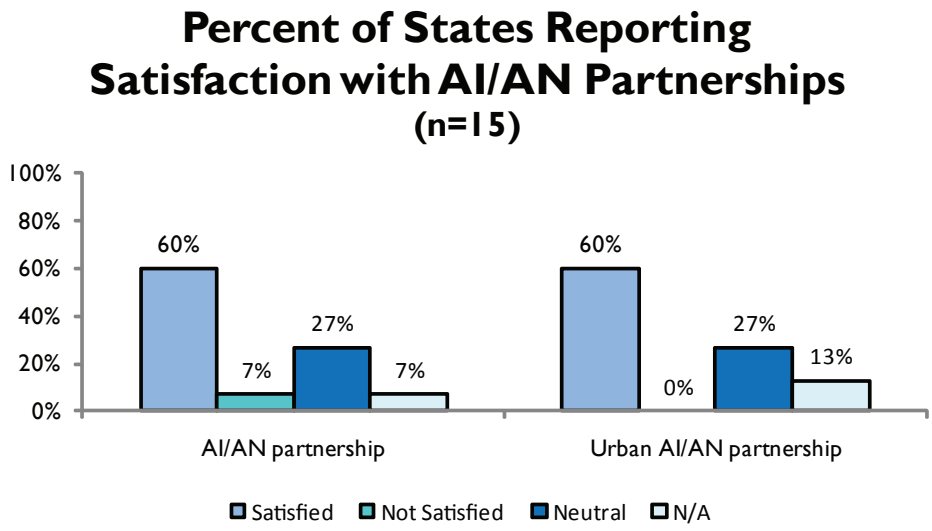
## State Partnerships (cont.)

States were asked whether or not they had offered trainings to staff or providers about working with Native populations in order to improve cultural competency or increase recruitment. Thirteen states responded to this question.

- 7 (47%) state BCCEDP reported trainings to **both** staff and providers
- 2 (15%) state BCCEDP reported trainings to **either** staff **or** providers
- 2 (15%) state BCCEDP reported they did not offer trainings to staff or providers
- 2 (15%) state BCCEDP reported they did not know

Finally, states were asked about their level of overall satisfaction with AI/AN partnerships within their state. Seven (47%) reported overall satisfaction with both their AI/AN and urban AI/AN partnerships. Additional results are below:

**State Survey, Question 16:** Please rate your overall satisfaction with the following partnerships. If it applies, would you say you were satisfied, neutral, or unsatisfied with the following partnerships: American Indian/ Alaska Native partnership overall, Urban Indian Health Organization partnership in your state.



# SECTION I: RESULTS FROM STATE BREAST AND CERVICAL CANCER EARLY DETECTION PROGRAMS

## State Barriers to Care

**State Survey, Question 17:** Have you identified any ***barriers in offering*** breast and cervical cancer screening services to American Indian and Alaska Native women?

**State Survey, Question 18:** Have you identified any ***barriers clients encounter*** in obtaining breast and cervical cancer screening services?

States were asked about barriers to care that could be experienced by American Indians and Alaska Native women in their state. State BCCEDP were asked both about barriers that providers may have in offering services, and barriers that women may encounter in obtaining services. Twelve out of fifteen respondents (80%) reported both types of barriers, while one reported no known barriers.

General financial barriers were mentioned by a number of respondents as significant for both providers offering services and for women accessing care. However, financial barriers were mentioned less often by state than by UIHO respondents (27% of state respondents vs. 53% of UIHO respondents).

Additional barriers related to offering services included: lack of providers, difficulty finding or following-up with patients, patient distrust of non-AI/AN providers, need for more education of clients, and a lack of awareness of available services.

The most common single barrier mentioned for women obtaining services was transportation. The other barriers reported dealt primarily with difficulties finding the right, culturally competent provider that women would be comfortable seeing.

In addition to barriers faced by AI/AN women in urban areas, many of states also reported barriers that are experienced by women living in rural/reservation areas. These included distance to services, difficulties with Indian Health Service (such as long wait times), and provider availability only on some reservations. It is important to note that many AI/AN women travel between rural/reservation and urban areas for health care services, and these barriers identified by the state BCCEDP suggest there remains significant challenges to offering as well as obtaining breast and cervical cancer screening services for the AI/AN population regardless of where they reside.

****Change over Time****

States were asked in 2005 about barriers women face in obtaining services. Transportation and geographic isolation were the most common barriers reported by states at that time. Other common issues mentioned in 2005 were cultural barriers/ beliefs, lack of insurance, and education.

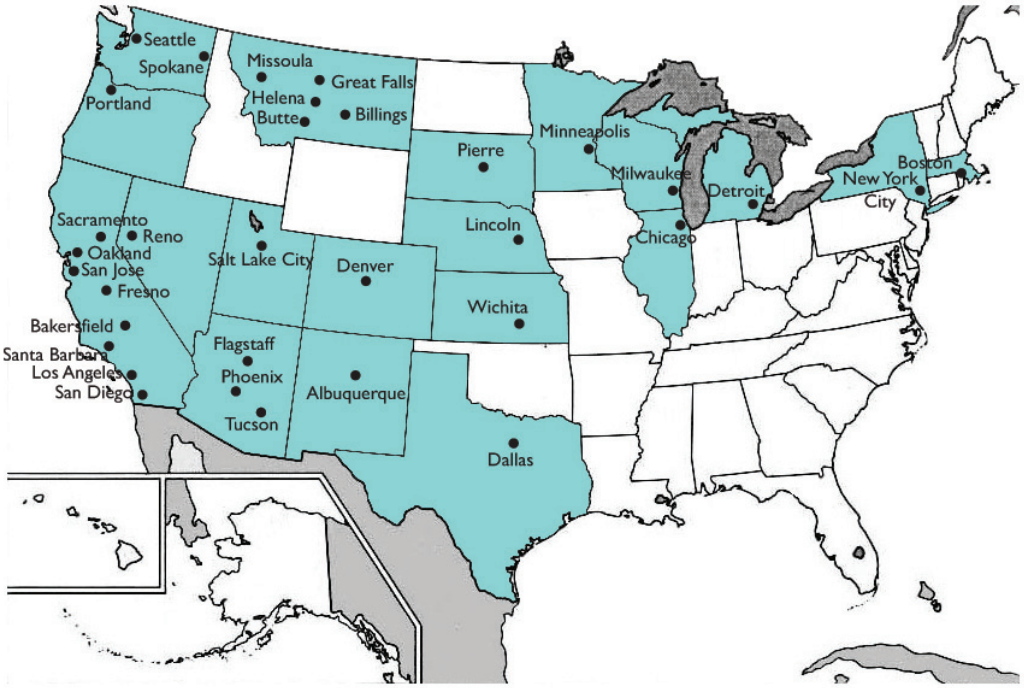
## Urban Indian Health Organization Respondents

Out of 32 currently operating urban Indian health organizations (UIHO), 23 (72%) responded to the survey. Twelve (52%) of these UIHO provide limited on-site direct services, 7 (30%) provide comprehensive direct services, and 4 (17%) provide primarily outreach and referral services.

The survey was completed by Executive Directors/CEOs (30%), Clinic Managers (26%), Medical Directors (13%), or other staff (30%).

**UIHO Survey, Question 7:** Does your organization currently have a contract or memorandum of agreement in place with your state's Breast and Cervical Cancer Early Detection Program (BCCEDP) to provide breast and cervical cancer screening to eligible women?

Thirteen (57%) of UIHO respondents had a current contract with their state Breast and Cervical Cancer Early Detection Program (BCCEDP), nine (39%) did not, and one did not know.




U.S. Map, UIHO Locations. States with UIHO highlighted. Not to scale.

****Change Over Time****

In 2005, 29% of 31 UIHO surveyed reported they had a current contract or MOA with their state Breast and Cervical Health Program. In 2010, this percent increased to 57%.

## UIHO Availability of Services

**UIHO Survey, Question 6:** Please tell me about the availability of the following breast and cervical cancer screening services for clients at your organization. For the following services, please let me know if the services are fully available, not available, or whether there is limited availability.

The UIHO were also asked whether certain services were fully available to their clients, not available, or whether there was limited availability. See page 11 for a definition of "fully available" and "limited availability".

The UIHO were asked about both on-site and off-site (referral) services, plus additional clinical capacity and patient support services.

| | (n=23, unless noted otherwise) | Fully Available | Limited Availability | Not Available |
|---|---|---|---|---|
| Breast Cancer Screening | On-site mammography | 0% | 4% | 96% |
| | Off-site (referral) mammography | 52% | 43% | 4% |
| | Mobile mammography | 9% | 22% | 70% |
| | On-site clinical breast exam | 74% | 9% | 17% |
| | Off-site (referral) clinical breast exam | 70% | 13% | 17% |
| Cervical Cancer Screening | On-site pelvic exams | 74% | 4% | 22% |
| | Off-site (referral) pelvic exams | 74% | 17% | 9% |
| | On-site pap test | 74% | 4% | 22% |
| | Off-site (referral) pap test | 74% | 22% | 4% |
| | On-site HPV testing (n=22) | 59% | 5% | 36% |
| | Off-site HPV testing (n=21) | 71% | 10% | 19% |
| Clinical Capacity | Female women's health provider | 83% | 13% | 4% |
| | Adequate staff time for case management of abnormal results | 52% | 44% | 4% |
| Diagnostic Care | Diagnostic care for abnormal mammograms | 26% | 4% | 70% |
| | Diagnostic care for abnormal paps | 23% | 23% | 54% |
| Treatment | Breast Cancer Treatment within 1 hour | 64% | 32% | 4% |
| | Cervial Cancer Treatment within 1 hour | 68% | 32% | 0% |
| Cancer Patient Support | Culturally appropriate cancer survivor support group and services | 23% | 32% | 45% |
| | Palliative care | 18% | 27% | 55% |

****Change Over Time****

In 2005, 69% of UIHO surveyed reported that clinical breast exams were available on-site. This increased to 83% in 2010. Reported on-site pelvic exam availability increased from 59% in 2005 to 78% in 2010.

Possible Data Limitation: A large proportion of UIHO reported that diagnostic care for abnormal mammograms and abnormal pap tests were not available. However, it is important to note that UIHO were not asked specifically about onsite and referral diagnostic care. It would not be uncommon for a UIHO to not have diagnostic care onsite, and the large proportion of UIHO who indicated that the service was not available may be reflective of this. However, UIHO may have interpreted and responded to this question differently. Further questions and analysis are needed to clarify the availability of diagnostic care available through UIHO, either onsite or by referral.

## UIHO Reimbursement for Services

The UIHO were asked whether or not they received reimbursement for certain services. For reimbursable services, UIHO were also asked to indicate the source(s) that provided funding.

**UIHO Survey, Question 8:** Do you receive reimbursement of any kind for xxx?

If yes, who reimburses you for these services: Medicare, Medicaid, Private Insurance, State's BCCEDP, Tribal BCCEDP, Other.

**12 (55%)** of 22 responding UIHO reported receiving reimbursement for **Breast Cancer Screening**. Of these 12 UIHO:

- 5 receive funding from Medicare
- 8 receive funding from Medicaid
- 6 receive funding from Private insurance
- 9 receive funding from their state BCCEDP
- 2 receive funding from another source

**12 (55%)** of 22 responding UIHO reported receiving reimbursement for **Cervical Cancer Screening**. Of these 12 UIHO:

- 8 receive funding from Medicare
- 10 receive d funding from Medicaid
- 6 receive funding from Private insurance
- 7 receive funding from their state BCCEDP
- 1 receive funding from another source

**4 (19%)** of 21 responding UIHO reported receiving reimbursement for **Outreach and Recruitment**. Of these 4 UIHO:

- 2 receive funding from their state BCCEDP
- 2 receive funding from another funding source

**3 (14%)** of 21 responding UIHO reported receiving reimbursement for **Case Management.** Of these 3 UIHO:

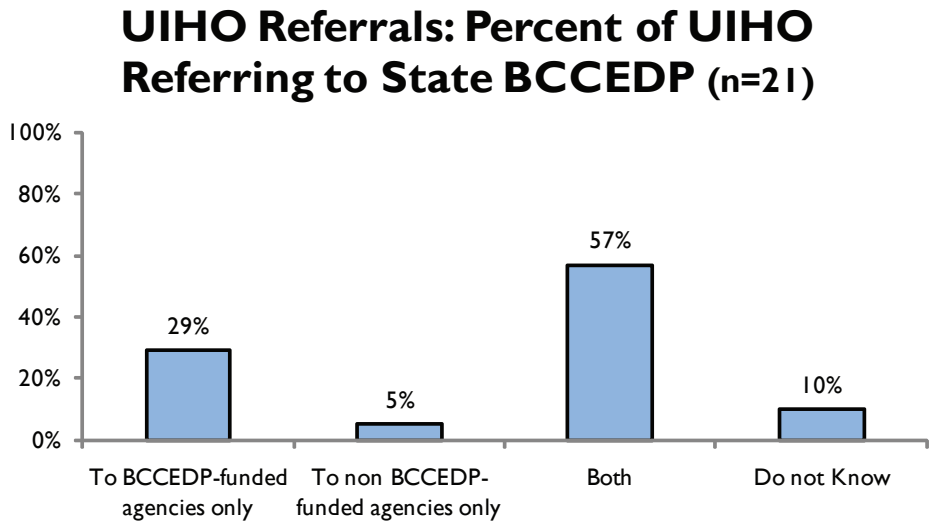
- 1 receive funding from Medicaid
- 1 receive funding from private insurance
- 2 receive funding from their state BCCEDP

## Referrals to Outside Agencies

**UIHO Survey, Question 13:**
**A)** Do you refer women to other agencies for screening, diagnostic or treatment services?

**B)** If yes, when you refer women for services, which agencies do you use: Agencies funded through state's BCCEDP, agencies not funded through your state's BCCEDP, Tribal BCCEDP, or don't know.

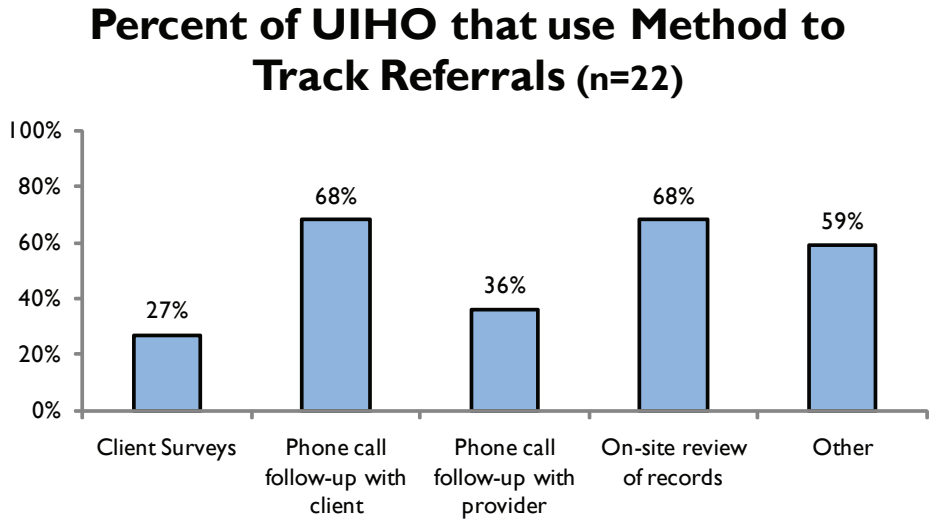
All UIHO refer patients to other agencies for at least some screening, diagnostic and/or treatment services. Eligible women ideally are referred to providers that contract with their state BCCEDP so the additional services are covered. The UIHO respondents were also asked to provide information about their referral agencies; the majority refers women both to BCCEDP-funded providers and non BCCEDP-funded providers.




**UIHO Survey, Question 14:**
**A)** Do you use any of the following methods to keep track of client referrals to make sure clients receive the referred service? Client surveys, phone call follow-up with client, phone call follow-up with referred provider, on-site review of client records.

**B)** Do you use any other method to keep track of client referrals? If yes what method?

UIHO were also asked how they kept track of patient referrals when they did refer to outside agencies. The most common methods were on-site review of records (68%) and follow-up patient phone calls (68%).



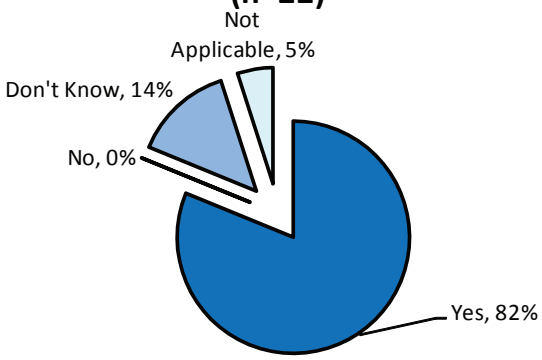
## Referrals to Outside Agencies (cont.)

Thirteen respondents (59%) mentioned that they used other internal agency tracking methods including the Resource and Patient Management System (RMPS), patient referral logs and spreadsheets. One agency noted they sub-contract with their local health department who keeps track of all referrals.

When patients are referred for follow-up services, the NBCCEDP standard is for patients to be seen within 60 days (diagnostic services following screening) or 90 days (treatment following diagnosis). UIHO were asked whether they believed this occurred with their clients, to the best of their knowledge. The majority reported they thought that their clients did receive these services within this time period.

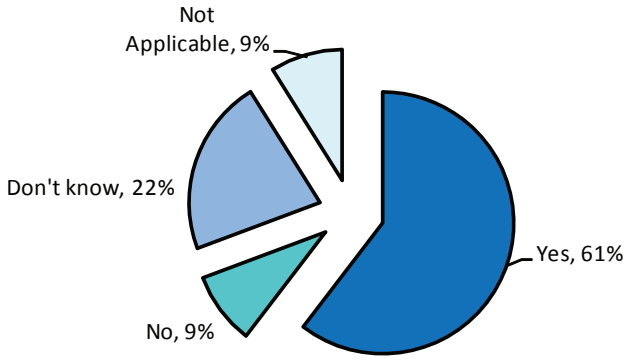
**UIHO Survey, Question 15:** To the best of your knowledge, would you say that your clients with abnormal screening results generally complete diagnostic tests within 60 days following their screening?

**Percent of UIHO that Report Patients Receive Diagnostic Services within 60 Days (n=22)**




**UIHO Survey, Question 16:** To the best of your knowledge, would you say that your clients with precancerous conditions or cancer generally start treatment within 90 days following their diagnosis?

**Percent of UIHO that Report Patients Begin Needed Treatment within 90 Days (n=23)**



## UIHO State Partnerships

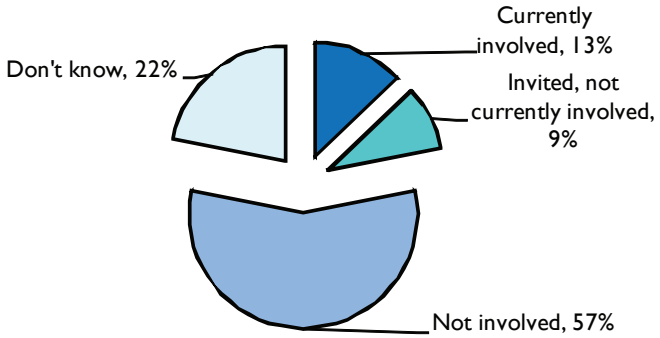
Several survey questions asked about partnerships between UIHO and State Departments of Health. UIHO were asked about current or past invitations to be part of a state advisory committee or cancer coalition, and about invitations to attend continuing education or training opportunities.

**UIHO Survey, Question 17:**
**A)** Has your state Department of Health ever invited you to be a part of their advisory committee, coalition for breast and cervical cancer, or comprehensive cancer control program?

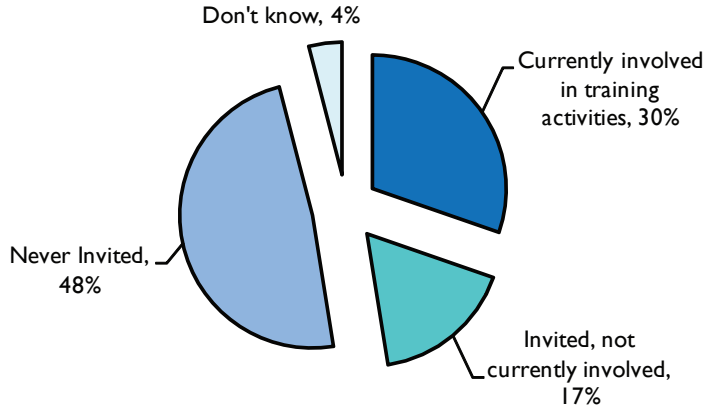
**B)** Would you say: Yes, we have been invited and we are currently involved; Yes, we have been invited but we are not currently involved; No we have never been invited; or Don't know?

**UIHO Survey, Question 18:**
Has your state Department of Health ever invited you to attend continuing education or other training opportunities?

### Percent of UIHO Reporting Involvement with DOH Cancer Programs (n=23)




### Percent of UIHO Reporting Invitations to DOH Training Opportunities (n=23)



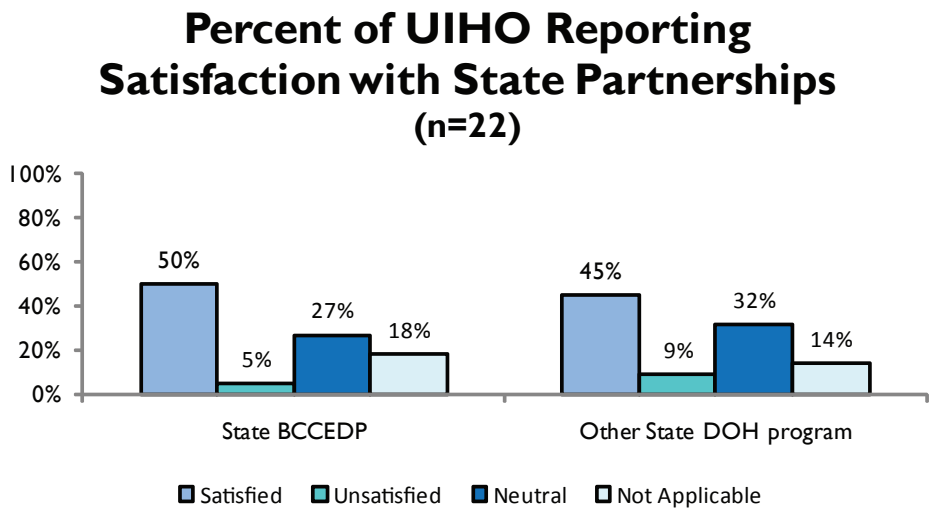

****Change over Time****

A similar number of UIHO reported that they had been involved in their state advisory committee or coalition for breast and cervical cancer in 2005 (23%) as in 2010 (22%), although there was an increase in the number of reported UIHO involvement with continuing education and training (32% vs. 47%).

## UIHO State Partnerships (cont.)

UIHO were also asked to provide information about their level of satisfaction with their current partnerships, both with their state BCCEDP and with other programs at their state Department of Health.

**UIHO Survey, Question 19:** Please rate your overall satisfaction with the following partnerships. If it applies, would you say you were satisfied, neutral, or unsatisfied with the following partnerships: State Breast and Cancer Early Detection Program; State Department of Health, other program.



## UIHO Barriers to Care

The UIHO were asked about barriers they may encounter in providing breast and cervical cancer screening services to urban AI/AN women, as well as barriers that their female patients may encounter in obtaining services.

The most common barriers mentioned included general **financial constraints,** which were identified as a barriers for both clinics offering services and the clients accessing services, and **transportation,** which was identified as a barrier primarily for clients obtaining services.

**UIHO Survey, Question 20:** Have you identified any ***barriers in offering*** breast and cervical cancer screening services to your clients?

Respondents also provided some detail with additional financial barriers faced by UIHO **offering services** including: lack of available trained staff, staff time, space, and lack of resources. Additional non-financial barriers UIHO felt they faced in offering services included: difficulties contacting patients and following-up with referrals, and lack of patient interest in screening.

**UIHO Survey, Question 21:** Have you identified any ***barriers your clients encounter*** in obtaining breast and cervical cancer screening services?

Respondents reported additional barriers for women in **obtaining services,** including: access to care especially for those without insurance, those who do not meet the age criteria and those living outside a specific geographic area; a general lack of resources; childcare issues; need for education related to importance of screening, and issues of trust. One respondent reported client feelings of fear and fatalism caused a barrier in accessing screening services.

****Change over Time****

In 2005, transportation was the most common barrier reported, while funding was the third most commonly reported barrier. The second most common barrier noted by UIHO in 2005 was a lack of patient interest/ education/awareness.

While lack of female providers was mentioned as a barrier 2005, in this survey 83% of UIHO reported they had a female care provider (see page 18).

# SECTION III: DISCUSSION

In 2005, the Urban Indian Health Institute (UIHI) conducted a survey among state breast and cervical cancer early detection programs (BCCEDP) and urban Indian health organizations (UIHO) to assess breast and cervical cancer screening capacity for urban AI/AN women. This survey provided a baseline understanding of breast and cervical cancer screening services available to urban AI/AN women. Five years later, the UIHI's WEAVING Project implemented a second survey, which was an expansion of and a follow-up to the survey conducted in 2005. This survey was intended as a self-assessment resource for UIHO and state BCCEDP to better understand strengths, needs and steps for the future, and to assist the WEAVING Project describe future technical assistance needs for state BCCEDP and UIHO.

Partnerships between UIHO and state BCCEDP can take many forms, including contract relationships for screening services, formal and informal referral relationships, and involvement in coalitions, advisory committees or other workgroups. The number of contracts reported between UIHO and state BCCEDP, as well as the number of UIHO who report referring to state BCCEDP either exclusively or in combination with other non-BCCEDP programs, is encouraging. From these successes, additional areas of partnership can also be expanded. For example, there are few urban AI/AN-specific representatives on state advisory committees and cancer coalitions, as well as few UIHO who report current involvement in their state department of health (DOH) cancer programs. Expanding opportunities for UIHO participation in state DOH programs, activities and trainings is one way to build these interagency partnerships, provide the building blocks for new partnerships, or help to reinforce existing partnerships between UIHO and state BCCEDP. Urban AI/AN representation and inclusion is also important because specific efforts are often needed to ensure urban AI/AN women are included in outreach, recruitment and screening efforts. These partnerships can lead to valuable opportunities for developing targeted, culturally appropriate outreach to urban AI/AN women, such as media campaigns, outreach at community events or other community-specific outreach and recruitment efforts.

A range of onsite and referral services were reported by both the UIHO and state BCCEDP, and demonstrate the valuable services, expertise and resources that contribute to partnerships. However, issues of access to care are still of concern and in need of attention. For example, several barriers to care were commonly reported by both UIHO and state BCCEDP, including financial barriers and transportation barriers. Other barriers reported by UIHO and state BCCEDP included lack of resources such as staff and staff time, challenges with patient follow-up, as well as issues of trust and the need for patient education on the importance of screening services. UIHO and state BCCEDP are encouraged to look at these challenges to access and service delivery in light of how a new or

strengthened partnership with their UIHO or state BCCEDP could help each partner address the barriers identified. In addition, programs are encouraged to consider ways to address access issues in light of changing health care policies, program eligibility and for individuals who may not currently be covered through existing eligibility criteria, but who remain un- and under-insured. Materials developed through the WEAVING Project, including reports, outreach and recruitment resources and shared success stories, are available to support UIHO and state BCCEDP as they work to address these challenges, build partnerships and respond to changing environments.

The results of the 2010 survey provide a more detailed picture to inform services available, successes, needs and possible next steps for UIHO and state BCCEDP to build on efforts to ensure urban AI/AN women receive life-saving breast and cervical cancer screening services. Agencies are encouraged to use these findings as a resource for internal program planning and development efforts, as well as a discussion point with the UIHO or state BCCEDP in their state to discuss common goals and vision for strengthening their partnerships, addressing service gaps, and building on the unique resources and strengths brought by each program partner.

**For additional information and reports on the urban AI/AN population nationwide and in your state, please visit the Urban Indian Health Institute at: www.uihi.org**

For additional information, questions, or concerns, please contact Jessie Folkman, Urban Indian Health Institute, Project Coordinator at jessief@uihi.org

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